TRANSITIONS INTO ADULTHOOD FOR CHILDREN WITH A SEVERE INTELLECTUAL DISABILITY: PARENTS' VIEWS

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Thesis Abstract

Introduction: Despite a growing body of intellectual disabilities literature around the transition into adulthood, most studies have focused upon physical aspects of the transition e.g. from school to employment or into adult services. My study sought to explore the transition into adulthood from a developmental/lifecourse perspective in order to address this current gap within the literature. Given that parents are often regarded as primary witnesses to their child's transition into adulthood, their views were explored in order to access knowledge around this particular transition.

Objectives: My study used a grounded theory approach to explore parents' views of the transition into adulthood of their child with a severe intellectual disability. A further aim was to understand whether and how parents made psychological adjustments for their child's transition into adulthood. This included an exploration of the emotional regulation processes that parents engaged in.

Method: Twelve parents of 11 children with a severe intellectual disability were recruited from charitable organisations. A Straussian grounded theory methodology was adopted to analyse the data.

Results: Parents viewed their child's transition into adulthood as a process over time. The core process involved making frequent comparisons with their perceived "norms" of adulthood. Parents engaged in a further five processes which included "defining adulthood", "noticing adult development", "perceiving barriers to adulthood", "worrying" and "making adjustments. My study highlighted that parents who defined adulthood as "turning 18" were likely to make adjustments to facilitate their child's adult development (e.g., "encourage age appropriateness"). Those who viewed chronological age as being unhelpful/meaningless were more likely to be accepting of their child's difficulties. Contrasting views appeared throughout these processes, demonstrating the diversity of parents' experiences and adjustments made.

Discussion: Parents engaged in a series of interactional processes for their child's transition trajectory, which was likely to influence how they made adjustments. These processes were explained using existing psychological theory and/or relating them to findings from previous studies. With regards to a grounded theory model, I proposed a transition model of parents' views and

adjustment grounded in the study findings. The visual representation of this model helped to shift away from the staged/linear idea of transition. Future intellectual disabilities studies could seek to explore the types (and function) of comparisons that parents make with others. Additionally, further research could explore fathers' views which are under-represented within this field. Clinical interventions may aim to challenge parent perceptions; encourage peer support; and embrace systemic working with parents through their child's transition into adulthood.

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Firstly, I would like to say a big thank you to all of the parents who took the time out from their busy lives to engage in this research. It would not have been possible for me to conduct this study without their willingness/desire to participate in it.

Secondly, this research would not have been completed without the help, support and guidance from my supervisors Dr Anna Tickle, Dr Nima Moghaddam and Dr Kathryn Almack. I would also like to give my thanks to the DClinPsy academic staff for their feedback on my research proposal and research panel presentations. This helped to shape and develop my thoughts regarding the research presented here.

Thirdly, I would like to thank all my close family and friends for their continued faith and encouragement throughout my DClinPsy training journey.

Lastly, to my very close relatives and family friends that I have unexpectedly lost over the last three years whilst embarking upon my own transition into "qualified life" – a sincere thank you.

Statement of Contribution

I, Sanchia Rima Biswas, declare that this research is the product of my own original work. The project design was developed in consultation with my research supervisors Dr Anna Tickle and Dr Nima Moghaddam. I reviewed the literature pertinent to this research with supervision from Dr Anna Tickle, Dr Nima Moghaddam and my field supervisor Dr Kathryn Almack. I sought ethical approval, recruited participants and collected the study data. I undertook the data analysis with supervision from Dr Anna Tickle throughout the analytic process. Dr Nima Moghaddam and Dr Kathryn Almack also kindly contributed to key aspects of the analysis including the development of a grounded theory model. I wrote this thesis with supervision from Dr Anna Tickle, Dr Nima Moghaddam and Dr Kathryn Almack.

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Systematic Literature Review

What are the factors that influence parental stress when caring for a child with an intellectual disability? A critical literature review[1].

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Abstract

Objective: This article critically reviewed empirical studies identifying factors that may influence parental stress when caring for a child with an intellectual disability. Understanding the factors influencing parental stress is important for several reasons, which include improving parental/child quality of life, supporting parental needs, and thus reducing potential economic burden in the long-term. This review is also imperative for ensuring high quality research within this field. **Method:** AMED, CINAHL Plus (EBSCOhost), EMBASE, Medline and PsycINFO were accessed to conduct a critical literature review. A total of 17 articles were reviewed. A bespoke quality assessment tool was developed to examine the susceptibility to bias for each of the included studies. **Results:** The review outlined a range of child, parent and socio-environmental factors that may influence parental stress. More specifically, factors associated with greater parental stress included child behavioral difficulties (e.g., challenging behavior), ineffective parental coping strategies (including avoidance and self-blame), and poor family environment (e.g., lack of cohesion amongst family members). These factors are critically discussed alongside contrasting evidence that was illuminated within this review. **Conclusions:** Parents of a child with an intellectual disability are not a homogenous group and are likely to show variability in the factors that affect their stress levels. Future clinical and

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research implications are proposed in light of the methodological limitations identified within the studies reviewed. For example, future research could investigate (1) the bi-directional effects that occur between variables, (2) *how* specific factors influence parental stress and (3) potential mediating/moderating factors of parenting stress.

Keywords: *Intellectual disability, stress, parent, systematic review.*

Statement of contribution

SB undertook the design of the review, the literature search, data abstraction and analysis and mosr of the writing, NM contributed to the analysis of data in the original studies reviewed and also the writing. AT contributed to the design of the review and the writing and editing of the paper.

Introduction

Background

Despite a vast amount of research on stress in parents of children with intellectual disabilities, there is still no single conceptualization of its etiology, course and impact within this population (Perry, 2004). For the purposes of this review, the definition provided by Lazarus and Folkman's (1984) transactional model of stress and coping has been used as it is a widely influential theoretical framework. This model defines stress as a complex interaction between an individual and the environment, which is appraised as being demanding and thus threatening to their wellbeing. Stress can significantly hinder an individual's ability to manage important daily routines or responsibilities (Peer and Hillman, 2012), as well as being associated with more physical health problems (Gallagher & Whiteley, 2013). Thus, the duties associated with parenting can be significantly impaired when experiencing stress.

The impact of raising a child with an intellectual disability on parental stress has been extensively researched. Early studies document that both mothers and fathers report more stress related to caring for their child with an intellectual disability compared to parents of typically developing children (Holt, 1958; Kanner, 1953). Despite this considerably entrenched stereotype, many of these studies incorporated single case designs or had methodological weaknesses. Additionally, the proportion of parents of a child with an intellectual disability who experience stress is unknown. There is emerging evidence indicating that children with an intellectual disability provide positive experiences for parents (Scorgie and Sobsey, 2000). This, together with a recognition of families' abilities to develop resilience to stress (Walsh, 2003), indicate the need for a balanced perspective when considering the impact of parenting a child with an

intellectual disability, as the experience will differ broadly for individuals. That said, identifying and understanding factors that impact on stress in parents is key to developing both proactive and reactive assessments and interventions to promote families' wellbeing. This is with the aim of reducing the likelihood of potential consequences of high levels of stress, including mental and physical health problems, abuse and family breakdown.

A number of comprehensive models have been proposed to understand parental stress, which have been operationalized within the intellectual disabilities literature (Lawton *et al.,* 1991; Lazarus and Folkman, 1984; Mash and Johnson, 1990; and McCubbin and Patterson, 1983). Hill and Rose (2010) reviewed the applicability of these models when understanding stress in parents of individuals with an intellectual disability. They concluded that these models were empirically supported within this field but that each model places an emphasis upon different factors that contribute towards parental stress. This suggests that there is no single model ideal for understanding parental stress when caring for a child with an intellectual disability and that the use of these models is dependent upon the situation in which they are being applied.

Specific factors that influence parental stress have been extensively researched. For example, there are empirical studies supporting the hypothesis that a higher incidence of child behavioral difficulties is associated with parental stress (e.g. Stores *et al.,* 1998). A lack of social skills displayed by children and inadequate communication between child and parent are also related to higher parental stress (Smith *et al.,* 2001). Similarly, potential parent factors associated with parental stress include coping strategies (Kim *et al.,* 2003) and their positive perceptions (Hastings and Taunt, 2003). Additionally, environmental factors such as socio-economic status (Willoughby and Glidden, 1995) and level of social support (Ben-Zur *et al.,* 2005; Heller and Factor, 1993; Lustig, 1999) have also been implicated in stress outcomes for parents. Despite such a broad range of factors being investigated under the umbrella of predictors of parental stress, little attention has been paid to synthesizing the findings across studies or to the methodological quality of the research conducted. Appraising and increasing the quality of such studies is imperative to strengthen the evidence base and develop the theories on which practice is based.

Rationale and Aims

It is important to review the empirical support for the factors that may influence parental stress when caring for a child with an intellectual disability. Research emphasizes the importance of considering parental stress when providing services for families, as it has been associated with lower parenting satisfaction, higher parental symptomatology, abusive behavior and insecure child attachment (Smith *et al.,* 2001). Thus, reviewing research within this area has important clinical implications. Firstly, identifying the stressors that parents may experience is valuable for informing clinical interventions for managing parental stress; secondly, a greater understanding of the factors that influence parental stress may highlight factors that are more or less pertinent amongst parents; thirdly, acknowledging different types of factors may be helpful in meeting the needs of parents, improving quality of life for parents/children and thus reducing potential economic burden in the long-term.

Reviews are usually considered to be either 'narrative' or 'systematic'. Traditionally more common, narrative reviews are without a clear and objective method, leaving them open to the subjectivity and bias of the author (Capriani and Geddes, 2003). In contrast, systematic reviews encourage the formulation of clear question (Goodwin and Geddes, 2004) and use specific, explicit strategies to identify, critically appraise and synthesize all relevant issues on a topic (Carney and Geddes, 2002). Whereas a narrative review is likely to focus in more detail on the results of the research reviewed, systematic reviews are more likely to highlight the methodological limitations of primary studies and the risk of publication bias (Goodwin and Geddes, 2004). This is key to assessing the empirical support for the factors being reviewed.

To date, there has only been one literature review that has sought to synthesize data to specifically identify the factors that may influence parental stress (Kwai-sang and Li-Tsang, 1999). In particular, it aimed to examine the adaptive factors that parents utilize to manage their experience of stress when caring for their child with an intellectual disability. This review illuminated a range of attributes that influenced parental stress including personal resources (e.g. personality,

level of education); strength of marital relationships; child characteristics (e.g. severity of disability, communication skills); engaging in support groups and the presence of a social network that parents were satisfied with.
However, an updated review is imperative for three reasons. Firstly, the previous review was not systematically conducted, i.e. it did not identify papers using predetermined inclusion and exclusion criteria. Secondly, it did not assess the quality of the studies included. Thirdly, it only considered studies that included 'two-parent' families and thus their findings may not be applicable to 'single-parent' families. Therefore to account for the studies focusing upon 'single-parent' families that the previous review may have excluded, this review will not restrict the inclusion of studies to a specific year.

This review aims to update and expand on the previous review by (1) systematically identifying and synthesizing the key findings of studies that identify the factors that influence parental stress when caring for a child with an intellectual disability and (2) offering a detailed appraisal of the methodological quality of the research and suggesting implications for further research and clinical practice. The aim is not to offer a detailed account of the major stressors for parents, as a narrative review might, but to critique the available evidence regarding those stressors.

Method

Definition of Intellectual Disability

Intellectual disability is evident in every culture and generation yet there is no universally accepted definition for it. Variations in terminology include 'mental retardation', 'developmental disabilities' and 'learning disabilities', which have all been used to describe an individual's intellectual functioning that is below average (Mildon *et al.,* 2003). Possible explanations for the absence of a clear definition could be reflected in the on-going changes in knowledge and societal responses to people with an intellectual disability (Bray, 2003); individual differences in opinions regarding cut-off points and what 'normality' should be; and difficulties in defining the concept of 'intelligence'. However, following the recent shift of the term 'mental retardation' to 'intellectual disability' in the

recently released Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5; American Psychiatric Association, 2013), the latter term is used for the purpose of this review.

Database Selection

AMED, CINAHL Plus (EBSCOhost), EMBASE, Medline, and PsycINFO databases were searched to identify published English-language journal articles. These databases were chosen as they had a large number of resources relevant to the topic.

Literature Search Strategies

The five electronic databases were individually searched in January 2014. Search strategies were customized for each database (see Appendix). Both medical subject headings (MeSH) and textwords were used as search terms. Additional studies were searched through trawling the references of included studies. As only primary resources (i.e. original research) were included, no searches were carried out to identify secondary (i.e. peer-reviewed articles reviewing or synthesizing original studies) or tertiary (non-peer-reviewed resources such as websites or books) resources.

The key concepts of the review included 'parents', 'intellectual disabilities' and 'stress'. Several search terms for each key concept were used to ensure that the search was covered in sufficient breadth. As an example, search terms used to retrieve articles focusing upon stress included terms such as 'burden', 'strain' and 'wellbeing'. Additionally, a truncation mark (*) was used to search for words with similar meanings but different endings. For example, the term 'intellectual disabilit*' would retrieve words such as 'intellectual disability' and 'intellectual disabilities'. Additionally, search terms were exploded (if necessary) to retrieve articles that may have used different terminology for the same concept. The search terms for each concept were combined together using Boolean operator (OR/AND) to yield a total search number for each database.

Inclusion/Exclusion criteria

Type of studies

Studies were included if they reported original research and were published in peer-reviewed journals, to control for quality, and in English language, for practical reasons. There was no restriction on the year of publication, other than the periods covered by the databases searched. The objective of all included studies was to examine variables that were associated with stress, i.e. stress was a dependent variable. Consequently, studies focusing upon the effectiveness of parenting interventions were excluded, as was one study in which stress was an independent, rather than dependent variable (Gallagher and Whiteley, 2013). Studies had to use a quantitative method of data collection and analysis. Those using a mixed methods design were included but only the quantitative data was extracted for the purpose of this review.

Type of sample

To be included, studies' participants had to be parents (biological, step-, adoptive or foster) of a child with an intellectual disability. Only papers that explicitly stated the child had an intellectual disability (or learning disability or other variations of the term) were included. For example, studies that included parents of children with a 'developmental delay' were excluded unless the authors stated that an intellectual disability was present. This was to ensure that all studies had a consistent sample.

Type of assessment measure

Only studies that explicitly stated that they used a measure of stress were included.

Data Extraction

The titles and abstracts of all studies were read and the eligibility criteria were applied. Titles and abstracts that did not have enough information to apply the criteria resulted in the full text being obtained. The search process is outlined using a QUORUM diagram as shown in Figure 1 below.

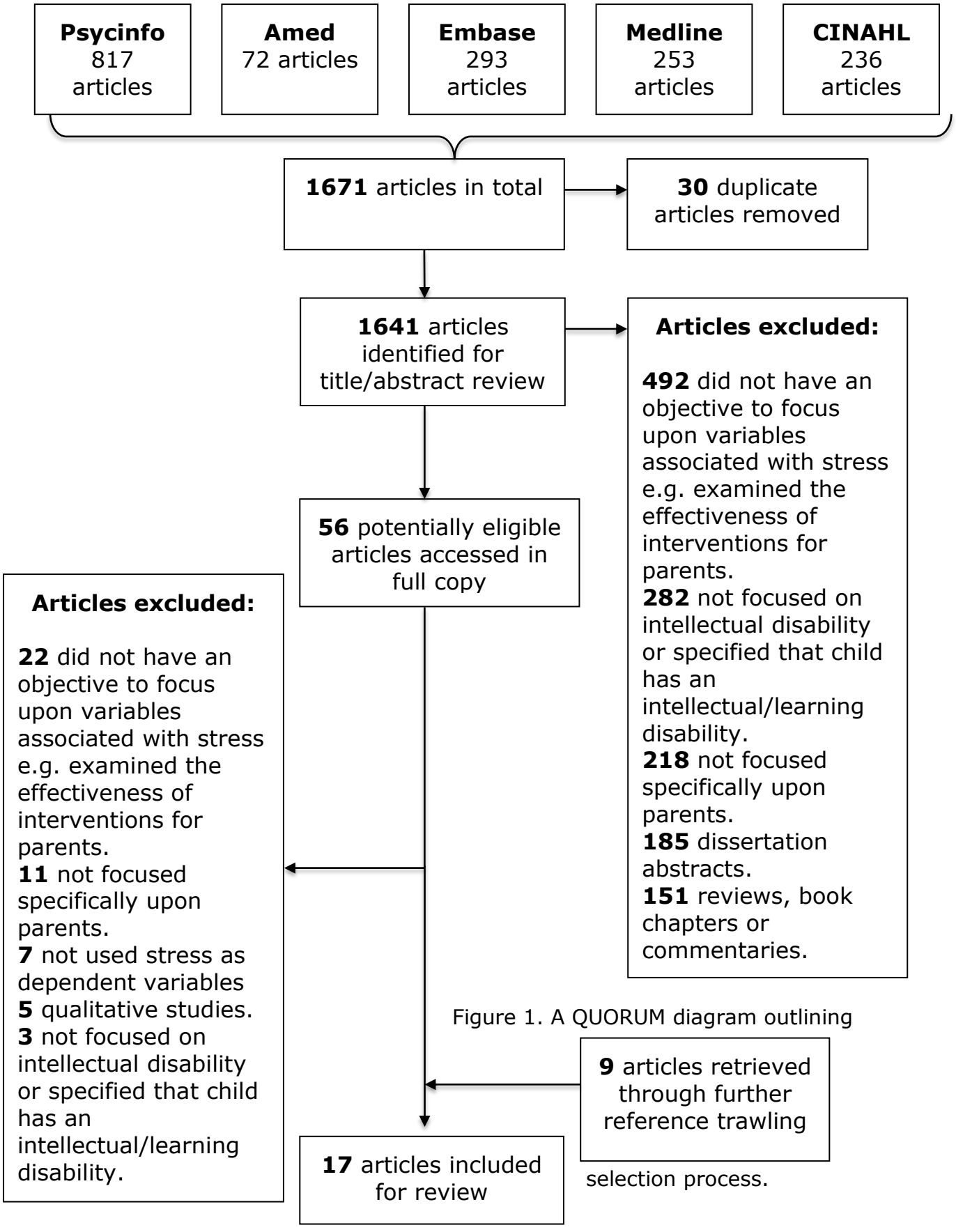

Figure 1. A QUORUM diagram outlining selection process.

A standard data extraction proforma was used to collect the following information from each article: study author(s), date of publication, location, study aims, study design, sample characteristics, stress outcome measure and the key study findings. Meta-analysis was not conducted due to the heterogeneity evident across studies regarding the sample characteristics.

Quality Assessment Tool

Whilst a number of quality rating tools for health research do exist, a majority of them have not undergone a rigorous development process and have not been adopted for widespread use within systematic reviews (Sanderson, *et al.,* 2007). Thus, given that there is no agreed 'gold standard' appraisal tool (Katrak *et al.,* 2004), a bespoke quality assessment tool was developed for this review to assess susceptibility to bias. The development of this tool was guided by two generic rating tools namely the Critical Appraisal Skills Programme (CASP, 2004) and the Newcastle-Ottawa Scale (NOS) due to their broad applicability and ease of use.

The bespoke tool assessed bias by focusing upon specific quality criteria including (1) acknowledgement of intellectual disability including its definition and the child's level of disability; (2) sample representativeness including the representativeness of the population and appropriateness of the sample selection; (3) the reliability and validity of the measures used to assess each variable; (4) design bias including controlling for confounding factors; (5) suitability of statistical analysis. For each criterion, a decision was made as to whether the criterion was present or absent according to specific assignment categories (see Table 1). Additionally, an overall judgment of susceptibility to bias (low, medium, high) for each study was subjectively decided. A numerical scoring system for assessing bias was not used as the accuracy and reliability of weighting individual components remains unclear (Sanderson *et al.,* 2007).

Table 1. Susceptibility to bias guidelines.

Quality criteria	***Assignment categories***
1. Intellectual disability	
Does the study provide a definition of intellectual disability?	***Yes***=There is a clear definition present ***No***=Definition is absent
Does the study specify the level of the child's intellectual disability?	***Yes***=Level of the child's intellectual disability is present ***No***=Level of the child's intellectual disability is absent
2. Sample representativeness	
How representative is the study sample?	***Highly***=Recruited from the general population ***Sufficiently***=Recruited from healthcare services or education populations (e.g. schools, special schools) ***Unlikely=***Unrepresentative

Quality criteria	***Assignment categories***
Is the selection method for study participants appropriate?	***Highly***=Random selection ***Sufficiently*** =Self-selected randomly ***No***=Not a random selection ***Unclear***=No information provided
3. Measures	
Have the studies defined the measures used to assess influencing factors and stress?	***Yes=****Measures have been defined* ***No=****Measures have not been defined*
Have the studies assessed the reliability of the measures used?	***Yes***=Reliability of the measures used have been reported ***No=***Reliability of the measures used have not been reported
Have the studies assessed the validity of the measures used?	***Yes***=Validity of the measures used have been reported ***No=***Validity of the measures used have not been reported

Quality criteria	***Assignment categories***
4. Design bias	
Have confounding factors been identified and controlled for?	***Yes***= Identified and controlled for confounding factors ***No***= Did not identify any confounding factors
Did the study report the analysis used to control the confounding factors?	***Yes***= Explicitly stated the statistical analysis used to control for confounding factors ***No***= Did not state how confounding factors were controlled ***NA***= Did not identify any confounding factors therefore not applicable
Did the study use a comparison group?	***Yes***= A comparison group was present ***No***= A comparison group was not present

Quality criteria	***Assignment categories***
5. Statistical analysis	
Is the analysis adequately powered?	***Yes***=Authors explicitly reported that the study was adequately powered ***Unclear***=No explicit comment to state whether the study was adequately powered
Has the effect size been reported?	***Yes***= Effect sizes for each factor significantly influencing parental stress have been reported ***No***= No effect sizes have been reported
Have Type I and/or Type II errors been controlled?	***Yes*** = Appropriate adjustment for Type I and or Type II errors ***No*** = Type I or Type II errors were not reported or controlled
Are assumptions met for using parametric tests?	***Yes*** = Explicitly states that assumptions have been met ***No*** = Uses parametric tests without explicitly stating whether data meets assumptions for the tests

Results[2]

Characteristics of Identified Studies

Seventeen studies were included in this review, presented in Table 2. They were conducted in the UK (n=7), USA (n=3), Australia (n=1), Israel (n=1), China (n=1), United Arab Emirates (n=1), Ireland, Jordan and Taiwan (n=1), Malaysia (n=1) and Finland (n=1). The studies adopted cross-sectional designs (n=13), longitudinal designs (n=2) or both (n=2). Studies included both mothers and fathers (n=5) or mothers only (n=12). The number of parents ranged from 44 to 246 with a total N across studies of 2256 (1931 mothers and 325 fathers). The age of parents ranged from 19 to 85 years and the age of children with an intellectual disability ranged from 0 to 59 years.

[2] Studies will be referenced using numbers in parentheses, which relate to the study numbers in Table 2. Effect sizes (*r*) will be provided in cases when it has been explicitly reported by studies (Please refer to Table 3).

Table 2. Study characteristics and findings.

Study	Authors (year)/ location	Study aims	Design	Sample	Stress measure	Key findings
1	Baxter (1992)/ Australia	To investigate the influence of parents' perceptions of their child's intellectual disability as mediators of parental stress	Cross - sectional	131 parents * (70 mothers and 61 fathers) of children with ID aged 3-19 years.	One item scale rated on a 5-point Likert scale.	*Child factors:* - Behavior problems and level of dependence predicted parental stress. *Parent factors:* - Parental worry about their child's behavior at home predicted parental stress. - Parent appraisals as salient mediators of parental stress.
2	Beck *et al.* (2004)/ UK	To examine whether children's behavior problems are a more powerful predictor of maternal stress than adaptive behavior.	Cross-sectional	74 mothers * of children with ID aged 3-19 years.	PSI-SF	*Child factors:* -Behavioral problems, lack of child pro-social behavior predicted levels of maternal stress. - Adaptive behavior did not predict maternal stress.

Study	Authors (year)/ location	Study aims	Design	Sample	Stress measure	Key findings
3	Ben-Zur *et al.* (2005)/Israel	(1) To examine mental health, resources and stress amongst mothers who kept their child at home vs placement. (2) To assess the association of mothers' resources with mental health and stress.	Cross-sectional	100 mothers (aged 41-85) of children with an ID aged 20-56 years.	QRS-F	*Child factors:* - Employment status and gender was associated with maternal stress. *Parent/social environmental factors:* - Parent mental health, hardiness, education level and perceived health were associated with maternal stress. - Economic status and social support predicted maternal stress. - Mothers' age and family status did not predict maternal stress.
4	Hassal *et al.* (2005)/ UK	(1) To test the Mash & Johnston (1990) model of parenting stress with mothers of children with ID. (2) To examine the effects of parental cognitions on parental stress.	Cross-sectional	46 mothers (aged 21-49) of children with ID aged 6-16 years	PSI-SF	*Child factors:* - Behavioral difficulties predicted maternal stress. *Parent factors:* - Parent satisfaction and locus of control predicted stress. Parent locus of control mediates parent stress.

Study	Authors (year)/location	Study aims	Design	Sample	Stress measure	Key findings
5	Hill and Rose (2009)/ UK	(1) To establish the importance of the variables in predicting stress. (2) To investigate the mediating effect of parent cognitive variables on the relationship between child and environmental characteristics and parent stress.	Cross-sectional	44 mothers (aged 51-84) of adults with ID aged 30-59 years.	PSI-SF	<u>*Child factors:*</u> - Maladaptive behavior did not predict parental stress. <u>*Parent factors:*</u> -Parent self-efficacy and locus of control predicted stress. -Parent satisfaction partially mediated the relationship between (1) adaptive behavior and stress and (2) social support and stress.
6	Huang *et al.* (1998)/China	Examined correlates of stress level in Chinese mothers of a child with MR**	Cross-sectional	135 mothers (aged 36-41) of children with MR aged 11-15 years.	PSI (translated from English into Chinese)	<u>*Child factors:*</u> - Level of intellectual functioning predicted maternal stress. <u>*Parent/social environmental factors:*</u> - Belief in Confucianism, negative neighbor attitudes towards their child predicted maternal stress. - Economic status of mother, age of mother, social support did not predict maternal stress.

Study	Authors (year)/location	Study aims	Design	Sample	Stress measure	Key findings
7	Khamis (2007)/ United Arab Emirates (UAE)	(1) To investigate predictors of parental stress and psychological distress. (2) To examine the contributions of child characteristics, parents' socio-demographics and family environment to parental stress.	Cross-sectional	225 parents (113 fathers; 112 mothers) (aged 21-85yrs) of children with ID aged 1-23 years.	QRS-F	<u>*Child factors:*</u> - Age is negatively predictive of parental stress. Severity of disability did not predict parental stress. <u>*Parent/social environmental factors:*</u> - Fathers' employment status, and family environment predicted parental stress.
8	Kim *et al.* (2003)/USA	To identify whether coping style affects maternal wellbeing (includes subjective caregiver burden).	Longitudinal	246 mothers (aged 56-85) of children with ID aged 35 years.	ZBS	<u>*Child factors:*</u> - Behavioral problems and an increase in behavioral problems over time predicted subjective caregiver burden over time. <u>*Parent/social environmental factors:*</u> - Problem-focused coping and emotion-focused coping predicted subjective caregiver burden at wave 1. Higher levels of emotion-focused coping and lower levels of problem-focused coping at wave 2 predicted higher levels of caregiver burden. wave 2. - Co-residency predicted subjective caregiver burden whereas mothers' age and a pile up of other life stressors (e.g., divorce) did not.

Study	Authors (year)/location	Study aims	Design	Sample	Stress measure	Key findings
9	Lloyd and Hastings (2008)/ UK	Examined whether acceptance, mindfulness and avoidant coping explain variance in maternal distress (included stress as a variable) at time 1 and time 2 (18 months later)	Cross-sectional and longitudinal	91 mothers (aged 28-58) of children with ID aged 3-19 years at time 1. 57 mothers at time 2.	QRS-F	*Child factors:* Behavior problems predicted maternal stress. *Parent/social environmental factors:* - Family deprivation and parent acceptance predicted stress. - Active-avoidance coping strategy did not predict stress and acceptance was not a predictor over time.
10	Lloyd and Hastings (2009)/ UK	(1) Examined the association between locus of control and parent stress at time 1 and time 2.	Cross-sectional and longitudinal	Time 1: 91 mothers (aged 28-58) of children with ID aged 3-19 years. Time 2: 57 mothers.	QRS-F	*Child factors:* - Behavior problems predicted maternal stress. *Parent/ social environmental factors:* -Family deprivation predicted stress over time. Locus of control did not predict stress over time.

Study	Authors (year)/location	Study aims	Design	Sample	Stress measure	Key findings
11	McConkey *et al.* (2008)/ Ireland, Taiwan & Jordan	To identify variables that have a negative impact upon maternal wellbeing (stress included as a variable).	Cross-sectional	209 mothers * (98 Taiwan; 62 Ireland; 49 Jordan) of children with ID aged 5-18 years.	QRS-F	*Child factors:* - Child behavior problems predicted stress. Other child demographics including gender and age did not predict stress. *Parent factors:* - Coping did not predict stress.
12	Neece and Baker (2008)/ USA	(1) To identify whether child social skills and behavior problems account for parent stress. (2) To identify whether child behavior problems and social skills interact in predicting stress. (3) To examine whether the relationship between parent stress, child social skills and child behavior problems are stable over time.	Longitudinal	189 mothers (mean age of 39) of children with ID aged 3-9 years.	FIQ	*Child factors:* - Cognitive status, behavior problems, social skills predicted stress at time 1 and time 2.

Study	Authors (year)/location	Study aims	Design	Sample	Stress measure	Key findings
13	Ong *et al.* (1999)/ Malaysia	To determine factors associated with parental stress among a group of Malaysian mothers of children with MR**.	Cross-sectional	75 mothers (mean age of 36.3) of children with MR aged 4-12 years.	PSI (translated from English to Malaysian)	*Child factors:* - Child behavior, IQ score predicted maternal stress. *Parent/social environmental factors:* - Mothers' employment status and number of children in the family predicted stress.
14	Peer and Hillman (2012)/USA	To examine the mediating influence of coping style on the relationship between stress influencing variables and parents stress perception	Cross-sectional	127 parents (96 mothers and 31 fathers) (aged 29-77) of children with an ID aged 2-26 years.	PSI-SF	*Child factors:* - Psychological severity of disability was a predictor of stress perception. -Physical severity was not a predictor of stress perception. *Parent/social environmental factors:* - Optimism, parent gender and social support predicted stress perception. - Coping style partially mediated the relationship between social support and stress perception. - Coping style was not a significant mediator between parental optimism and stress perception.

Study	Authors (year)/location	Study aims	Design	Sample	Stress measure	Key findings
15	Quine and Pahl (1991)/UK	To investigate (1) the factors associated with stress amongst mothers of children with severe LD	Cross-sectional	166 mothers * of children with LD aged 0-16 years.	MI	*Child factors:* - Severity of physical and intellectual impairment, academic skills, communication skills, age, behavior and sleep problems, mobility, dependency and caretaking demands predicted maternal stress. *Parent/social environmental factors:* - Maternal demographics, coping strategies and level of social support predicted maternal stress.
16	Saloviita *et al.* (2003)/ Finland	To examine the predictive power of selected variables from the Double ABCX model in explaining parental stress.	Cross-sectional	236 parents (aged 19-84)(116 mothers, 120 fathers) of children with ID aged 1-10 years.	QRS-FIN	*Child factors:* - Challenging behavior predicted parental stress. *Parent/social environmental factors:* - Maternal stress was predicted by the definition of the situation as a 'catastrophe', informal support, marital relationship, negative coping strategies, formal support, adaptive behavior. - Paternal stress was predicted by definition of the situation as a 'catastrophe', marital relationship, negative coping strategies, challenging behavior, instrumental support, locus of control, social support and adaptive behavior.

Study	Authors (year)/location	Study aims	Design	Sample	Stress measure	Key findings
17	Stores *et al.* (1998)/UK	To investigate the association between children's daytime behavior problems and maternal stress.	Cross - sectional	71 mothers * of children with ID aged 3.8-18 years.	MI	<u>*Child factors:*</u> - Level of irritability, hyperactivity and stereotypical behavior (e.g., repetitive habits) predicted maternal stress. - Lethargy and inappropriate speech (e.g., excessive and repetitive speech) did not predict maternal stress.

Note: * Parent age not reported; ** This is the term cited by the authors of the article; PSI= Parenting Stress Index (Abidin, 1990; 1995); PSI-SF= Parenting Stress Index-Short Form; QRS-F= Questionnaire on Resources and Stress (Friedrich *et al.,* 1983); QRS-FIN= Questionnaire on Resources and Stress, Modified Finnish version; FIQ= Family Impact Questionnaire (Donenberg and Baker, 1993); MI= Malaise Inventory (Rutter *et al.,* 1970); ZBS = Zarit Burden Scale (*Zarit et al.,* 1980); LD= Learning Disabilities; ID= Intellectual Disabilities; MR= Mental Retardation

Table 3. Effect-size of the relationship between factors and parental stress.

Study	*Significant factors influencing parental stress*	*Effect-size (r)*
1	Child behavioral problems	.32[a]
	Level of child dependence	.26[a]
	Parental worry about their child's behavior at home	U
2	Child pro-social behavior	-.33*
	Child behavioral problems	.50*
3	Mother's mental health	-.53[d]
	Social support	.53[d]
	Hardiness	-.47[d]
	Economic status	-.30[a]
	Education level	-.34[c]
	Perceived health	-.21[a]
	Child gender	.20[b]
	Child employment status	-.37[a]
4	Child behavioral difficulties	.48[a]
	Parent satisfaction	U
	Parent locus of control	.67[a]
5	Parent self-efficacy	-.63[a]
	Parent locus of control	.62[a]
6	Child intellectual functioning	-.03[b]
	Belief in Confucianism	-.04[b]
	Neighbors' attitude	.03[b]
7	Child age	-.11*[b]
	Father's employment status	-.12*[b]
	Family environment	.09*

Study	*Significant factors influencing parental stress*	*Effect-size (r)*
8	Co-residence	.13[a]
	Child behavioral problems	.13[b]
	Increase in behavioral problems over time	.20[c]
	Problem-focused coping	-.11[a]
	Changes in problem-focused coping	-.15[c]
	Emotion-focused coping	.28[c]
	Changes in emotion-focused coping	.31[c]
9	Child behavioral problems	.33*[c]
	Family deprivation	.21*[c]
	Parent acceptance	-.20*[c]
10	Child behavior problems	.21*[c]
	Family deprivation	.12*[c]
11	Child's problem behaviors	.26*[c]
	Poorer family functioning	.31*[c]
	Poorer maternal mental health	.19*[c]
12	Child cognitive status	.17*[c]
	Child behavioral problems	.24*[c]
	Child social skills	-.13*[b]
13	Child IQ	-.57[a]
	Child behavior	.36[a]
	Number of children in the family	.20[a]
	Maternal unemployment	.27[a]

Study	*Significant factors influencing parental stress*	*Effect-size (r)*	
14	Parent optimism	-.52*[a]	
	Parent gender	.01*[b]	
	Social support	-.13*[a]	
	Psychological severity of disability	.09*[a]	
15	Child behaviour problems	.30[a]	
	Child age	-.22[a]	
	Recent maternal ill health	.62[c]	
	Parents' perceived coping skills	-.51[c]	
	Parental acceptance of child	-.37[c]	
	Financial worries	.32[c]	
	Social class	.30[c]	
16	Child challenging behavior	*Mothers**	*Fathers**
	The definition of the situation as a 'catastrophe'	X	.23
	Informal support	.48	.49
	Marital relationship	-.41	X
	Negative coping strategies	-.34	-.36
	Formal support	.28	.34
	Instrumental support	-.22	X
	Adaptive behavior	X	-.20
	Locus of control	-.12	.16
		X	-.19
17	Child irritability	.49[c]	
	Child hyperactivity	.50[c]	
	Child stereotypic behavior	.29[a]	

Note: *r* values indicate effect-sizes where *r*=.1 is denotes a small effect-size, *r*= .30 denotes a medium effect-size and *r*=.50 denotes a large effect-size. U=unknown/not reported; * *r* estimates are based upon standardized beta (B) coefficients as research proposes that B values can be used as an indicator of effect-size (see Nathans *et al.,* 2012); [a] findings are significant at p<.01 level; [b] findings are significant at p<.05 level; [c] findings are significant at p<.001 level; [d] findings are significant at p<.0001 level; X=no significant relationship was found.

Factors Influencing Parental Stress[3]

The studies identified factors that influenced parental stress. These factors were related to child, parent and social environmental characteristics. Additionally, four studies identified intervening variables (mediators) of the relationship between specific influencing factors and parental stress (1,4,5,14). A synthesis of the results revealed contrasting evidence as outlined below.

Child variables

All studies found a range of child variables that significantly influenced parental stress. Over half the studies found that a higher incidence of child behavioral difficulties significantly predicted higher parental stress (1,2,4,8,9,10,11,12,13,15,16,17). From the studies that had reported the effect size for child behavioral difficulties, the *r*-value ranged from .13 to .50, indicating mixed findings for the strength of its contribution to parental stress. Additionally, a lower age (*r*=.11) (7) and lower level of intellectual functioning (6,12,13,14,15) predicted higher parental stress. Similarly a lower level of social skills, including a lack of empathy and helping behavior, predicted higher parental stress with *r* ranging from -.13 to -.33 (2,12). Furthermore, children with lower intellectual functioning, poor social skills and behavioral difficulties were found to predict parental stress over time (8,12). However, in contrast, one study found that behavioral difficulties did not significantly increase parental stress (5). Similarly, two studies found that child demographic characteristics such as their age (11) or the severity of the disability (5) did not significantly influence parental stress.

[3] The reviewed studies have examined factors that 'predict' or 'influence' parental stress. This article has used the same terminology although it is acknowledged that no causal relationship between the factors and parental stress can be assumed (as discussed further in the discussion of limitations section).

Parent variables

Fourteen studies (1,3,4,5,6,7,8,9,10,11,13,14,15,16) found important parent variables that significantly influenced parental stress. Many of these related to parents' sense of agency and their emotional or cognitive responses to their circumstance. For example, low self- efficacy (r=-.63) (5) and having an external locus of control (4,6,10) predicted higher levels of parental stress, although one study (16) found locus of control to influence parental stress for fathers only and was not maintained over time. A lack of acceptance of their child's disability with r ranging from -.20 to -.37 (9,15); appraisal of the situation as a 'catastrophe' (r=.23) (16); and worrying about their child's behavioral difficulties (1) predicted higher levels of parental stress.

There were mixed results regarding parents' coping strategies. Two studies found stress to be predicted by coping strategies such as avoidance or self-blame (11,15) By contrast, one study concluded that coping strategies did not influence parental stress (11) whereas another highlighted that certain coping styles such as active-avoidance coping did not influence parental stress (9). A longitudinal study highlighted that emotion-focused, rather than problem-focused, coping predicted stress at both time points, but that participants who used more emotion-focused coping over strategies over time reported increasing levels of burden while those who decreased such strategies found their perceived burden to decrease (8). Other parental factors identified to predict stress were cultural beliefs (6); perceived health (3); education level (3); being unemployed (7,13) and the employment status of both mothers (13) and fathers (7).

Social environmental variables

Ten studies found social environmental variables that significantly predicted parental stress. These included variables related to the family environment (r=.09) such as a lack of family cohesion and organization/rules applied to operate family life (7); perceived negative attitudes of others (6); co-residency with the child with an intellectual disability (8); family deprivation such as having a low family income, where r ranged from .12 to .21 (9,10); dissatisfaction within marital relationships; a low economic status; the number

of children within the family (13) and a low level of social support (3,14,15,16). In contrast, one study found that social support did not influence parental stress (6).

Intervening variables

Only four studies assessed mediators of the relationship between influencing factors and parental stress. One study revealed that parent perceptions, such as of themselves as being inadequate, mediated parental stress when caring for a child with an intellectual disability (1). Similarly, another study identified that parents' sense of satisfaction partially mediated the relationship between (a) social support and parental stress and (b) adaptive behavior and parental stress (5). By contrast, one study found no evidence that parent satisfaction functioned as a mediator (4). Instead, this study revealed that parent locus of control mediated the effects of family support on parent stress. Lastly, one study identified parental coping style only as a partial mediator of perceived stress in parents of individuals with an intellectual disability (14). Specifically, this study found that parental coping style mediated the relationship between social support and perceived stress but not between parental optimism and perceived stress.

Methodological Quality of Included Studies

Results of the susceptibility to bias for each study are presented in Table 4. The results are considered for each quality criterion in turn.

Intellectual disability

None of the studies provided a definition for intellectual disability. Eleven studies reported the level of intellectual disability that the child had (1,2,6,7,8,9,10,12,15,16,17). However, there was variability in the reporting of classification systems used to determine the child's level of disability. Some either used no such system or omitted this information (1,3,6,7,13,14,15,16) while others reported use of an adaptive behavior assessment (2,4,5,9,10) or a subtest of one (11). Two relied on previous assessments (8,17) and just one

study reported use of a classification system including both a measure of intellectual ability and adaptive behavior (12).

Sample representativeness

Only one study was considered to use a highly representative sample, as it recruited both from agencies providing services for people with intellectual disability or mental illness and also advertised for participants in general newspapers (8). No other study recruited from a general population. Two studies recruited participants from within special schools and local education centers (7,11) and three studies recruited participants from a database or register of or with known cases of people with intellectual disabilities in Israel (3), Finland (16) or a single urban district in the UK (5). The remaining twelve studies recruited participants through advertising within special schools only (1,2,4,6,9,10,17), a hospital setting (13), a community mental health agency (12,14) or from both health, education and social services (15). Recruitment from special schools, education centers, health services or databases suggests that the study samples were only sufficiently representative i.e. they did not account for parents of children with intellectual disabilities who were not accessing education or health services or captured by local databases. Additionally, given that some participants were recruited from one country (e.g. Finland, China) or area (e.g. south-east England), it is important to note that their findings may not be representative of wider regions. By contrast, one study recruited participants across three countries: Ireland, Taiwan and Jordan (11). However, the authors explicitly stated that it should not be assumed that all participants were representative of their culture.

Furthermore, the selection method was highly appropriate for five studies (1,6,7,15,16) in which participants were randomly selected. A random selection of participants is highly appropriate as this reduces the likelihood of bias compared to non-randomized samples. Ten studies did not explicitly state whether random selection was used (2,3,4,5,8,9,10,12,14,17) and therefore the quality of their selection method remains unclear. One study did not have an appropriate selection method as a random selection procedure was not used (13). Instead, this study automatically included participants into the study once

they had been referred to the hospital. Although this non-random sample is deemed to be inappropriate according to the quality criteria guidelines, it may have its advantages. For example, including all parents of children that had been referred to the hospital may improve the applicability of the findings to those accessing services within hospitals.

Measures

All studies but one (17) provided a clear definition of the measures used to assess influencing factors and parental stress. Six studies did not report the reliability and validity of the tools used to measure stress or the identified factors (2,6,9,10,13,17). Only three studies reported both values (4,14,15). The remaining eight studies reported the reliability values only (1,3,5,7,8,11,12,16). Generally, these studies used potentially reliable tools for measuring stress and its influencing factors. This was reflected in their reported values for internal consistency as measured by Cronbach's alpha ($\alpha \geq 0.7$). In particular, three studies used translated versions of the Parenting Stress Index (PSI) (6,13) and Questionnaire on Resources and Stress (QRS-F) (16). Even though the authors reported high internal consistencies for these measures, the representativeness of them may be limited to the specific populations included in the studies (China, Malaysia and Finland).

Design bias

Ten studies reported having controlled for confounding factors (1,2,7,8,9,11,12,14,15,16). This included demographic variables for parent and child including their gender, age, socio-economic status, relationship status, mental health status and the residential status of the child. Further confounding factors included the number of children that parents had, their previous coping experiences and level of social support. Of the ten studies, confounding factors were controlled for when entered into regression analyses. (1,2,8,9,12,14,15) or by using additional statistical analysis including Multivariate Analysis of Variance (MANOVA) (7,11) and Mahalanobis' Distance (16).

Two studies used a comparison group of parents of a child with typical development (12,13), one had a comparison group of children with mental illness (8) and another had comparison groups of children with Down's Syndrome, children with no intellectual disability and siblings (17). One study explicitly reported that they had accounted for group differences in maternal health, child health and maternal education by ensuring that these variables were covaried in all analyses (12). However, the three other studies stated that there were no significant differences between the groups (8,13,17).

Statistical analysis

None of the studies explicitly stated whether the analysis was adequately powered and only one study used a correctional analysis (Bonferroni) to control for type 1 error (13). Only five studies reported whether the data was suitable for parametric analyses (4,5,9,10,16). In particular, these studies had reported whether the variables were normally distributed. Additionally, all studies reported the effect-sizes for each individual factor that was significantly associated with parental stress.

Overall susceptibility to bias

Six studies were judged to have a low susceptibility to bias (1,7,11,14,15,16), three had a medium susceptibility (4,8,12) and eight studies had a high susceptibility (2,3,5,6,9,10,13,17). Those with a low susceptibility to bias typically had a representative sample, reported appropriate reliability or validity values of their measures and controlled for confounding factors. However, those with a high susceptibility to bias potentially had an unrepresentative sample, did not report reliability or validity of measures used, did not identify and control for confounding factors or encompassed all of these limitations (10,13).

Table 4. Susceptibility to bias results.

Quality criteria	***Study***																
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Intellectual disability																	
Definition	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Level	Y	Y	N	N	N	Y	Y	Y	Y	Y	N	Y	N	N	Y	Y	Y
Sample representative																	
Population	S	S	S	S	S	S	S	H	S	S	S	S	S	S	S	S	S
Appropriate selection	H	U	U	U	U	H	H	S	U	U	S	U	N	S	H	H	S
Measures																	
Definition	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N
Reliability	Y	N	Y	Y	Y	N	Y	Y	N	N	Y	Y	N	Y	Y	Y	N
Validity	N	N	N	Y	N	N	N	N	N	N	N	N	N	Y	Y	N	N
Design bias																	
Confounding factor	Y	Y	N	N	N	N	Y	Y	Y	N	Y	Y	N	Y	Y	Y	N

Quality criteria																	
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Analysis used	Y	Y	NA	NA	NA	NA	Y	N	Y	NA	Y	Y	NA	Y	Y	Y	NA
Comparison group	N	N	N	N	N	N	N	Y	N	N	N	Y	Y	N	N	N	Y
Statistical analysis																	
Adequate power	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U
Effect-size	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Type I or Type II error	N	N	N	N	N	N	N	N	N	N	N	N	Y	N	N	N	N
Assumptions met	N	N	N	Y	Y	N	N	N	Y	Y	N	N	N	N	N	Y	N
Overall bias judgment	L	H	H	M	H	H	L	M	H	H	L	M	H	L	L	L	H

Note: Y=Yes; N=No; U=Unclear; H=Highly appropriate; S=Sufficiently appropriate; NA= Not Applicable; H=High likelihood of susceptibility to bias; M=Medium likelihood of susceptibility to bias; L=Low likelihood of susceptibility to bias

Discussion

This section provides a critical discussion of the findings from the review. Firstly, the methodological quality of the included studies are discussed followed by the key findings of the review. Future implications are then outlined which includes suggestions for improving the quality of future research. Lastly, limitations of the included studies and of this review are provided.

Methodological Quality

The quality assessment showed some evidence of good quality characteristics but also highlighted that some studies encompassed serious methodological limitations. Sometimes these were limitations of the design, such as narrow recruitment strategies or not accounting for type I or type II errors to control for potential factors that may have confounded the results. It was unclear whether other methodological issues were a limitation of the design and conduct of studies or of how they were reported. For example, authors frequently did not report reliability or validity values of the measures used; did not acknowledge effect-sizes of the relationship between factors and parental stress; and failed to comment whether their statistical analysis was adequately powered. Such issues could be easily addressed by researchers in order to improve the quality of studies.

Interestingly, the studies that had sufficiently representative samples, used measures with good reliability and validity and accounted for confounding factors also incorporated larger sample sizes (n>100) and included both mothers and fathers as participants (Baxter, 1992; Huang *et al.*, 1998; Khamis, 2007; Peer & Hillman, 2012). This suggests that these studies may have been more likely to be representative of parents caring for a child with an intellectual disability and that their findings may be more applicable to both mothers and fathers.

A surprising finding was that no study provided a definition for 'intellectual disability'. This brings into question precisely what characteristics the authors considered to be representative of an individual with an intellectual disability. It

is therefore unclear how the authors categorized their sample and how generalizable their results may be. Providing a definition could have helped to understand the similarities or discrepancies of parents' experiences in relation to stress when caring for their child. Future studies could enhance the quality of their research by providing an understanding of how they define an intellectual disability. While there is acceptance of a broad description of intellectual disability, specific definitions vary. Providing a specific definition within research studies is critical for informing our understanding of how intellectual disability is conceived across different cultures and how it may impact the experiences of the individual and their families.

Key Findings

The review highlighted contrasting evidence within three types of variables: child, parent and socio- environmental. Each will be discussed in turn.

In relation to child variables, the majority of studies reviewed concluded that a higher incidence of child behavioral difficulties predicted higher parental stress. However, the effect-sizes reported for this relationship ranged from small to large. The heterogeneity of effect sizes suggests that future studies would benefit from moderator analyses, to identify variables that affect the magnitude of relationship between child behavioral difficulties and parental stress. Additionally, one study did not find a significant relationship between these variables (5). This could possibly be accounted for by methodological weaknesses. For example, the validity values for the measures used were not reported, which may not have been adequate enough to assess parental stress or behavioral difficulties.

With regard to parental factors, there were significant inconsistencies in relation to whether particular coping strategies were predictive of parental stress. Some studies found this to be the case, supporting psychological models such as Lazarus and Folkman's (1984) transactional model, which emphasizes how individuals utilize coping strategies to reduce their stress. One study that found an association between coping styles and stress also highlighted that coping strategies changed across time were associated with changes in stress (Kim et

al., 2003). This emphasizes the importance of not assuming that coping styles are static, even without intervention to change them.

By contrast, the relationship between stress and coping was not supported by one particular study (11). Despite this cross-cultural study being judged to have a low susceptibility to bias, the lack of association between stress and coping could have been due to having a self-selected sample. For example, cultural differences amongst mothers who were not known to the services or who declined to participate in the study may have been significantly masked.

Social and environmental factors were also found across the studies. Three studies in this review found that a lower level of social support predicted higher levels of parental stress (3,15,16). However, one study did not support this finding (6). This could relate to the use of the PSI measure after translation from English into Chinese with no report of its reliability or validity. Whilst cultural adaptation of measures has considerable advantages, such as a greater ability to investigate differences and similarities within a diverse population (Hambleton, 2005), research highlights that the mere translation of a measure does not ensure reliable results (Maneesriwongul and Dixon, 2004). Thus, future research using culturally adapted measures could consider including an analysis of the psychometric properties of the original measure and its new version (International Test Commission, 2010) to improve the reliability of their results.

Limitations and Implications

Before considering the implications of these findings, it is important to draw upon the limitations of the reviewed studies. In general, a majority employed cross-sectional designs, where causality cannot be inferred. Underlying mechanisms that may lead to parental stress were not generally considered, with only four examining mediating factors of parental stress. Although the papers (and this review) are couched in terms of 'factors that influence parental stress', it is difficult to discern causality from the correlational evidence to date. Therefore the possibility of bi-directional relationships between factors and parental stress remains unclear. For example, it could be hypothesized that

parental stress may influence some of the factors that are being analyzed as putative causes of parental stress.

Parental wellbeing could contribute to child behaviors (Blacher et al., 2005) and/ or affect parent perceptions of self-efficacy in a way that ultimately impacts upon child behavioral difficulties. Additionally, research suggests that unhelpful thinking styles are associated with stress (Williams and Garland, 2002). Thus, parents may magnify or catastrophize the perceived severity of factors (such as having a poor family environment) when under stress. Little attention was paid to such possibilities in the reviewed studies.

It is difficult to draw conclusions about the magnitude of particular factors due to the omission of explicit effect-sizes in the reporting of many studies, the reporting of which is recommended to convey the full meaning of results (American Psychological Association, 2009).

Fathers made up less than 15% of the total sample across the included studies, suggesting they are significantly underrepresented in the literature about parental stress for those caring for a child with intellectual disabilities. It is unclear whether this relates to mothers being overrepresented amongst parent carers of children with intellectual disabilities, but warrants further investigation.

Notwithstanding these limitations, the findings from this review offer some support to existing research. Most crucially, the illuminate contrasting evidence in relation to the factors that influence parental stress, highlighting the heterogeneity of parents of a child with an intellectual disability and likely variability in the triggers and responses to individuals' stress. This poses a challenge to the development of evidence-based practice relating to supporting parents of children with intellectual disabilities to promote both their wellbeing and that of their child. It is important for clinicians to apply the available evidence cautiously when working with individual parents or families and be open to the possibility of a range of influential factors, with varying relationships.

Looking across the reviewed studies, it is evident that there are a number of recurring factors that we could seek to influence as clinicians (with potential to thereby modulate experiences of stress). Possible foci of intervention would appear to be in: (1) managing *child behavior* (behavioral interventions on the basis of functional analysis); (2) working with *parent perceptions* (e.g., interventions challenging catastrophizing versus optimistic thinking and beliefs around self-efficacy/coping); (3) promoting *social support* (e.g., connecting parents and families with others in their situation; facilitating groups and signposting to networks); (4) working relationally and systemically with families to address *family environment* and *marital* factors; and (5) recognizing the real impact of *deprivation* and financial worries – as clinicians we may have an important role in coordinating with local services that can provide advice and support regarding social welfare, employment, and debt management. Overall, a holistic, multi-level approach would seem most apt to promote the wellbeing of parents of children with intellectual disabilities. This would seem consistent with recommended practice in working with individuals with intellectual disabilities in any case – i.e., a whole-systems approach.

Furthermore, this review has highlighted implications for future research in terms of both design and reporting. Firstly, it would be useful to conduct prospective studies that investigate the interaction between parent, child and socio-environmental factors upon parental stress. This would provide a more detailed understanding of the potential bi-directional effects that occur between variables. There is a need for research into *how* specific factors influence parental stress, or vice versa, in order to inform clinical practice. In particular, further research of potential mediating/moderating factors that may impact parenting stress would enhance our understanding of possible mechanisms. Secondly, future research is needed to examine whether changing predictive factors actually influences parental stress outcome (e.g., does an intervention reducing child behavior problems lead to reductions in parental stress?).

Thirdly, further investigations into paternal stress would be fruitful for addressing the under-representation of fathers within research in this field. This could highlight potential similarities or differences between maternal and paternal stress, informing clinical practice with parents of both genders.

Similarly, given intellectual disabilities are found globally, greater representation of families from a range of cultural backgrounds will increase the relevance of theory to international practice.

This review did not restrict the age range of the children with an intellectual disability, which was 0 – 59 years. Age range is an important factor for generalizing results or comparing key findings between studies or when applying them to clinical practice. However, whilst there is empirical support within this field for child age as a predictor of parental stress (Baker *et al.,* 2003; Orsmond *et al.,* 2003), the review findings were not fully supportive of this assumption. Therefore it is difficult to definitively conclude whether age is a significant issue and future research is warranted to investigate the relationship between child age and parental stress further.

For researchers and journal reviewers / editors, this review emphasizes some simple steps that improve the quality of published papers. These include reporting the reliability and validity of measures, power calculations, effect sizes, type I and II errors and whether assumptions are met for analysis.

The limitations of this review must be acknowledged. Firstly, this review only included published studies, perhaps reflecting a publication bias. Secondly, the quality assessment tool was adapted for the purposes of this review. Therefore certain quality criteria that could be important to assess within studies (such as their clinical/research implications) may have been excluded. Due to the scope of the literature review, only one researcher conducted the quality assessment of the included studies and therefore inter-rater reliability could not be established.

Finally, this review used standardized beta (B) values to estimate effect-sizes when they were not reported as a Pearson's *r*-value. This technique has been outlined by recent research (see Nathans *et al.,* 2012). However, it is noteworthy that using B values can often be problematic in cases where variables are correlated with each other. For example, a given B value may receive more credit for explaining the variance that it shares with one or more independent variables (Pedhazur, 1997).

Conclusion

This review illuminates contrasting evidence and offers some support for existing research focusing upon parental stress when caring for a child with an intellectual disability. The findings emphasize the need for researchers to consider improving components of both the design and reporting of studies to enhance their quality. The review also provides a number of implications for future clinical practice and research. These implications suggest adopting a whole-systems approach into both research and clinical practice to aid understanding of parental stress when caring for a child with an intellectual disability.

References

* Denotes included in review.

Abidin, R. R. 1990. *Parenting Stress Index.* Odessa, FL: Psychological assessment resources.

Abidin R. R. 1995. *Parenting Stress Index.* 3rd Ed. Odessa, FL: Psychological assessment resources.

American Psychiatric Association. 2013. Intellectual disability. *American Psychiatric Publishing*, www.dsm5.org (accessed 23 June 2013).

American Psychological Association. 2009. *Publication manual of the American Psychological Association*. 6th Ed. Washington, DC: Authors.

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C. and Low, C. 2003. Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time, *Journal of Intellectual Disabilitly Research,* 47(4-5): 217-230. DOI: 10.1046/j.1365-2788.2003.00484.x

*Baxter, C. 1992. Appraised significance of intellectual disability for parents of children in three age cohorts: exploring the stress process, *Journal of Intellectual Disability Research*, 36(6): 519-529. DOI: 10.1111/j.1365-2788.1992.tb00570.x

*Beck, A., Hastings, R. and Daley, D. 2004. Pro-social behaviour and behaviour problems independently predict maternal stress, *Journal of Intellectual & Developmental Disabilities*, 29(4): 339-349. DOI:10.1080/13668250400014509

*Ben-Zur, H., Duvdevany, I. and Lury, L. 2005. Associations of social support and hardiness with mental health among mothers of adult children with intellectual disability, *Journal of Intellectual Disability Research*, 49(1): 54–62. DOI: 10.1111/j.1365-2788.2005.00662.x

Blacher, J., Neece, C.L. and Paczkowski, E. 2005. Families and intellectual disability. *Current Opinion in Psychiatry,* 18(5): 507 - 513.

Bray, A. 2003. Definitions of intellectual disability: Review of the literature prepared for the national advisory committee on health and disability to inform its project on services for adults with an intellectual disability, *Donald* Beasley,

www.donaldbeasley.org.nz/publications/NHC_Definitions.pdf (accessed 27 July 2013).

Carney, S.M. and Gesses, J.R. 2002. *Systematic reviews and meta-analyses. Evidence in Mental Health Care.* Brunner Routledge: Hove.

CASP. 2004. Critical Appraisal Skills Programme. *CASP*, http://www.casp-net.uk (accessed 20 January 2014).

Cipriani, A. and Geddes, J. (2003). Comparison of systematic and narrative reviews: the example of the atypical antipsychotics. *Epidemiologia e Psichiatria Sociale*, 12(3): 146 - 154. DOI: http://dx.doi.org/10.1017/S1121189X00002918

Donenberg G. and Baker, B. L. 1993. The impact of young children with externalizing behaviors on their families, *Journal of Abnormal Child Psychology,* 21(2): 179–98. DOI: 10.1007/BF00911315

Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S., Evison, F. and Glover, G. 2012. People with learning disabilities in England 2011: Service & Supports. *Improving health and lives*. http://www.improvinghealthandlives.org.uk (accessed 20 July 2013).

Friedrich, W. N., Greenberg, M. T. and Crnic, K. 1983. A short- form of the questionnaire on resources and stress, *American Journal of Mental Deficiency*, 88(1): 41–48.

Gallagher, S. and Whiteley, J. (2013). The association between stress and physical health in parents with intellectual disabilities is moderated by children's challenging behaviours. *Journal of Health Psychology*, 18(9): 1220 - 1231. DOI: 10.1177/1359105312464672

Goodwin, G.M. and Geddes, J.R. 2004. Introduction to Systematic Reviews. *Journal of Psychopharmacology*, 18(2): 249 - 250. DOI: 10.1177/0269881104042629

Hambleton, R. K. 2005. 'Issues, designs, and technical guidelines for adapting tests into multiple languages and cultures' in R.K Hambleton, P.F. Merenda and Spielberger, C.D. (Eds.), *Adapting education and psychological tests for cross-cultural assessment.* Mahwah, NJ: Lawrence Erlbaum.

*Hassall, R., Rose, J. and McDonald, J. 2005. Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support, *Journal of Intellectual*

Disability Research, 49(6): 405-418. DOI: 10.1111/j.1365-2788.2005.00673.x

Hastings, R. P. and Taunt, H. M. 2002. Positive perceptions in families of children with developmental disabilities, *American Journal of Mental Retardation,* 107(2): 116–127. DOI: 10.1352/0895-8017(2002)107<0116:PPIFOC>2.0.CO;2

Heller, T. and Factor, A. 1993. Aging family caregivers: support resources and changes in burden and placement desire, *American Journal of Mental Retardation,* 98(3): 417-426.

*Hill, C. and Rose, J. 2009. Parenting stress in mothers of adults with an intellectual disability: parental cognitions in relation to child characteristics and family support, *Journal of Intellectual Disability Research,* 53(12): 969-980. DOI: 10.1111/j.1365-2788.2009.01207.x.

Hill, C. and Rose, J. 2010. Parenting stress models and their application to parents of adults with intellectual disabilities, *British Journal of Developmental Disabilities*, 56(110): 19-37. DOI:10.1193/096979510799103023

Holt, K. S. 1958. The home care of the severely mentally retarded, *Paediatrics*, 22(4 Pt 1): 744-755.

*Huang, W., Rubin, S. E. and Zhang, F. 1998. Correlates of stress level in Chinese mothers of a child with mental retardation, *International Journal of Rehabilitation Research*, 21(2): 237-240. DOI:10.1097/00004356-199806000-00011

International Test Commission. 2010. International Test Commission guidelines for translating and adapting tests*. International Test Commission*, http://www.intestcom.org/upload/sitefiles/40.pdf (accessed 10 July 2013).

Kanner, L. 1953. Parents' feelings about retarded children, *American Journal of Mental Deficiency*, 57(3): 375-383.

Katrak, P., Bialocerkowski, A. E., Massy-Westropp, N., Kumar, S. and Grimmer, K. A. 2004. A systematic review of the content of critical appraisal tools, *BMC Medical Research Methodology*, 4(22): 1-11. DOI: 10.1186/1471-2288-4-22.

*Khamis, V. 2007. Psychological distress among parents of children with mental retardation in the United Arab Emirates. *Social Science & Medicine*, 64(4): 850-857. DOI:10.1016/j.socscimed.2006.10.022

*Kim, H. W., Greenberg, J. S., Seltzer, M. M. and Krauss, M. W. 2003. The role of coping in maintaining the psychological wellbeing of mothers of adults with intellectual disability and mental illness, *Journal of Intellectual Disability Research*, 47(4-5): 313-327. DOI:10.1046/j.1365-2788.2003.00493.x

Kwai-sang Yau, M. and Li-Tsang, W. P. 1999. Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes, *British Journal of Developmental Disabilities*, 45(1): 38-51. DOI: 10.1179/096979599799156028

Lawton, M. P., Moss, M., Kleban, M. H., Glicksman, A. and Rovine, M. 1991. A two factor model of care-giving appraisal and psychological well-being, *Journal of Gerontology,* 46(4): 181-189. DOI: 10.1093/geronj/46.4.P181

Lazarus, R. S. and Folkman, S. 1984. *Stress, appraisal and coping.* New York: Springer.

*Lloyd, T. and Hastings, R. P. 2008. Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: cross-sectional and longitudinal relationships, *Journal of Intellectual Disability Research*, 52(1): 37-48. DOI: 10.1111/j.1365-2788.2007.00974.x.

*Lloyd, T. and Hastings, R. P. 2009. Parental locus of control and psychological wellbeing in mothers of children with intellectual disability, *Journal of Intellectual and Developmental Disability*, 34(2): 104-115. DOI:10.1080/13668250902862074

Lustig, D. C. 1999. Families with an adult with mental retardation: predictors of family adjustment, *Journal of Applied Rehabilitation Counseling*, 30(3): 11-18.

Maneesriwongul, W. and Dixon, J. K. 2004. Instrument translation process: A methods review, *Journal of Advanced Nursing*, 48(2): 175-186. DOI: 10.1111/j.1365-2648.2004.03185.x

Mash, E. J. and Johnston, C. 1990. Determinants of parenting stress: illustrations from families of hyperactive children and families of physically

abused children, *Journal of Clinical Child Psychology*, 19(4): 313–28. DOI: 10.1207/s15374424jccp1904_3.

*McConkey, R., Truesdale-Kennedy, M., Chang, M., Jarrah, S. and Shukri, R. 2008. The impact of mothers of bringing up a child with intellectual disabilities: A cross-cultural study, *International Journal of Nursing Studies*, 45(1) 65-74. DOI:10.1016/j.ijnurstu.2006.08.007

McCubbin, H. I. and Patterson, J. M. 1983. The family stress process: the double ABCX model of adjustment and adaptation. In H.I. McCubbin, M. Sussman, and J.M. Patterson (eds.) *Social stress and the family: Advances and developments in family stress theory and research,* pp. 7-37. New York: Haworth.

Mildon, R., Matthews, J. and Gavidia-Payne, S. 2003. *Understanding and supporting parents with learning difficulties*. Melbourne: Victorian Parenting Centre.

Nathans, L. L., Oswald, F. L. and Nimon, K. 2012. Interpreting multiple linear regression: A guidebook of variable importance, *Practical Assessment, Research & Evaluation,* 17(9): 1-19.

*Neece, C. and Baker, B. 2008. Predicting maternal parenting stress in middle childhood: the roles of child intellectual status, behaviour problems and social skills, *Journal of Intellectual Disability Research*, 52(12): 1114-1128. DOI: 10.111/j.1365-2788.2008.01071.x

*Ong, L. C., Chandran, V. and Peng, R. 1999. Stress experienced by mothers of malaysian children with mental retardation, *Journal of Paediatrics and Child Health,* 35(4): 358-362. DOI: 10.1046/j.1440-1754.1999.00383.x

Orsmond, G. I., Seltzer, M. M., Krauss, M. W. and Hong, J. 2003. Behaviour problems in adults with mental retardation and maternal wellbeing: Examination of the direction of effects, *American Journal of Mental Retardation,* 108(4): 257-271.

Pedhazur, E. J. 1997. *Multiple regression in behavioural research: Explanation and prediction*, 3rd Ed. Stamford, CT: Thompson Learning.

*Peer, J. W. and Hillman, S. B. 2012. The mediating impact of coping style on stress perception for parents of individuals with intellectual disabilities, *Journal of Intellectual Disabilities*, 16(1): 45-59. DOI: 10.1177/1744629512440783

Perry, A. 2004. A model of stress in families of children with developmental disabilities: Clinical and research applications, *Journal on Developmental Disabilities*, 11(1): 1-16.

*Quine, L. and Pahl, J. 1991. Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' Transactional model of coping, *Journal of Community & Applied Social Psychology,* 1(1): 57-70. DOI: 10.1002/casp.2450010109

Rutter, M., Tizard, J. and Whitmore, K. 1970. *Education, Health and Behaviour*. London: Longmans.

*Saloviita, T., Italinna, M. and Leinonen, E. 2003. Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX model, *Journal of Intellectual Disability Research,* 47(4/5): 300-312. DOI: 10.1046/j.1365-2788.2003.00492.x

Sanderson, S., Tatt, L. D. and Higgins, J. P. T. 2007. Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic review and annotated bibliography, *International Journal of Epidemiology*, 36(3): 666-76. DOI:10.1093/ije/dym018

Scorgie, K. and Sobsey, D. 2000. Transformational outcomes associated with parenting children who have disabilities, *Mental Retardation,* 38(3): 195-206. DOI: 10.1352/0047-6765(2000)038<0195:TOAWPC>2.0.CO;2

Smith, T. B., Oliver, M. N. I. and Innocenti, M. S. 2001. Parenting stress in families of children with disabilities, *The American Journal of Orthopsychiatry,* 71(2): 257–61. DOI: 10.1037/0002-9432.71.2.257

*Stores, R., Stores, G., Fellows, B. and Buckley, S. 1998. Daytime behaviour problems and maternal stress in children with Down's syndrome, their siblings, and non-intellectually disabled and other intellectually disabled peers, *Journal of Intellectual Disability Research,* 42(3): 228-237. DOI: 10.1046/j.1365-2788.1998.00123.x

Walsh, F. 2003. Family Resilience: A framework for clinical practice., *Family Process*, 42(1), 1 - 18. DOI: 10.1111/j.1545-5300.2003.00001.x

Williams, C. and Garland, A. 2002. A cognitive-behavioural therapy assessment model for use in everyday clinical practice, *Advances in Psychiatric Treatment,* 8, 172-179. DOI: 10.1192/apt.8.3.172

Willoughby, J. C. and Glidden, L. M. 1995. Fathers helping out: Shared child care and marital satisfaction of parents of children with disabilities, *American Journal of Mental Retardation,* 99(4): 399-406.

World Health Organization. 2001. The world health report 2001 - mental health: New understanding, new hope. *Geneva*. http://www.who.int/whr/2001/en/ (accessed 11 July, 2013).

Zarit, S. H., Reever, K. E., and Bach-Peterson, J. 1980. Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist* 20(6): 649-55. DOI: 10.1093/geront/20.6.649

Appendix – Search strategies

AMED

	Searches	***Results***
1	Learning disability/	2932
2	learning disorders/	1004
3	Mental retardation/	1680
4	"learning disabilit*". mp. [mp=abstract, heading words, title]	3363
5	"intellectual disabilit*". mp. [mp=abstract, heading words, title]	2007
6	Developmental disabilities/	510
7	1 or 2 or 3 or 4 or 5 or 6	6535
8	exp parents/	1484
9	"foster parents".mp. [mp=abstract, heading words, title]	1
10	"adoptive parents".mp. [mp=abstract, heading words, title]	3
11	"single parent".mp. [mp=abstract, heading words, title]	16
12	caregiver*.mp. [mp=abstract, heading words, title]	3290
13	8 or 9 or 10 or 11 or 12	4675
14	stress.mp. or Stress psychological/ or Distress/ or Depression/ or Anxiety/ or Wellbeing/	9008
15	"caregiver burden".mp.	107
16	14 or 15	9094
17	7 and 13 and 16	72

CINAHL Plus (EBSCOhost)

	Searches	***Results***
S1	(MH "Parents") OR (MH "Biological Parents") OR (MH "Expectant Parents") OR (MH "Adoptive Parents") OR (MH "Single Parent") OR (MH "Foster Parents") OR (MH "Caregivers") OR (MH "Fathers") OR (MH "Mothers") OR (MH "Parents of Disabled Children")	61348
S2	(MH "Mental Retardation") OR (MH "Developmental Disabilities")	16878
S3	(MH "Stress") OR (MH "Stress, Psychological") OR (MH "Caregiver Role Strain (NANDA)") OR (MH "Caregiver Burden") OR (MH "Distress")	35003
S4	"intellectual disabilit*"	4358
S5	"learning disabilit*"	5213
S6	"mental retard*"	13020
S7	S2 or S4 or S5 or S6	22149
S8	S1 and S3 and S7	236

EMBASE

	Searches	***Results***
1	caregiver/	35466
2	caregivers.mp.	30761
3	adoptive parent/ or expectant parent/ or divorced parent/ or single parent/ or parent/	59845
4	stepparent.mp.	59
5	biological parent.mp.	208
6	1 or 2 or 3 or 4 or 5	104807
7	stress.mp. or life stress/ or physiological stress/ or parental stress/or stress/ or depression/ or anxiety/ or wellebing	702134
8	distress.mp.	120596
9	caregiver burden/	2712
10	learning disorder/	20700
11	intellectual impairment/ or mental deficiency/	61972
12	"learning disabilit*". mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	7621
13	"intellectual disabilit*".mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	8022
14	"mental retard*". mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	31829
15	10 or 11 or 12 or 13 or 14	95781
16	7 or 8 or 9	805223
17	6 and 15 and 16	302
18	limit 17 to english language	293

Medline

	Searches	***Results***
1	parents/ or fathers/ or mothers/ or single parent/ or surrogate mothers/	71573
2	Caregivers/	20901
3	19 or 20	90997
4	Stress, Psychological/ or Stress, Physiological/or Distress/ or Anxiety/ or Depression/ or Wellbeing	137311
5	"caregiver burden".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keywork heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	1472
6	"learning disabilit*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, keywork heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	5722
7	Intellectual Disability/	46461
8	"intellectual disabilit*].mp. [mp=title, abstract, original title, name of substance word, subject heading word, keywork heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	48348
9	"mental retard*'.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keywork heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	25290
10	Developmental Disabilities/	14581
11	24 or 25 or 26 or 27 or 28	77466
12	22 or 23	138470
13	21 and 29 and 30	264
14	limit 13 to english language	253

PsychINFO

	Searches	***Results***
1	exp Expectant Parents/or exp Parents/or exp Adoptive Parents/ or exp Foster Parents/ or exp Single Parents/	67831
2	exp Caregivers/	17233
3	exp Single Mothers/ or exp Mothers/	30731
4	exp Single Fathers/ or exp Fathers/	8135
5	exp Stepparents/	711
6	caregiver*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	33168
7	1 or 2 or 3 or 4 or 5 or 6	98105
8	exp Psychological Stress/	7199
9	stress.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	157338
10	exp Caregiver Burden/	4168
11	exp Physiological Stress/	2737
12	exp Distress	14123
13	exp "Depression (Emotion)"	20941
14	exp Anxiety/	48039
15	exp Mental Health/or exp Well Being/	57324
16	8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	272353
17	exp Learning Disabilities/	23394
18	learning disabilit*.mp [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	22484
19	exp Intellectual Development Disorder/	38018
20	"intellectual disabilit*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	7826
21	exp Developmental Disabilities/	10768
22	"mental retard*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]	26125
23	17 or 18 or 19 or 20 or 21 or 22	78184
24	7 and 16 and 23	858
25	limit 24 to english language	

Journal Paper

The transition into adulthood for children with a severe intellectual disability: Parents' views[4].

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Abstract

Objectives: This study used a grounded theory approach to explore parents' views of the transition into adulthood of their child with a severe intellectual disability. The study also sought to explore the processes that parents engage in for making psychological adjustments appreciate their role during this transition. This study is imperative for developing a psychologically informed theory that can be understood by both parents and clinicians.

Method: Twelve parents of 11 children with a severe intellectual disability were recruited from charitable organisations. Semi-structured interviews were conducted individually using a combination of open-ended structured questions and non-directed probing. "NVivo 10" software was used to assist the grounded theory coding and analysis process.

Results: Analysis developed five processes that parents engaged in during their child's transition into adulthood: "defining adulthood", "noticing adult development", "perceiving barriers to adulthood", "worrying" and "making psychological adjustments. Common to these was seen to be a core process of "making comparisons with perceived 'norms'". Contrasting findings are critically discussed alongside extant literature. Additionally, a transition model of parents' views and adjustments is proposed, grounded in the study findings.

Conclusion: Parents engage in a series of interactional processes throughout the transition trajectory, which are likely to influence how they make adjustments. Clinical interventions may aim to challenge parent perceptions; encourage peer support; embrace systemic ways of working with parents through their child's transition into adulthood; and use the presented model developed from this study to help parents understand their experiences and any adjustment-related problems.

Key words: Intellectual disabilities, parents, transition, adulthood.

Introduction

Transitions from one life stage to another are challenging and complex events for most people (Task Force, 2009). Moving from adolescence into adulthood can be difficult, with some individuals and their families viewing it as a crisis period (Pittman, 1987). For people with intellectual disabilities[5], the challenges associated with the transition into adulthood may be compounded (e.g., with finishing school, changes or a reduction in professional healthcare support; Blacher, 2001; Neece, Kraemer, Blacher, 2009), especially in the context of more severe levels of disability (Task Force, 2009). Consequently, the transition process may occur more slowly for individuals with an intellectual disability as more challenges may need to be negotiated for it to be successful. Indeed, commonly identified transitional tasks (e.g., financial and residential independence, educational attainment, employment, involvement in a romantic relationship and parenthood; Roy, Rousseau, Fortier and Mottard, 2012) would be more difficult to accomplish in the context of a severe intellectual disability.

Disruptions within the transition process may be stressful for parents of a child with a severe intellectual disability. Research suggests that parental stressors heighten when they perceive themselves (or child) to deviate from cultural norms e.g. having *more* involvement in their child's adult life as opposed to less involvement as their child transitions into adulthood (Ferguson, Gerguson and David, 1988). Additionally, the types of meaning that parents make when confronted by transitional stress (e.g., global versus situational) are suggested to have implications upon parental adjustments, the wellbeing of their child and wider family system (Park, 2010). Thus, exploring parents' views has clinical implications for (1) broadening our understanding of how parents experience their child's transition into adulthood, (2) identifying clinical interventions to help support families who have difficulty in adjusting to this transition, and (3) using our study findings to raise further areas for exploration to inform psychological assessment, formulation and intervention within clinical practice.

[5] Intellectual disabilities is conceptualized according to the definition provided by the DSM-5 (American Psychiatric Association, 2013).

Existing transition theories: A critique

The term "transition" can be defined as the inner psychological processes involved in adapting to changes in life events (Bridges, 2004). Existing transition theories aim to explain significant changes that occur within the life cycle (e.g., family life cycle; Carter and McGoldrick, 1980; Hopson and Adam's seven stages model , 1977). However, some of these theories may be viewed as being rigid and inflexible when they describe that people enter transition stages in a linear fashion (e.g., Bridges, 1991). Additionally, some theories were developed over 20 years ago (including the oscillation theory; Breunlin, 1988). Thus, although there are various frameworks for understanding transition processes, it is unclear whether these fit with the views of parents of a child with a severe intellectual disability today[6].

Parents' views

Existing intellectual disabilities literature focusing upon parents' views of their child's transition into adulthood has explored perceptions of their child's vulnerability to risk (e.g., Almack, Clegg and Murphy, 2008; Heslop, Mallet, Simons and Ward, 2002) and the parent/professional relationship (e.g., Clegg, Sheard, Cahill and Osbeck, 2001; Knox, 2000). Research suggests that parents caring for a child with an intellectual disability may view the transition as being stressful (Cummins, 2001). A recent systematic review of 17 empirical studies identified that factors such as child behavioural difficulties (e.g., challenging behaviour), unhelpful parental coping strategies (including avoidance and self-blame) and poor family cohesion were associated with parental stress when caring for their child with an intellectual disability (Biswas *et al.,* 2014). However, the authors were unable to discern causality from the correlational data represented in the studies. Thus, parental stress may influence some of the factors assumed as being "causes" of parental stress.

[6] Please see extended introduction (sections 1.5, 1.6 & 1.7) for further details about transition models, transitions within a service context and a life-course perspective.

By contrast, individuals with an intellectual disability may provide positive experiences for their parents (Grant, Ramcharan, McGrath, Nolan and Keady, 1998; Scorgie and Sobsey, 2000). Possible explanations for these contrasting experiences could include some parents having more effective strategies than others (Cummins, 2001). This relates to the Transactional Stress Coping Model, which emphasizes that an individual's appraisal of a situation may mediate stress levels (Lazarus, 1966). This could suggest that parents who appraise the transition into adulthood as stressful may have more negative experiences than parents who appraise the situation as rewarding[7].

Rationale and research questions

There are no current retrospective studies within the intellectual disabilities field that explore parents' views of the transition into adulthood of their child using a developmental lens, or the processes they engage in to make adjustments for their child's transition. It was imperative to address this gap Thus, the research questions for this study were:

(1) How do parents view the transition into adulthood for their child with a severe intellectual disability?
(2) What processes (if any) do parents engage in to make psychological adjustments for this transition (e.g., in terms of coping or emotional regulation)?

Grounded theory was deemed to be the most appropriate method of analysis to answer the research questions for a number of reasons. These included that it was suitable for open-ended research questions that focused upon patterns and processes (Tweed & Charmaz, 2012); it was appropriate for data collection techniques such as semi-structured interviews (Willig, 2001); and it was particularly suitable for exploring areas in which there is limited research. More specifically, Corbin and Strauss's (2008) guidelines were chosen and applied as they acknowledge the role of contextual processes implicated in parental adjustments, and outline a pragmatic approach that facilitates the systematic development of a psychologically informed theory.

[7] Please see extended introduction (section 1.9) for further details about parents' views.

Method

Design and participant recruitment

This study used a retrospective cross-sectional exploratory design.
A non-probabilistic purposive sample (i.e., focusing particularly upon parents who viewed their child as an adult) was adopted to encourage variation with regards to parents' views. We received recruitment support from charitable organisations including Mencap (Nottingham and Kirklees), IRIS project (Nottingham), MIND and the Foundation for People with Learning Disabilities. We advertized our study through charity newsletters, social media websites and in online forums. Individuals who volunteered to participate were considered if they (i) were a male or female parent (biological, step-parent, adopted parent or foster parent) of an adult[8] with a severe intellectual disability; (ii) could read, write and speak English; and (iii) had witnessed their child's transition into adulthood – this was necessary as little experience would limit the data and subsequent theory of the phenomenon being studied (Cutcliffe, 2000).

Fourteen parents contacted the first author (SB) in response to the study adverts. Two parents were excluded as their child had been clinically diagnosed with a mild intellectual disability, which did not meet the eligibility criteria for the study. There were no drop-outs during the recruitment process. The total sample included 12 White British parents (aged 44 to 78 years) of which there were seven mothers, three fathers, one step-mother and one step-father[9].

Ethical approval and considerations

Ethical approval was obtained from the Institute of Work, Health and Organizations at the University of Nottingham in October 2013.
Prior to the interviews, the first author (SB) provided all participants with an information sheet that had details about the study such as its potential value/contribution to understanding, how it would be conducted and how the findings would be disseminated. They were also given a consent form outlining that they would be able to withdraw from the research, including from the interview discussion without reason at any time. All participants were given

[8] Participants defined the term "adult" in the interviews.
[9] Please see extended methodology (sections 2.3 & 2.4) for further details about study design and study sample.

pseudonyms to ensure anonymity. All participants were offered the chance to ask any questions related to the study before and after the interview. They were all debriefed about the study after interview[10].

Data collection[11]

The first author (SB) conducted twelve individual[12] semi-structured interviews between December 2013 and December 2014. All participants were interviewed individually in order to gain an in-depth exploration of their experiences. This study included face to face (n=3), Skype (n=2) and telephone interviews (n=7). Each interview lasted between 60-90 minutes. The initial interview schedule covered four broad areas related to the research questions including understanding of the term "adulthood"; understanding of their child's transition into adulthood; parent perceptions of their son or daughter as an adult; and the adjustments that participants made in light of this transition. As salient concepts emerged from interviews, further questions were incorporated into the interview schedule (see Table 5). Thus, in line with the principles of theoretical sampling (Corbin and Strauss, 2008), the initial interview schedule was revised three times and became more focused upon developing concepts and categories. Towards the end of the research process, the model was shared with the final three participants. This was done via semi-structured telephone interviews. The participants were sent an electronic copy of the model to aid understanding. Sharing the model provided participants with the opportunity to relate their experiences to key aspects of it. The purpose of these interviews were to therefore seek participants' opinion of the developing model and to identify further relationships between the concepts or categories.

[10] Please see extended methodology (section 2.5) for further details about ethical considerations.
[11] Please see extended methodology (sections 2.6 & 2.7) for further details about data collection and study procedure.
[12] Parents of the same child were also interviewed separately.

Table 5. Examples of semi-structured interview questions (and topics).

Interview schedule 1
• What does adulthood mean to you? *(Definition of adulthood)* • How did you know your child had become an adult? (e.g., any markers?) *(Adulthood and their child)* • How did your child's transition into adulthood affect you? *(Parental adjustments)* • Were there any changes in the way you viewed your child once they had become an adult? *(Parent perception of child)*
Interview schedule 2
• How did you cope with the adjustments in your life? *(Parental adjustments)* • What does independence look like for your child (e.g., cognitive/behavioural)? *(Adulthood and independence)* • Have you ever been aware of your child's sexuality developing? *(Adulthood and sexuality development)*
Interview schedule 3
• Tell me about your experiences of services when your child entered adulthood? *(Adult care services)* • When were the worries about his/her adulthood heightened and when were they less so? *(Worries and transition)* • What expectations did you have, if any, of how involved you would be in their care once he/she had become an adult? *(Parental adjustments)*
Interview schedule 4
• When did you start thinking about what your child's adult like would look like? *(Time and adulthood)* • How did you manage the barriers that you experienced? Were these expected or found out along the way? *(Coping techniques)* • From the map, some parents spoke about the changes they made when their child became an adult. Some of these changes related to their ideas of a "normal" adulthood. Were the changes you made when your child became an adult a way to move closer to the norms of adulthood? If so why? If not why not? *(Perceived norms and sharing model)*

Data analysis

The interviews were transcribed within Microsoft Word (Version 14) and then imported into a qualitative data analysis software "NVivo 10" (QSR, 2014)[13]. All transcripts were analysed according to the grounded theory guidelines outlined by Corbin and Strauss (2008). The first author (SB) read each transcript line by line. Words or phrases were highlighted to facilitate the process of "open-coding". Coding checks were provided by the second author (AT). Some quotes used "in vivo" codes whereby vertabim quotes from participants were used to label the codes (Birks and Mills, 2011). The open codes were grouped together to form "concepts". Constant comparisons between the concepts were made whilst clustering them together to form "themes". "Axial coding" was used to identify contrasting data within the concepts or themes. Salient themes throughout the transcripts were then grouped together to form "categories", which were labelled accordingly. The final stages of analysis involved re-visiting the data for evidence to further develop the categories and then identifying the "core category" that tied all the categories together. The final three interviews were similar to the previous interviews when exploring topics of interest in order to add depth to existing categories. However, they were unique in terms of sharing the model. This was helpful for explicitly exploring connections between the developed categories whilst providing participants with an opportunity to validate or refute the model. Supervision was sought from the second (AT), third (NM) and fourth authors (KA) throughout the analytic process. This encouraged new insights and minimized the risk of the first author (SB) influencing the data with her own assumptions[14].

Evaluating quality

Evaluation criteria set out by Corbin and Strauss (2008; 1990) was used to evaluate the "credibility" of our research. Specifically, the criteria focus upon "fit", "applicability", "concepts", "contextualisation of concepts", "logic", "depth",

[13] Please see extended methodology (section 2.7.4) for the advantages and disadvantages of using CAQDAS.
[14] Please see extended methodology (section 2.7.5) for further details about the data analysis.

"variation", "creativity", "sensitivity" and the "use of memos" throughout the research process[15].

Results

Parents frequently made comparisons to perceived "norms"[16] when making sense of their child's transition into adulthood and the subsequent adjustments made. This process was salient throughout the development of categories. "Making comparisons" was thereby deemed to be the core process that parents engaged with. Parents made comparisons with their own personal experiences and the experiences of children without intellectual disabilities in general. The five processes encapsulated within this core category are elaborated upon below[17].

Defining adulthood

This was an implicit process that all parents engaged in for understanding their child's transition into adulthood. Ten parents reflected upon physical changes such as "developing breasts" (Jack), "getting bigger" (Tina) and "growing body hair" (Sarah). Some parents defined adulthood in terms of age i.e. "turning 18" (Carla), thereby highlighting the legal markers of adulthood. However, whilst most parents found age to be important for defining adulthood, three believed it to be meaningless. These parents viewed themselves as becoming adults before the age of 18 years. They emphasized the importance of social markers as signs of adulthood rather than age:

"There was nothing different for me from when I was 16 to when I was 18. I smoked when I was 13, started drinking from the age of 16, I started work at 15…I always thought of myself as an adult from the time that I actually started work…" – Rebecca

[15] Please see extended methodology (section 2.9) for further details about evaluating quality.

[16] Perceived "norms" were underpinned by a shared understanding; this largely reflected upon growing up in the UK milieu i.e. influenced by family culture, media, professionals etc.

Thus, there were contrasting views when defining the term "adulthood"; some held a chronological view whereas others placed importance upon the social aspects of becoming an adult. Parents' definition of adulthood seemed to influence how they noticed adult development in their child with a severe intellectual disability[18].

Noticing adult development and sexuality

All parents noticed adult development in their child through identifying biopsychosocial changes. This was defined as being biological (e.g., physical), psychological (e.g., thoughts, feelings, behaviours) and social (e.g., socio-environmental and cultural) factors. These changes were largely related to notions of independence. Some parents explained that they had noticed their child become an adult through an increase in independent behaviours:

"I think she has become more independent in doing more things for herself…little things like I know she makes her own bed where she is, she is collecting her washing, putting it in the washing basket"
- Carla

Some parents believed that their child's transition into adulthood was a continuous process:

"He used to be repetitive in his conversations but now more recently he is acquiring basic language skills at a later stage as he is 57 now…so maybe his transition into adulthood is still on-going" – Rick

This highlights how the nature of transition may vary in time-length. Indeed, for an "average" non-disabled 18 year old, adulthood does not happen overnight but is a gradual process that is signposted in different ways (Arnett, 2000). From the findings, this included subtle (e.g., "having more regulated memories"; Rick) and more overt developments (e.g., "going to the pub with a friend"; Jack).

[18] Please see extended results (section 3.3) for further details of this category.

This study illuminated the difficulties of noticing and comprehending adult development. Amy explained that whilst her daughter visually looked like an adult, her adult development was impeded by her difficulties in daily functioning:

"Although physically she is an adult, it's difficult to notice development because in her mind she's not an adult. And so developmentally, cognitively, emotionally, she isn't, but physically she is. it's a bit of a paradox really" - Amy

Noticing adult development was a key process that parents engaged in when understanding their child's transition into adulthood. Sometimes it was difficult for parents to notice signs of adulthood due to the severity of their child's intellectual disability. Such barriers to noticing adult development are likely to impact upon whether or how parents adjust for their child's transition into adulthood. For example, if a parent struggles to notice signs of adult development in their child, they may be less inclined to make any changes to encourage their child's transition into adulthood.

For five participants, an important process that appeared to be related to this category was noticing their child's sexuality development. Some parents were mindful of the physical and cognitive "paradox" when attempting to understand sexually related behaviours:

"His physical and mental development didn't marry up and that's why he displayed behaviours like plumping pillows at night and tactile things rather than masturbating or something normal boys would do" - Rick

This lack of synchrony between the child's physical and cognitive-emotional development left parents unsure of how to best support their child's sexuality development. Sarah questioned whether there was a link between her son's "mental" and "physical" abilities. In doing so, she demonstrated how she noticed her son's sexuality development through more subtle ways:

"There is nothing coming from him mentally but physically his body might be telling him a different story, and I don't know how the two marry up or whether

they don't marry up and he's finding it difficult, it's hard to tell. I noticed him giggle when he saw a girl walk past so I know he likes girls" – Sarah

Thus, similar to noticing adult development, parents noticed their child's sexuality develop in both subtle and overt ways. However, they seemed to struggle to manage their child's sexuality development. This was evident in descriptions of "not knowing enough" (Amy), and seeking professional support. One parent agreed with healthcare professionals to use medication as a way to suppress their child's sexual needs. Whilst such strategies may help to contain an individual's sexual frustrations (and parent and staff anxieties), it could also be seen as inhibiting the child's adult development[19].

Perceiving barriers to adulthood

Most parents perceived barriers to adulthood when viewing their child's development as deviating from perceived "norms". This included being unable to plan for activities related to adulthood (e.g., a career); needing to rely upon professional support to facilitate adult development; and their child's limited cognitive or social skills and personal responsibility. For most parents, these barriers were not necessarily expected or planned for.

Parents highlighted barriers within professional systems. Most felt that a "cut-off age" of 18 years within services fostered a culture of exclusion. This, together with limited information provided by services left parents feeling unsupported for their child's transition. Some parents voiced their disappointment in the contradictory nature of services with regards to parental involvement in their child's care:

"The social worker kept saying to us all the time, 'of course you're not responsible for him anymore', I sort of joked with her when she said 'you're not responsible' and I said 'oh good, does that mean I can, I can nip off to the cinema then and just leave him here?' and she says 'oh no of course not'" – Sarah

[19] Please see extended results (sections 3.4, 3.4.1 & 3.4.2) for further details of "noticing adult development", "noticing sexuality development" and "responding to sexuality development".

Sarah's quote demonstrates how professionals also draw upon "normative" ideas of adulthood i.e. that parental responsibility and accountability generally reduce as young people reach the legal age of adulthood. This, coupled with policy agenda for promoting autonomy and self-determination for young people with an intellectual disability e.g. Valuing People (Department of Health [DoH], 2001) may be frustrating for parents. Such contradictory attitudes of healthcare staff do not take into account the parallel need to protect vulnerable young people with severe intellectual disabilities or the on-going parental responsibilities should anything "go wrong".

This study also found contrasting parent views with regards to services treating their child as an adult. Some felt that this approach was helpful for encouraging "normal" adult development, whereas others believed that it had negative consequences as described by Samantha below. This could be indicative of how an inconsistent approach between parents and professionals may be harmful for the young individual:

"She went to the cinema with them [residential care staff] and the other residents but they were choosing films that weren't suitable for her because of her slow development. So, from that she has now been diagnosed with severe levels of anxiety because of what they had been letting her watch" – Samantha.

It seems that different services have different approaches in how they treat young adults with a severe intellectual disability. Parents may perceive challenges in knowing how to negotiate the apparent paradox between their child's physical and intellectual development with professionals. Consequently, it may be difficult to provide a consistent approach around the child's transition into adulthood.

Another perceived barrier related to the nature of having an intellectual disability. Five parents explained how the severity of their child's intellectual disability often prohibited "normal" activities:

"If you were to do normal things like take her to the cinema to watch a film, it would just mean nothing to her as she can't understand on that level. She'd get bored and her behaviour would deteriorate so I can't take her out to these places" - Amy

Evidently, parents made frequent comparisons to normative activities when thinking about the barriers to their child's adult development. Difficulties in decision-making were viewed as being a challenge to their child achieving a "normal" adult life:

"My daughter can't make decisions for herself like neuro-typical children, I'm going to be making decisions for her for the rest of her life or the rest of my life" - Samantha

Whilst parents explained that being unable to make decisions (i.e., due to having limited cognitive ability) was a barrier for their child's adult development, some acknowledged that "total free choice" (Jack) would put their child at risk:

"Staff took her to the hairdressers and gave her a book to choose hairstyles from. My daughter chose something that looked awful and staff were saying, 'but she chose it'. And we were saying, 'but when you gave her the book, she didn't know that you were asking her what she wanted'" – Jack

These contrasting views highlight the ambiguous nature of adulthood and difficulties for parents in managing the unexpected dilemmas that they experience. Some parents coped by taking control of the situation e.g. making decisions about their child's future. In doing so, they did not appear to view their own actions as being barriers to their child's adult development. This could be interpreted as a "parents know best" approach, which they may have adopted in response to a perceived lack of support from services or an awareness that they ultimately hold responsibility for their child's wellbeing[20].

[20] Please see extended results (section 3.5) for further details of this category.

Worrying – The "black hole" of transition

All parents viewed their worries as an on-going process that occurred before and during their child's transition. The term "black hole" was offered by Sarah when making reference to the worries that she (and other parents) experienced around the time of their child's transition into adulthood. One of the key worries for all parents was the risk of their child being abused by others in care or in the community. One parent reported that his son had been financially exploited as a result of having a "normal lifestyle":

"When we allowed him to live a normal lifestyle like living in a single house on his own he then got abused by a group of teenagers, they were stealing his money from his wallet when he was stood at the bus station" – Rick

Being aware of cases of abuse within the media (e.g., Winterbourne View) was a common trigger to worrying. Three parents of children with limited verbal ability explained that their worries were often compounded with further worry around how they (and care staff) would know if their child had been abused:

"There was a big worry sending her [daughter] away. There are horror stories about care homes and things, with abuse, and the worry was if she goes away and she's abused, how would she be able to tell us? Because if she went very quiet, that wouldn't be her, but then the carers don't know her. So they wouldn't pick up on it either" – Amy

Thus, most parents faced dilemmas of wanting their child to become independent but worrying about the risk of abuse. These worries, along with further concerns about their child's future, made it difficult for parents to know how to adjust, especially if services offered little support[21].

Making psychological adjustments

All parents made adjustments for their child's transition into adulthood. Adjustments related to making changes for their child (e.g., encouraging "age

[21] Please see extended results (section 3.6) for further details of this category.

appropriateness") and for themselves (e.g., seeking support from others to manage their worries).

Some parents explained that encouraging "age appropriateness" was important for reducing their child's vulnerability within society:

"I don't really want him to go out the house with toys because I think other people will think 'why has that adult got a toy in his hand' and so I'm trying to protect him from comments" - Sarah

Parents encouraged their child to engage in activities that they viewed as being "age appropriate", hoping that it would increase their child's independence:

"We helped him to gain a very active social life, we took him to nightclubs because he was entitled to go there like a normal young person would be, we took him to bars and gave him money to go order his drink as he could legally drink, so we were there with him for these things whereas with normal adults they go with their friends" - Rick

However, Rick's quote also highlighted the limits of encouraging independence e.g. the high levels of parental input. Accompanying their child to access "age appropriate" community settings such as nightclubs, suggests that developing independence is not a spontaneous process for individuals with a severe intellectual disability. As a result, parents may find themselves in a dilemma of wanting their child to have a "normal" adult life whilst knowing that there are barriers to achieving it.

By contrast, two parents were more accepting of their son or daughter's "child-like" interests and did not support the notion of encouraging "age appropriateness":

"She still plays with babies toys a lot of the time, she will watch Thomas the Tank Engine, she likes to just pick things up and twiddle with them like little plastic beakers and little cars. When she was 18 we bought her a slide which she loves going down even at her age, she still likes that. All this time she uses it I

wont get rid of it just because society says she's too old for it because she's still very much at a toddler level" - Jack

Parents who did not perceive chronological age as important may be more accepting of their son or daughter's "child-like" interests compared to others who view age as important. It seems that sometimes parents do not encourage their children to make changes to their lifestyle just because they perceive them to be an adult. Parents may take an accepting stance when thinking about the barriers towards their child achieving a "normal" adulthood:

"One way is to make some adaptations and accommodations for my learning disabled child, and the other way to go is to say this is our passport out the normal, we are going to throw ourselves into a new learning disabilities sub-culture, which I think has been an accurate description and liberating way of viewing my son's adult life" – Rebecca.

Rebecca also explained that the "learning disabilities sub-culture" was helpful for her to network with other parents of children with an intellectual disability. Some parents proactively sought information from similar others:

"I didn't want my son to leave home and I eventually found somewhere as I have a couple of friends who have older boys with learning disabilities and they told me about the place where their children went to." - Sarah

Establishing a supportive network helped parents to gain knowledge about the transition process. It also encouraged parents to feel supported when making adjustments (e.g., accepting "child-like" interests). However, two fathers felt reluctant to share their difficulties with others. This could have been due to avoiding being a burden on other people or avoiding issues that were burdensome for them. This finding may also be indicative of gender differences between the types of adjustments made. Parents also made adjustments for their child's transition by "doing research" (Carla) to inform their understanding of the transition process.

Three parents demonstrated ways in which they had not made any adjustments in light of their child's transition. This was largely related to staying involved in their child's care:

"We wrote the support plan for our daughter, we even arranged meetings with the staff teams to discuss Jane. It was good because we were sort of in control and not being pushed aside…" – Samantha

From Samantha's quote, it could be argued that some parents avoid making adjustments to reduce the threat of losing responsibility or being excluded by healthcare professionals. However, staying involved was not always a planned process:

"I didn't expect to have as much input as I've had at all, it almost threw me! I thought I would go from being primary carer to not having any input at all. But, I've had a lot of input so it's still like as if I am a primary carer even though I am not looking after her" – Carla

Making adjustments was a process that all parents experienced. Parents who viewed chronological age as meaningful were likely to make adjustments that encouraged "age appropriateness" for their child. By contrast, those who did not view chronological age as important were more accepting of the incongruence between their child's interests and age. For these parents, viewing themselves as being part of a "learning disabilities sub-culture" appeared to bring a more positive outlook to their child's adult life. Parents also made adjustments to manage their worries[22].

Sharing the model

The grounded theory model of the key categories[23] was shared with the final three participants (Samantha, Roger and Louise) and they appeared to understand each of the processes within it. However, there were contrasting

[22] Please see extended results (section 3.7) for further details of this category.
[23] Whilst the categories that developed from the findings are grounded in parental views, we acknowledge that parents of a child with a severe intellectual disability may engage in alternative/additional processes that are not incorporated in our model.

opinions around the concept of trying to stay in line with the perceived "norms" of adulthood (i.e., encouraging "age appropriateness"). For example, Samantha strongly identified herself and her daughter within a "learning disabilities tribe" whereas Louise and Roger endorsed the idea of wanting their child to stay in line with the "norms" of adult development:

"I've found it extremely liberating to not have to compare with norms, practically from diagnosis. Normal rules do not apply to us. We can make up our own rules. And as far as I'm concerned, I'm just not interested what normal people do. I look at other people with learning disabilities or with a learning disabled child or young adult, and I see them as part of my tribe, yes, they are my tribe. The norms, they are not my tribe. I'll live in peace with them but they are not my tribe" – Samantha

"I try to make him live as normal life as possible but knowing that I'm going to have to make some changes to make it happen. I mean it's the old saying where they have to fit into our world rather than the other way round, we tend to automatically think about what's normal and what people ought to be doing" – Roger

Possible explanations for this difference could be related to feelings of guilt as hypothesised by Louise (step-mother):

"They [biological parents] feel like it's their fault that their child is like that. So, they should be trying to make it right for them and make them fit in society, but, there's a guilt thing about why their child is like that and, I've spoken to several parents like this and they find it difficult to move them on. There's that guilt factor about their child being brought into the world by them but I didn't have that so maybe it's easier for me as I don't have that guilt whereas they can't move them past Fireman Sam, Postman Pat or whatever because of that guilt" – Louise

Thus, the type of parental relationship (i.e., biological or step-parent) could influence whether they choose to make adjustments, and how they may make them.

Developing a grounded theory model

We developed a model to visually capture the inter-related processes that parents engaged in during their child's transition into adulthood. The model reflects a synthesis of the data-driven insights shared by parents in this study. It is acknowledged that this model may be applicable to parents of a child with and without an intellectual disability[24] (see Figure 2). In summary, the core process underpinning this model relates to parents making frequent comparisons with perceived "norms" of the transition into adulthood (e.g., comparing with children from normative lifecycles). Parents hold definitions of "adulthood", which have been derived from their views of the "normal" social world around them (i.e., influenced by family, culture, social media). Drawing upon their conceptualizations of adulthood, parents may identify specific changes in their child to acknowledge adult status. Perceived barriers (whether expected or unexpected) may heighten parents' worries. This may encourage them to make adjustments to facilitate their child's adult development whilst serving to manage their own worries.

[24] Please see extended discussion (section 4.6) for further details about this and the model.

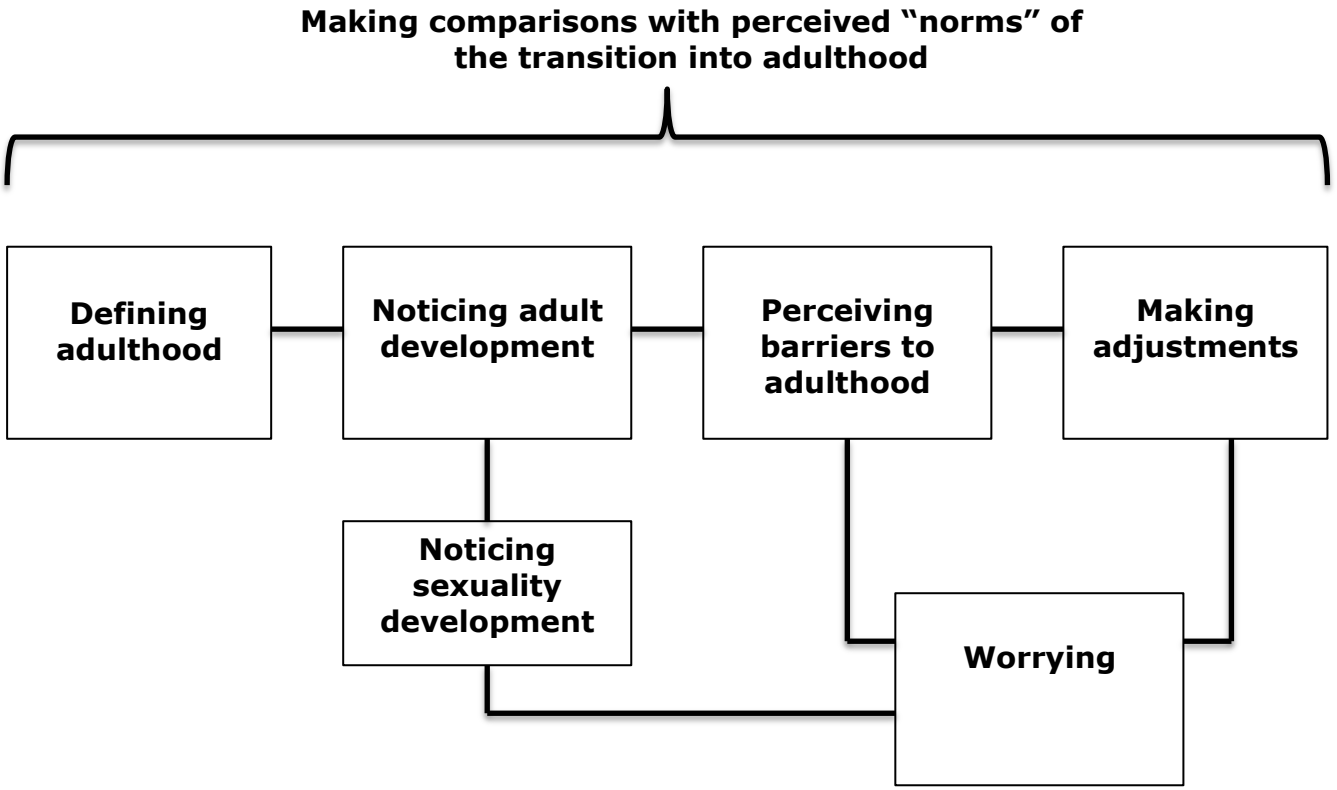

Figure 2. A transition model of parents' views and adjustment

Below, we have offered examples of how this model can be applied to parents' experiences. The examples provided are derived from parent perceptions in our study.

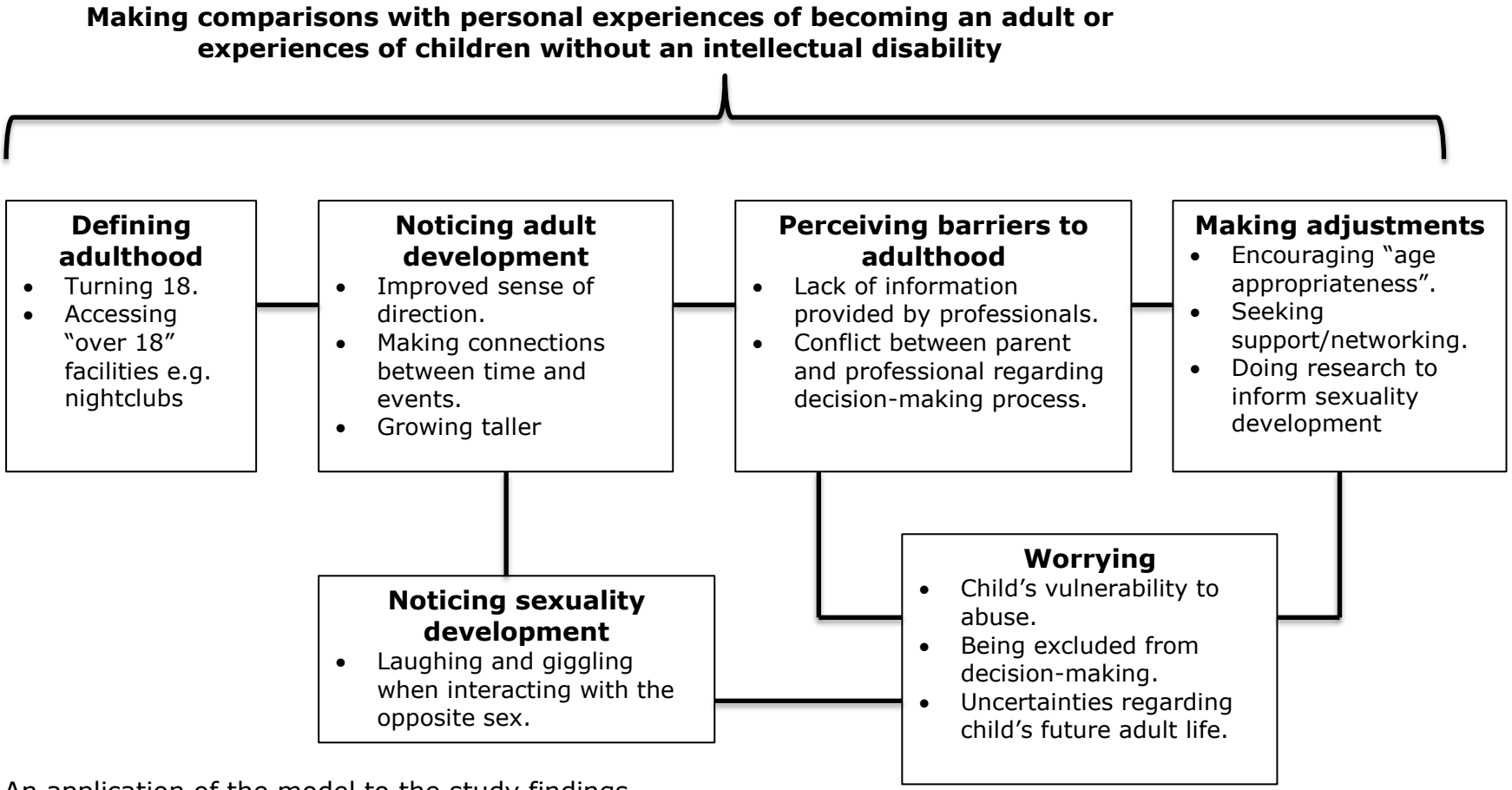

Figure 3. An application of the model to the study findings.

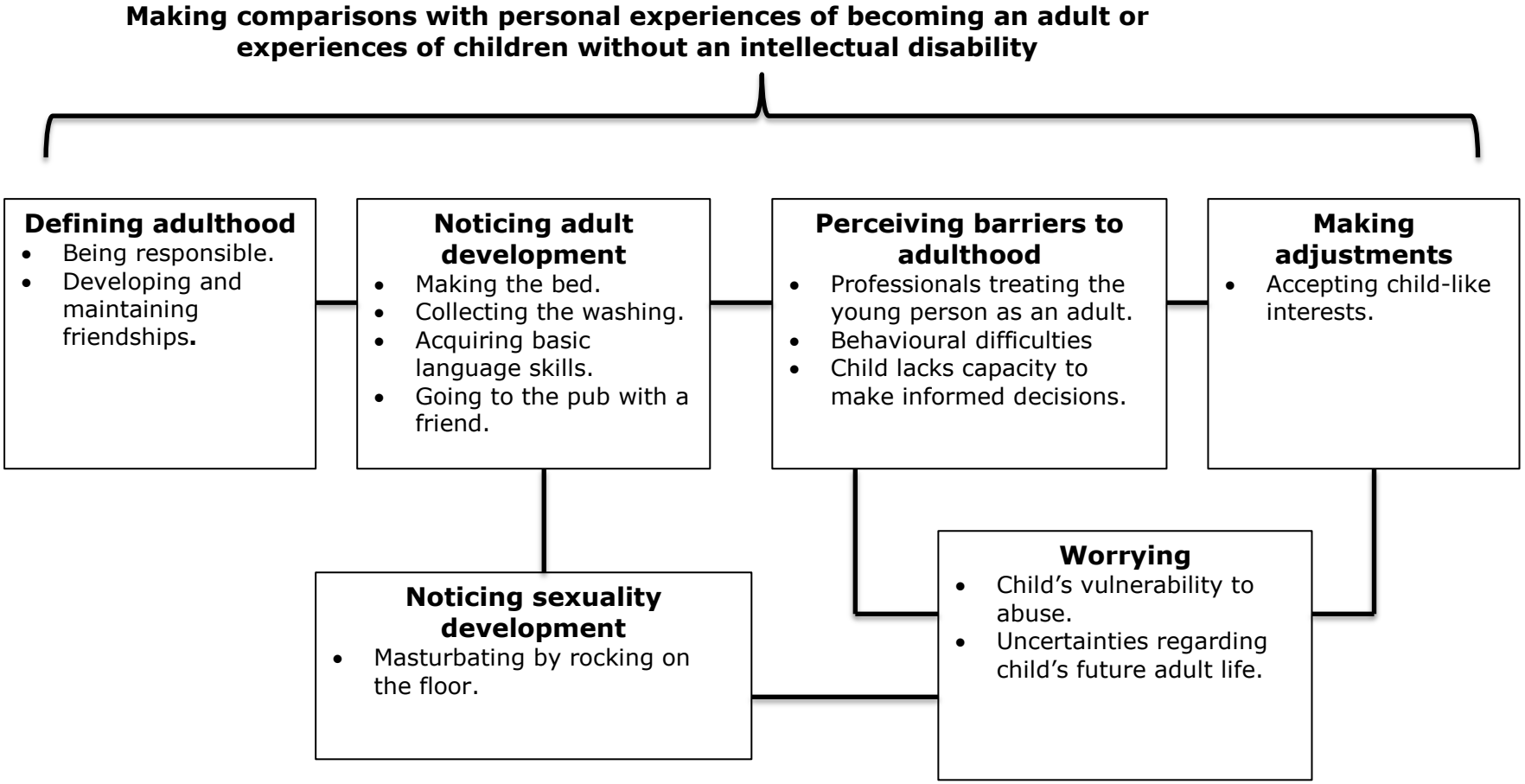

Figure 4. An application of the model to the study findings where age is perceived to be meaningless.

Parents of a child with a severe intellectual disability are not a homogenous group. Indeed, the findings from this study highlighted contrasting parent perceptions (e.g., some parents found age to be meaningless) and so the content of the boxes in the model may vary accordingly (see Figure 4).

The findings also highlighted some exceptions where parents did not necessarily engage in all processes within the model. For example, some parents did not report noticing sexuality development in their child even when prompted during the interview. Additionally, as discussed earlier, three parents reported ways in which they did not make any adjustments (i.e., staying involved in their child's care). Two of these parents had expected a continuity of care for their child, whilst the remaining parent reflected an unanticipated experience. In light of Figure 3 and Figure 4, our model is well suited to account for variability within parents' experiences concerning their child's transition into adulthood.

Discussion

This study was designed to address two research questions: (1) How do parents view the transition into adulthood for their child with a severe intellectual disability? (2) What processes (if any) do parents engage in to make psychological adjustments for this transition (e.g., in terms of coping or emotional regulation)? The key findings from this study are organised and discussed below in relation to these questions.

(1) Parents' views

Parents seemed to draw upon their own conceptualizations of adulthood and this influenced how they noticed adult development in their child. Parents also identified perceived barriers to their child's transition, which largely related to the conflict they encountered with professionals.

Conceptualizing adulthood

Parents drew upon the perceived "norms" and "adult rights" to make sense of the term "adulthood". For example, parents reflected upon their own experiences of becoming an adult and particular symbols of adulthood (e.g., celebrating 18th birthdays, "legally drinking"). This helped some to legitimize their views about the importance of chronological age when conceptualizing

adulthood. For others, chronological age was less important. Some viewed age to be unhelpful as it fostered a culture of "exclusion" within professional systems (e.g., school, college or child services). This contrast in parent views has implications for services to accept the differences in parents' definition of adulthood. If services impose their views upon the individual with an intellectual disability (e.g., that they should be treated as adults upon turning 18) then this may cause tension with parents who view chronological age as unhelpful[25].

When noticing adult development in their child, parents' descriptions were closely in line with Western ideations of "independence" (Arnett, 2000). For example, parents referred to changes related to their child's behaviour (e.g., making the bed), cognitive abilities (e.g., knowing where the bus stops are) and social skills (e.g., turn-taking in conversations). At a broad level, there is some overlap of our findings with existing empirical literature focusing upon the transition into adulthood for children without intellectual disabilities. Jablonski and Martino (2013) used grounded theory to explore how parents perceive adulthood status within their child. Consistent with our study, parents' conceptions of adulthood related to biological (e.g., experiencing first menstrual period, growing taller), social (e.g., having intimate relationships, establishing friendships, getting a job) and legal markers (e.g., turning 18). Further markers included financial responsibility (e.g., buying a house and paying bills) and making important life decisions (e.g., choosing which academic subjects to undertake at college or university). These markers were absent from parent data in our study. Instead, parents and professionals seemed to be responsible for managing the child's finances and life decisions. Indeed, individuals with a severe intellectual disability may never achieve normative constructs of adulthood. Thus, specific adjustments that parents make may be more pronounced (e.g., accompanying their child to a nightclub, liaising with healthcare professionals) when supporting their child's adult development in comparison to parents of children from normative lifecycles.

[25] Please see extended discussion (section 4.3) for further details of "conceptualizing adulthood".

Perceived barriers to adulthood: Parents vs professionals

Parents perceived barriers within the professional system. This included services being unsupportive towards parents; excluding the child and parent; and a general lack of negotiation between parents and professionals. Similar barriers have been identified in previous research (Knox, 2000; Swain and Walker, 2003) andare likely to increase parents' worries about their child's transition process.

Swain and Walker (2003) highlight inherent power imbalances between parents of a child with a disability and professionals. Our findings showed that parents worried about being over-ruled by healthcare professionals in decision-making processes. Previous intellectual disabilities research found that parents often made adjustments that involved fighting with professionals in order to gain control over decisions made (Knox, 2000). "Fighting talk" (Todd and Shearn, 2003) was not apparent in our findings. Instead, we found that some parents tried to gain control over decisions by aquiring knowledge e.g. by "doing research".

Conflict over decision-making raises a clinical dilemma concerning whose voice is privileged in every day decisions. A lack of negotiation between parents and professionals may result in the young adult's needs being unmet, which may limit their adult development. Keeping the child in view is essential for establishing an effective triangle of care, whilst informing parent and professional perspectives. However, this can often be difficult to achieve if the child is not consulted during the decision-making process.

Our study highlighted a common parent perception that their child was unable to make informed decisions about their care; indeed, from parents' accounts, their child often seemed to be excluded from involvement in decision-making. In reality, a more systemic interplay between the parents, child and professionals would determine best practice in terms of how decisions are made e.g. by making reference to the Mental Capacity Act Code of Practice[26] (MCA; DoH,

[26] The MCA framework offers a legal basis for making decisions in the best interest of individuals who lack capacity to do so (DoH, 2005).

2005). One of the statutory principles of the MCA relates to making practicable steps to help vulnerable individuals make a decision. This means that even if a child lacks capacity to make an informed decision, they may still be able to contribute to the decision-making process, if this is communicated sensitively. Whilst using such legislations may give rise to further conflict in terms of whose decision is "the best", the MCA does offer advice about resolving disputes in best interests decision-making e.g. by inviting an independent mental capacity advocate.

Further ways of managing conflict include embracing the three-way partnership between the parent, professional and young adult where possible. Previous research highlights the notion of "relational autonomy", in which an individual fosters self-development and understanding within the content of relationships with others (Mackenzie & Stoljar, 2000). This relational model is suggested to be more suitable for the care of individuals with an intellectual disability (Widdershoven & Sohl, 1999). Based upon the current study findings, clinical interventions may aim to increase joint working in which decision-making is an interactive and triangular process (i.e., between the young person, parent and professional). In doing so, this would have implications for (1) broadening conceptions of autonomy in terms of it being relational, (2) keeping the young individual involved in the decision-making process as much as possible as emphasised by the MCA (2005) and (3) understanding that adulthood for individuals with (and without) an intellectual disability is not necessarily about being able to make decisions independently but being supported to understand the options available.

(2) Parents' psychological adjustments

In this study, psychological adjustments reflected the changes that parents made in order to cope with their child's transition. Parents made frequent comparisons with perceived "norms", which served to either heighten or lower their levels of worry. Parents often sought support from family and parent networks to help them cope with their child's transition. Some parents accessed professional support particularly when responding to the dilemmas associated with their child's sexuality development.

Making comparisons with perceived "norms"

Parents frequently made comparisons to the perceived "norms" of adulthood when making sense of their child's transition. This involved reflecting upon their personal experiences of adulthood and experiences of children without an intellectual disability. A key finding included that worrying appeared to heighten when parents viewed their child's adult development as deviating away from the perceived norms. Thus, making comparisons with normative lifecycles was an important process that contributed towards parental worry and subsequent coping strategies.

One possible interpretation of parents' heightened worry can be derived from the social comparison theory (Festinger, 1954). This theory explains that individuals have a drive to evaluate aspects of the self in relation to others in similar situations. This includes accomplishments, traits, possessions and aspects of significant others e.g. one's children (Gibbons & Buunk, 1999). Parents' views of how their child is managing the transition may be important for evaluating their own role as a parent. Indeed, if parents perceive their child to be struggling to do "adult tasks", this may impact upon the parent's self-esteem and confidence in being a "good enough" parent. Thus, making comparisons has implications for understanding both parent and child (i.e., family) adjustments.

In situations where the self-concept is threatened, individuals may react by (a) making minimal comparisons (Brickman and Bulman, 1977), (b) avoiding upward comparisons (Steil and Hay, 1997) and (c) self-enhancing by making downward comparisons (Crocker, Thompson, McGraw and Ingerman, 1987). Social comparison theorists suggest that making comparisons may motivate individuals to change (Miller and Kaiser, 2001). It can also increase levels of hope and aspiration as opposed to resentment. Making comparisons with families who are viewed as being well-functioning is considered to be a process that individuals engage with during periods of stress, novelty or change (Aspinwall, 1997; Molleman, Pruyn and Van Knippenberg, 1986). Thus, making comparisons with others is likely to occur during periods of uncertainty (e.g., transition) and appears to have an adaptive function (Festinger, 1954; Taylor, Buunk and Aspinwall, 1990).

Applying the social learning theory to our findings, we argue that parents may compare their child to normative lifecycles in order to improve their child's abilities. Parents may encourage "age appropriateness" to help shift their child's adult development to be in line with the "norms". By contrast, parents who do not make comparisons may be more accepting of their son or daughter's "child-like" interests. However, research suggests that the meanings that people derive from social comparisons may be unhelpful (Bogart and Helgeson, 2000; Dibb and Yardley, 2006). Thus, some parents may avoid comparing themselves (or their child) to normative lifecycles in anticipation of negative outcomes (e.g., heightened anxiety)[27].

Accessing support

Some parents sought social support to cope with their child's transition. Accessing parent support groups provided them with emotional support and reduced feelings of isolation. This is consistent with Kerr and McIntosh (2000) who found that contact with other parents provides a sense of "normality" in what had previously been considered to be an "abnormal" situation; helps parents to visualise a positive future for their child; provides parents with a forum to resolve feelings of guilt, confusion or anxiety; and enables them to share experiences which helps to reduce feelings of isolation. Thus, seeking support from similar others seemed an important part of the adjustment process when coping and adapting to their child's transition. Indeed, making comparisons with similar others may foster (a) a "proximity" effect that develops as a result of segregated environments in which in-group members are readily available for comparison, (b) a "similarity" effect in which individuals who have been stigmatised search for similar stigmatised others to allow for more accurate self-evaluations, and (c) a "self-protective" effect where comparing with advantaged out-groups may have negative effects upon an individual's self-esteem (Crocker and Major, 1989). These effects may encourage a sense of belongingness for parents whilst helping to reduce feelings of anxiety and stress associated with transitions.

[27] Please see extended discussion (section 4.2) for further details of "making comparisons".

Some parents also sought professional support when managing the dilemmas associated with their child's sexuality development. Research suggests that sexuality development is an ambiguous area for both parents and staff (Hollins and Sinason, 2000). There is some evidence that parents of a child with an intellectual disability find it more difficult than professionals to accept their child's sexuality (Rose, 1990). However, parents may be misjudged by society as being "in denial" of their child's sexuality, when in reality, they may be worrying about how to best support their development. It would be helpful for future intellectual disabilities research to explore parent views towards their child's sexuality development to provide more contemporary perspectives held by parents, and reduce the likelihood of their actions being misunderstood[28].

Strengths, limitations and research implications

A key contribution of this study is that it moves away from the staged idea of transition (e.g., Bridges, 1991; Hopson and Adams, 1977 . Our grounded theory model offers a hypothetical way of representing how the dynamic processes that parents engage in for their child's transition may be interlinked. Future research could test and build upon this model in terms of identifying potential causal mechanisms[29]. Additionally, the female:male ratio of the study sample was 2:1 respectively. This reflects an improvement in the gender variation within intellectual disabilities research where the number of male participants is fairly small or non-existent (Towers and Swift, 2006). Yet, future intellectual disabilities research might shed further light on how fathers experience and cope with their child's transition into adulthood[30]. Limitations of our study include that all participants were from a White British background. Thus, there was limited opportunity to explore whether there were any differences in cultural views e.g. in their definition of "adulthood" or its markers. This highlights an area that future intellectual disabilities research could focus upon as it may help to understand any variations in how parents from different cultures make

[29] Please see extended discussion (section 4.9.5) for further details about recommendations for future research regarding the grounded theory model.
[30] Please see extended discussion (sections 4.7, 4.8 & 4.9) for further details about the strengths and limitations of our study, and further implications for clinical practice/future research.

adjustments for their child's transition into adulthood. Additionally, whilst grounded theory was an appropriate method of analysis for exploring the nature of parental processes, it provided limited insight into the meanings that parents assigned to their experiences (e.g., what it meant to be a parent vs carer). Future qualitative research could employ alternative methods (e.g., interpretative phenomenological analysis) to address this limitation.

Clinical implications

There is a paucity of intellectual disabilities research on understanding parents' views and adjustments for their child's transition into adulthood. Gaps in our understanding of parents' experiences could lead to erroneous assumptions and mis-applications of "normative" models of transition to individuals with a severe intellectual disability. Our study sought to address these gaps by (1) broadening our understanding of how parents viewed their child's transition into adulthood, (2) developing a grounded theory to capture the processes that parents utilised to make adjustments,(3) raising areas for future research to explore to inform clinical practiceand (4) identifying psychological interventions to help support families who may struggle to adjust with this transitional process.

Looking across the study findings, it is evident that there are a number of areas that we could seek to influence as clinicians in order to support parents' psychological adjustments and general experiences of their child's transition into adulthood. Possible foci of intervention could include:

1. Promoting social support e.g. facilitating parent support groups in which comparisons with similar others can be made more positively.
2. Challenging parent perceptions e.g. catastrophizing beliefs around the transition process.
3. Staff and parent training in sexuality development for young people with severe intellectual disabilities.
4. Working systemically with families to embrace partnership working. This may include acknowledging parents' definition of adulthood, finding ways to negotiate what is "normal" and working towards a shared understanding with parents.

5. Using our transition model of adjustment as an explanatory framework to help parents understand that adjustment related difficulties are normal and can be worked through.

Conclusion

This study has contributed to our understanding of how parents experience and make adjustments for the transition into adulthood of their child with a severe intellectual disability. Most parents conceptualized their child's transition into adulthood as an anxiety-provoking process. We developed a transition model of adjustment that is grounded in parents' views, and acknowledges the diverse experiences that they may encounter for their child's transition. Our findings provide a number of implications for future clinical practice and research. These implications warrant the need for further exploration of this transition process to aid our understanding of how it is perceived by parents, and how they make adjustments for it.

References

Almack, K., Clegg, J. and Murphy, E. 2008. Parental negotiations of the moral terrain of risk in relation to young people with intellectual disabilities, *J. Community. Appl. Soc. Psychol.*, 19, (4), 286-298.

American Psychiatric Association. 2013. Intellectual disability, American Psychiatric Publishing, www.dsm5.org (accessed 23 June 2013).

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, *55*(5), 469.

Aspinwall, L. G. 1997. Future-oriented aspects of social comparisons. In B. P. Buunk and F. X. Gibbons (Eds.), Health, coping, and well-being: Perspectives from social comparison theory (pp. 125-166), Mahwah, NJ, Erlbaum.

Averill, J. R. 1973. Personal control over aversive stimuli and its relationship to stress, *Psychol. Bullet.,* 80, (4), 286.

Birks, M. and Mills, J. 2011. Grounded theory: A practical guide, Los Angeles, Sage Publications.

Biswas, S., Moghaddam, N. and Tickle, A. 2014. What are the factors that influence parental stress when caring for a child with an intellectual disability? A critical literature review, *Int. J. Dev. Dis.,* Advance online publication.

Blacher, J. 2001. Transition to adulthood: Mental retardation, families, and culture. *Am. J. Ment. Retard,* 106, (2) 173-88.

Bogart, L. M. and Helgeson, V. S. 2000. Social comparisons among women with breast cancer: A longitudinal investigation, *J. Appl. Soc. Psychol.,* 30, (3), 547-575.

Breunlin, D. C. 1988. Oscillation theory and family development. In C. J. Falicov (Ed.), Family transitions: Continuity and change over the life cycle (pp. 133–158), New York, The Guilford Press.

Brickman, P. and Bulman, R. J. 1977. Pleasure and pain in social comparisons. In J. Sulls and R. Miller (Eds.), Social Comparison Processes, (pp.149-186), London, John Wiley & Sons.

Bridges, W. 1991. Managing transitions: Making the most of change, Reading, Mass: Addison-Wesley.

Bridges, W. 2004. Transitions: Making sense of life's changes, Cambridge, Da Capo Press.

Carter, E. A. and McGoldrick, M. 1980. Family life cycle: A framework for family therapy, New York, Gardner Press.

Clegg, J., Sheard, C., Cahill, J. and Osbeck, L. 2001. Severe intellectual disability and transition to adulthood, *Brit. J. Med. Psychol.*, 74, (2), 151-166.

Corbin, J., and Strauss, A. 1990. Grounded theory research: Procedures, canons and evaluative criteria, *Qual. Sociol.,* 13, (1)*,* 3-21.

Corbin, J. and Strauss, A. 2008. Basics of qualitative research: Techniques and procedures for developing grounded theory (3rd ed), London, England, Sage Publications.

Crocker, J., and Major, B. 1989. Social stigma and self-esteem: The self-protective properties of stigma. *Psychl Rev*, 96, (4)*,* 608-630.

Crocker, J., Thompson, L. L., McGraw, K. M. and Ingerman, C. 1987. Downward comparison, prejudice and evaluations of others: Effects of self-esteem and threat, *J. Pers. Soc. Psychol.,* 52, (5), 907.

Cummins, R. A. 2001. The subjective well-being of people caring for a family member with a severe disability at home: A review, *J. Int. Dev.l Dis.*, 26, (1), 83-100.
Cutcliffe, J. R. 2000. Methodological issues in grounded theory. J. Adv. Nurs., 21, (6), 1476-1484.
Department of Health. 2001. Valuing People: A new strategy for learning disability for the 21st century: A white paper, UK, Department of Health.
Department of Health 2005. Mental Capactiy Act. London, HMSO.
Dibb, B. and Yardley, L. 2006. How does social comparison within a self-help group influence adjustment to chronic illness? A longitudinal study, *Soc. Sci. Med.,* 63, (6), 1602-1613.
Ferguson, P. M., Ferguson, D. L. and Jones, D. 1988. Generations of hope: Parental perspectives on the transitions of their child with severe retardation from school to adult life, J. Ass. Pers. Sev. Handicaps., 13, (3), 177-187.
Festinger, L. 1954. A theory of social comparison processes, *Human Relations*, 7, 117-140.
Gibbons, F. X. and Buunk, B. P. 1999. Individual differences in social comparison: Development of a scale of social comparison orientation, *J. Pers. Soc. Psychol.*, 76, (1), 129.
Grant, G., Ramcharan, P., McGrath, M., Nolan, M. and Keady, J. 1998. Rewards and gratifications among family caregivers: Towards a refined model of caring and coping, *J. Int. Dis. Res.*, 42, (1), 58-71.
Heslop, P., Mallett, R., Simons, K. and Ward, L. 2002. Bridging the divide at transition: What happens for young people with learning difficulties and their families? Plymbridge, UK, British Institute of Learning Disabilities.
Hollins, S. and Sinason. 2000. Psychotherapy, learning disabilities and trauma: New perspectives, *The Brit. J. Psychiat.,* 176, (1), 32-36.
Hopson, B. and Adams, J. D. 1977. Towards an understanding of transition: Defining some boundaries of transition dynamics. In J. Adams, J. Hayes and B. Hopson (Eds.), Transition: Understanding and managing personal change (pp. 3-25), Montclair, NJ, Allenheld & Osmun.
Jablonski, J. F. and Martino, S. D. 2013. A qualitative exploration of emerging adults' and parents' perspectives on communicating adulthood status. *The Qual Rep.*, 18, (37), 1-12.
Kerr, S. M., and McIntosh, J. B. 2000. Coping when a child has a disability: Exploring the impact of parent-to-parent support. Child: care, health and development., 26, (4), 309-322.
Knox, M. 2000. Family control: The views of families who have a child with an intellectual disability, *J. Appl Res. Int. Dis.*, 13, (1), 17-28.
Lazarus, R. S. 1966. Psychological stress and the coping process, New York, McGraw-Hill.
Mackenzie, C. and Stoljar, N. 2000. Feminist perspectives on autonomy, agency, and the social self. Oxford: Oxford University Press.
Miller, C. T. and Kaiser, C. R. 2001. A theoretical perspective on coping with stigma, *J. Soc issues.,* 57, (1), 73-92.
Molleman, E., Pruyn, J. and Van Knippenberg, A. 1986. Social comparison processes among cancer patients, *Br. J. Soc. Psychol.,* 25, 1-13.
Neece, C. L., Kraemer, B. R., & Blacher, J. 2009. Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellect. Dev. Disabil,* 47, (1), 31-43.

Park, C. L. 2010. Making sense of the meaning literature: an integrative review of meaning making and its effects on adjustment to stressful life events, *Psych. Bullet.*, 136, (2), 257.
Pittman III, F. S. 1987. Turning points: Treating families in transition and crisis. WW Norton & Co.
QSR International Pty Ltd. 2014. NVivo qualitative data analysis software: Version 14 [computer software], http://www.qsrinternational.com/support_downloads.aspx (accessed 20 January 2014).
Rose, J. 1990. Accepting and developing the sexuality of people with mental handicaps: Working with parents, *Ment. Handicap.,* 18, 4-6.
Roy, L., Rousseau, J., Fortier, P., & Mottard, J. P. 2013. Transitions to adulthood in first- episode psychosis: a comparative study. *Early. Interv. Psychiatry*, 7, (2), 162-169.
Scorgie, K. and Sobsey, D. 2000. Transformational outcomes associated with parenting children who have disabilities, *Ment. Retard*., 38, (3), 195–206.
Shanahan, M. J. and Neufeld, R. W. 2010. Coping with stress through decisional control: Quantification of negotiating the environment, *Br. J. Math. Stat. Psychol,* 63, (3), 575-601.
Steil, J. M. and Hay, J. L. 1997. Social comparison in the workplace: A study of 60 dual-career couples, *Pers. Soc. Psychol. Bullet.,* 23, 427-438.
Swain, J. and Walker, C. 2003. Parent-professional power relations: Parent and professional perspectives, *Disability and Society,* 18, (5), 547-560.
Task Force. 2009. Transitions for people with developmental disabilities: A report of the NCIOM Task Force on transitions for people with developmental disabilities. North Carolina: NCIOM
Taylor, S. E., Bunk., and Aspinwall, L. G. 1990. Social comparison, stress, and coping, Pers. Soc. Psychol. Bullet., 16, 74-89.
Thompson, S. C. 1981. Will it hurt less if I can control it? A complex answer to a simple question, *Psychol. Bullet.,* 90, (1), 89.
Todd, S. and Shearn, J. (1996). Struggles with time: The careers of parents with adult sons and daughters with learning disabilities, *Disability and Society,* 11, (3), 379-401.
Towers, C. and Swift, P. 2006. Recognising fathers: Understanding the issues faced by fathers of children with learning disabilities, London, Foundation for People with Learning Disabilities, http://www.fpld.org.uk (accessed 3 June, 2014).
Tweed, A. and Charmaz, K. 2012. Grounded theory methods for mental health practitioners. In D. Harper, & A. R. Thompson (Eds.). Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners. Oxford, England: Wiley-Blackwell.
Widdershoven G., and Sohl C. 1999. Interpretation, action, and communication: Four stories about a supported employment program. In T. A. Abma Telling Tales: On Evaluation and Narrative (pp. 109-30). Stamford: JAI Press.
Willig, C. 2001. Introducing qualitative research in psychology: Adventures in theory and method. Berkshire, England: Open University Press.

Extended Paper

Chapter 1. Introduction

1.1 Chapter Introduction

This qualitative study aimed to gain a retrospective account of parents' views of the transition into adulthood of their child with a severe intellectual disability (see definition in Appendix A). It is important to review the literature that has influenced our understanding of the terms "intellectual disability" and "transition". Therefore, I start this chapter by introducing the history of the evolving terminology of "intellectual disability" and review its importance when considering the transition into adulthood. To provide a background to the study, I focus specifically on literature about the transition into adulthood for people with intellectual disabilities. Both empirical studies and governmental documents used within a service context are considered. Existing theoretical and empirical literature relating to parents' views of this transitional process are reviewed and critiqued to provide a focus and rationale for this study. Bringing this background literature together and acknowledging the current gaps in knowledge (for example, around transitions for people with severe intellectual disabilities), I then provide a summary of the chapter and outline the aims of the study.

1.2 Evolution of "Intellectual disabilities" Terminology

The evolution of the terminology associated with individuals with intellectual disabilities reflects the changes in societal attitudes towards them over time. Historically, terms such as "idiot", "imbecile" and "moron" were used to describe people with intellectual disabilities (Linneman, 2001). By the early 1900s, medical and diagnostic approaches began to locate disability within the individual. For example, intellectual disability was described as being "a long-term physical, behavioural, psychological, cognitive or sensory impediment" (Gilson & DePoy, 2002, p. 154). Towards the end of the 1960s and throughout the rest of the 20th century, the term "mental retardation" was used (Linneman, 2001). Within the UK, the term "learning disabilities" was used until the recent shift in terminology whereby the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5; American Psychiatric Association, 2013) replaced the term "mental retardation" with "intellectual disability". This is now the common term used to describe an individual's intellectual and adaptive functioning that is below average.

1.3 Models of Disability

Another radical shift in the evolution of intellectual disability was the movement away from the medical model to a social model of disability. Both models are outlined below.

1.3.1 The medical model. This model posited that disability was an impairment of the biological system. As such, problems were viewed as being located within an individual (Brett, 2002). At the beginning of the 20th century, "symptoms" were often treated through medical interventions, which fostered an overall outlook that a person can be "fixed" or "cured". If the individual could not be "fixed", then they (and their families) were generally perceived as being "problematic" or "deviant" (Goffman, 1963). This model was criticised for overlooking the web of social and material factors in which problems may have been embedded (Franzblau & Moore, 2001). It also made it difficult to identify other problems an individual could be experiencing (e.g., mental health difficulties) as this was often conflated with the individual's disability (Mason, 2007). Additionally, locating problems within an individual often made them feel like they were to blame. This had a negative impact upon their self-esteem, whilst perpetuating a form of social oppression (Oliver, 1996).

The medical model was deemed to be disempowering for individuals and their families. Professionals used the model to maintain their dominance over the parent and professional "partnership" (Dale, 1996). It was suggested that the medical model and professional practice conspired together to maintain the exclusion of disabled individuals and their families within society (Brett, 2002). This, together with the model's assumptions that all problems could be reduced to individual pathology, warranted the need for an alternative model that considered wider factors of disability.

1.3.2 The social model. The shift to a social model of disability in the 1970s rejected medical assumptions around disability. Instead, this model argued that disability was a product of society as opposed to an individual's impairments. The social model of disability acknowledged the "disabling effects" of society upon those with intellectual disabilities such as the absence of human rights, limited personal support and discrimination (Bigby, Fyffe & Ozanne, 2008). Recognising such barriers allowed for a series of Acts and legislations to be put in place to encourage equality, diversity and independence for people with intellectual disabilities such as the Disability Discrimination Act (1995) and

Valuing People Now (Department of Health [DoH], 2001a). As a result, the social model of disability promoted more inclusive ways of living in society.

These legal Acts and legislations have focused more upon people with intellectual disabilities in general as opposed to specific sub-groups within it. Whilst there is a clear argument that dimensions of difference (e.g., severity) within governmental documents have been somewhat overlooked, sub-categorisation of disability also poses some risks. For example, sub-categorisation may place wider needs e.g. available support, individual history and socio-economic status as less of a priority. Despite research suggesting that families of people with severe intellectual disabilities may struggle more than families of people with mild to moderate intellectual disabilities (Learning disability task force, 2004), it is arguable that some families of people with severe intellectual disabilities do not struggle. Thus, sub-categorisation may endorse a "one size fits all" view, which may not be helpful to those who fall outside of common trends.

1.4 Defining "Transition"

A number of transitions may be experienced over the life course involving developmental, personal, relational, situational, societal or environmental change (Kralik, Visentin, van Loon, 2006). Bridges (2004) defined "transition" as the inner psychological process involved in adapting to new situations. This definition will be used for the purpose of our research. The process of adapting to transitions is considered to occur when an individual becomes *aware* of change and engages in activities such as seeking information and social support in order to make sense of the changes (Kralik et al., 2006). Our study aimed to understand parents' views (i.e., parents' inner psychological processes) of their child's transition into adulthood.

1.5 Transition and Service Context

Within the UK, inclusion criteria for accessing adult intellectual disability services is typically based upon being aged 18 or over and having a diagnosis of an intellectual disability. However, in practice, some services rely more upon an individual's IQ score as opposed to other criteria. Research emphasises that people should have access to intellectual disability services best able to meet their needs rather than being accepted based upon IQ score or their birth date

(Royal college of psychiatrists; 2010). This is important to consider especially since people have different levels of ability and needs, which may be best met through a developmental approach.

In order to facilitate a person-centred approach, a White Paper known as "Valuing People: A new strategy for Learning Disability for the 21st Century" proposed a new vision to "improve the life chances of people with learning disabilities" (DoH, 2001a). In order to ease the transition process, one of the government objectives was to introduce a network of personal advisors from the Connexions service to guide, advise and support young people with intellectual disabilities and their families. Additionally, emphasis was placed upon individuals having more choice and control over their lives by including them in decision-making and planning for their future. Furthermore, the government set out provisions to ensure that carers received the right support in their caring role; obtained accessible information about services; were respected and treated as individuals in their own right; and had their voices heard at a regional and national level (DoH, 2001a).

Strengths of this White Paper include that it helped to provide attention to the needs of young people with intellectual disabilities and their carers, whilst highlighting a strong objective to improve continuity of care as children move into adulthood. This was deemed to be a particular strength at the time since people with intellectual disabilities appeared to have little recognition in terms of their future needs, funding and resources. However, whilst such governmental legislation exists, there is a lack of a reliable and valid framework for targeted implementation and evaluation. Indeed, published projects that have evaluated the impact of "Valuing People" (e.g., Hatton, Emerson & Lobb, 2005) suffer from a number of limitations including that data is collected from local agencies as opposed to people using services directly; there is inconsistency in the terminology used to define individuals with an intellectual disability; and information collected is largely numerical. This means that important information regarding an individual's experience (relevant for outcomes) may not be easily obtained. Hatton et al's (2005) report was unable to assess change over time regarding the transition into adult life due to limited resources. Thus, it is unclear whether the objectives (and sub-objectives) are being put into practice or whether they are having an impact (national, regional or local) as intended.

1.6 Transition into Adulthood: A Life-course Perspective

The concept of "adulthood" is constantly evolving. Historical literature suggests that "adulthood" may take different forms within different eras and cultures (Cote, 2000). For example, young men leaving home at an early age for work purposes during the 1950s was considered to be "normal" for that era. For women, adulthood was related to being married or being a mother. In contemporary society, notions of adulthood largely related to independence. However, recent research highlights that young people may live at home longer now or return back home later on (Settersten & Ray, 2010). Thus, constructs of adulthood are constantly changing. Similarly, the "norms" of adulthood are dynamic i.e. they are not stable over time.

The transition process may include legal, social, cognitive, emotional and physical changes for the young person. For example, by the age of 18, people have the right to vote and to legally make their own decisions. At a social and cognitive level, young individuals may be expected to learn how to achieve tasks that enhance their ability to take responsibility for themselves and develop independent relationships with others. Physical bodily changes (e.g., increase in levels of oestrogen or testosterone) may also be indicative of sexuality development. However, not all young people will experience the same transition process given that transitions may be dependent upon biopsychosocial factors including age, gender, race, culture and socio-economic status.

For people with intellectual disabilities, the notion that they (and their families) may experience slower and more stressful transitions into adulthood compared to individuals without intellectual disabilities is not unknown. Societal expectations of adulthood for people with intellectual disabilities are often similar to their non-disabled peers. For example, Tarleton and Ward (2005) highlighted that people with intellectual disabilities were expected to work, go to college and have a social life. Additionally, various markers of adulthood for individuals with intellectual disabilities have been mainly related to independence. These include leaving home, pursuing relationships with friends, paid employment and getting married (Heslop, Mallett, Simons & Ward, 2002; Tarleton & Ward, 2005).

Such markers and expectations of adulthood can become problematic if achieving independence is hindered by factors such as parental concerns for safety, lack of service support, difficulties managing money and making balanced decisions (McConkey & Smyth, 2003). Additionally, societal views

around adult appropriate roles and relationships dominate intellectual disabilities services; self-determination, empowerment and autonomy are prevalent policy discourses (Pilnick, Clegg, Murphy & Almack, 2010; Schalock, Verdugo & Gomez, 2011). However, research contests the appropriateness of expecting people with intellectual disabilities to meet such societal expectations of adulthood (Almack, Clegg & Murphy, 2008). Currently, there is no research exploring parental views of adult appropriate roles in relation to their child with a severe intellectual disability.

Nevertheless, it is important to note that these existing studies, along with most of the transition literature within the intellectual disabilities field in general, have focused upon individuals with mild to moderate intellectual disabilities. Moreover, studies that have focused upon individuals with severe intellectual disabilities have often explored physical aspects of the transition into adulthood rather than acknowledging the developmental view of it, in which there is a sparse but growing literature (Stewart et al., 2010). Clegg, Sheard, Cahill and Osbeck (2001) used grounded theory analysis to explore the transition from child to adult services of ten individuals with severe intellectual disabilities, from the perspective of parents and adult service staff. In particular, their grounded theory model of transition illuminated the core concept for parents as being a "reluctant referee". This entailed parents feeling apprehensive about the transition process, perceiving it as a burden and describing it as a "rollercoaster ride", even though some transitions had been smooth. The model then goes on to relate parent perspectives of transition to parent perspectives of communicating with adult services. This study is useful as it highlights the differences in parent and staff perspectives of the transition process into adult services, and has implications for adult services to improve their delivery.

However, the theory that Clegg et al. (2001) developed is strongly driven by perspectives on service-related transitions into adulthood. Whilst it demonstrates how divergent perspectives between parents and professional staff may have a negative impact upon parents' experiences (e.g., feeling abandoned and misunderstood by services), it does not account for any processes that occur for the child or their parents around the transition. Additionally the theory does not shed any light on parental coping strategies for managing the difference in views or the changes that arise for parents and their child during

the transition process. These issues highlight the difficulties in applying this theory to transitions using a developmental context as the views underpinning the theory are heavily based upon experiences of interacting with adult services. Thus, there is an imperitive need to develop a new theory that is grounded in developmental perspectives and acknowledges that the transition into adulthood for individuals with severe intellectual disabilities is more than just a question of service provision.

1.7 Existing Transition Models

Transition models endeavour to describe how individuals respond to change. A number of models have been developed to help understand lifecycle transitions. Some of the key transition models are outlined below.

1.7.1 Family lifecycle model. This model delineates a sequence of cyclical transitions in which family development is suggested to occur (Carter & McGoldrick, 1980). This includes stages such as leaving home, getting married, having children and preparing for older adult life. The model places an emphasis upon "interconnectedness", suggesting that transitions are likely to have an impact upon all family members.

The family lifecycle model would suggest that parents experience their child's transition into adulthood as a stressor, which causes them to focus upon their current stressful circumstances or anticipate further stress in the future (Carter & McGoldrick, 1980). As such, issues related to the transition into adulthood may give rise to a range of complex difficulties for the individual with a severe intellectual disability and their families (Todd & Shearn, 1996). For example, the young individual may leave home at a later stage in life than is socially expected. Thus, families may appear "out of synchrony" with normative lifecycles (Goldberg, Magrill, Hale, Damaskinidou, Paul & Tham, 1995).

Criticisms of the family lifecycle model include that it is based heavily upon the norms of traditional nuclear families where minority family lifecycles are conceptualised as deviating away from this norm (Goldberg et al., 1995). Whilst Carter and McGoldrick (1980) explained that their theory should not be used in a rigid fashion to understand family development, minority-family systems may be compared to socially constructed "norms" within society. This can be problematic for adults with intellectual disabilities and their families as they are perceived to be "out of synchrony" as opposed to diverse and unique.

As such, the family lifecycle model may serve to undermine family experiences rather than embracing them. Additionally, Falicov (1988) questioned the stage concept of the model, emphasising that families do not necessarily follow stage expecations in an orderly manner. The model does not give a clear explanation of how transitions actually work i.e. the processes that family members engage in. Furthermore, by equating transitions with events such as birth, marriage and death, the model ignores other transitions that may be of importance to families (e.g., job loss).

1.7.2 Life-course theory. This theory can be understood metaphorically in terms of "clocks" and "calendars". Mills (2000) suggested that biological, physical and human development clocks run in parallel with social clocks that represent the norms, values and rules of when life events are expected to occur. Calendars are based upon religious, family, employment or public service institutions (Grant, 2005). The life-course may be viewed as a journey through different time trajectories. Grant (2005) highlights that each journey facilitates elements of agency, choice and control over the directions taken. Arguably, the fit between different clocks and calendars may not be as neat for individuals with intellectual disabilities and their families due to differences in family culture, and transition time points.

1.7.3 Hopson and Adam's (1977) seven-stage model of transition. Hopson and Adams (1977) defined transition as a process requiring personal awareness and new behavioural responses. A seven-stage model was considered to help a range of people understand the many transitions that they experience in life (Hopson & Adams, 1977) (see Figure 5). The stages included immobilisation (e.g., a sense of being overwhelmed), reaction (e.g., denial), self-doubt (e.g., becoming conscious of the implications and challenges that transition presents), accepting reality and letting go (e.g., moving on from the past), testing (e.g., engaging with the new reality), searching for meaning (e.g., reflecting upon the significance of the transition) and integration (e.g., internalising the new meanings assigned to the new reality and incorporating them into their new roles and outlook) (Hopson & Adams, 1977).

The model is depicted as a smooth curve indicating changes in relation to mood over time as an individual passes through the successive stages of transition. Hopson and Adams (1977) emphasised that the nature of change would trigger an unpredictable cycle of reactions and feelings. They also

highlighted that the model may not represent everyone's experiences; that people's transition experiences are rarely as smooth as the model presents; and that the stages are not progressive i.e. people may occupy different stages of the model at varied time lengths and mood intensities.

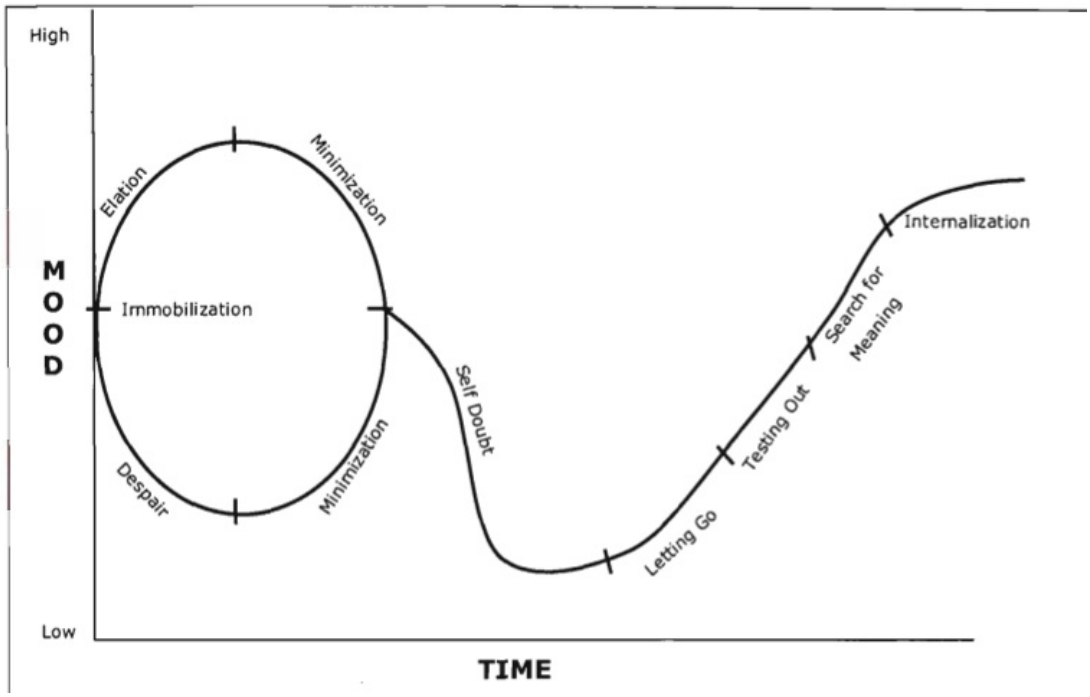

Figure 5. Hopson and Adams (1977) model of transition (adapted from Hopson, 1981).

Whilst this model is suggested to be useful when discussing transition processes with individuals (Blair, 2000), it has been criticised for being too rigid. Additionally, the model does not indicate any mechanisms of movement between stages and is based upon individuals experiencing normative lifecycles.

1.7.4 Bridges' (1991) transition model. This model portrays transition as a three-stage process, which involves an individual eventually accepting and adapting to the new situation (see Figure 6). Bridges (1991) described that transition starts off with "ending" where people let go of the way things used to be. This stage may include emotions such as fear, anger, denial, uncertainty and sadness. The second stage is the "neutral zone", which was suggested to be an in-between state i.e. people are no longer where they were but are still not where they want to be. People may experience feelings of resentment towards

change and anxiety of the unknown. Whilst this stage may be distressing, it was argued to provide opportunities for creative adaptation to change (e.g., new ways of thinking; Bridges, 1991). The final stage is the "new beginning", in which people were suggested to accept their new reality.

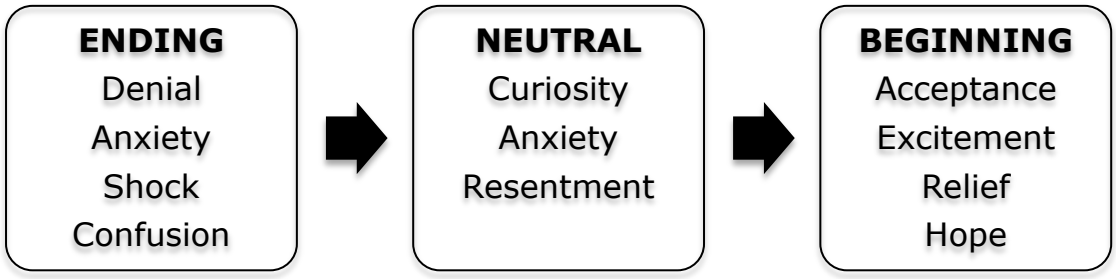

Figure 6. Bridges' (1991) transition model.

Bridges' (1991) model linked the transition sequence to individual experiences. Bridges (1991) emphasised that people enter the stages successively. However, it is unlikely that all transitions are a linear process. It could be argued that an individual may transit straight from the "ending" stage into the "beginning" stage if they are feeling excited or hopeful at the prospect of moving on. Similarly, in relation to Hopson and Adams' (1977) model, an individual may still experience a sense of "self-doubt" whilst "searching for meaning". Thus, individuals may react differently to change. They may move back and forth within transition sequences or experience stages simultaneously.

1.7.5 Oscillation theory. "Oscillation" can be defined as "a series of deviations with smaller or larger amplitudes from an established equilibrium in family functioning" (Molinari, Everri & Fruggeri, 2010, p. 237). This theory derived from direct observations of family development[31]. Breunlin (1988) argued that oscillations were an inevitable characteristic of transitions. He hypothesised that change occurred through an oscillation between levels of

[31] The term "family development" was defined as a function of individual competence (Breunlin, 1988).

developmental functioning (see Figure 7). This contrasts with models such as the family lifecycle in which the transition process is suggested to look like a step function curve[32] when depicted over time i.e. where discontinuous leaps would be made to the next stage (Falicov, 1988).

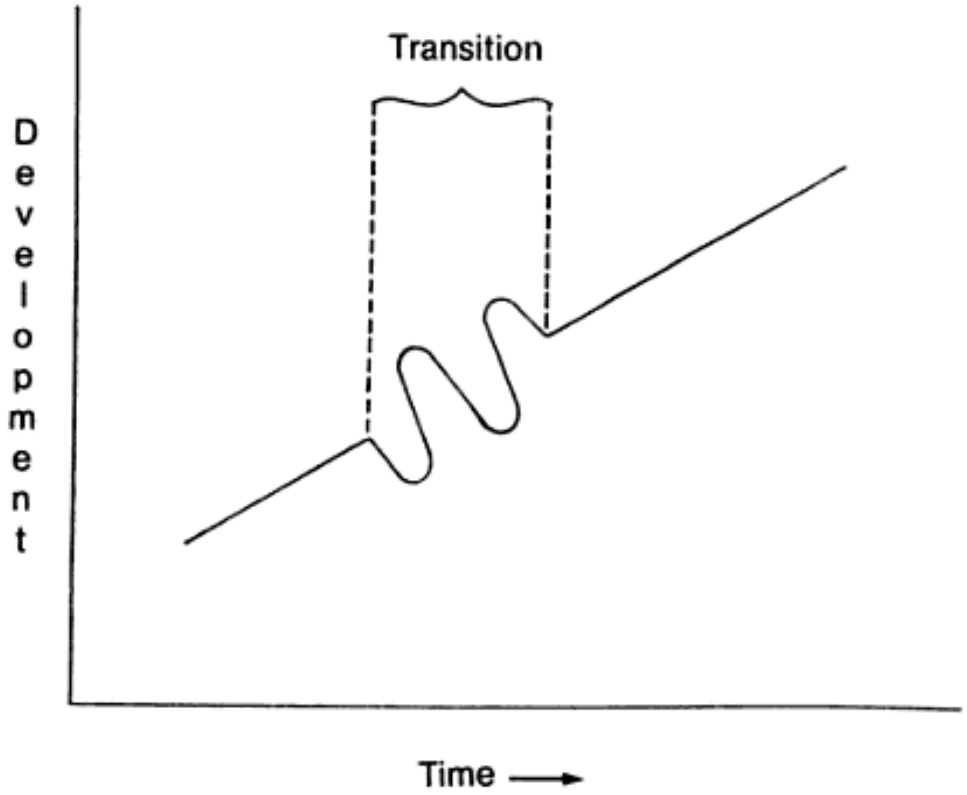

Figure 7. An oscillation in the family development process (Falicov, 1988)

The oscillation theory offers a more systemic way to think about the process of change over time. It also acknowledges that individuals may engage in a series of microtransitions at the same time. Understanding how individuals co-regulate multiple processes during transition may offer some indication of how they adjust to life challenges (Walsh, 2006). A further strength of the oscillation theory relates to its clinical applicability. For example, the theory could be used to detect oscillations within family systems that give rise to symptoms (e.g., anxiety). Interventions could then be delivered to dampen or eliminate this oscillation to reduce symptoms and restore the level of

[32] The "step-function" curve derived from an application of the Mental Research Institute theory of change to the family lifecycle model, and not from empirical studies of family development (Falicov, 1988).

equilibrium. However, this theory was based upon the observation of normative family development during the child-rearing years; a time when the curve is positive and competence becomes increasingly complex (Breunlin, 1988). Thus, it is uncertain whether the shape of the developmental curve would be the same for families of an individual with intellectual disabilities or if the term "family development" can be operationalised in a different way. Nevertheless, this theory offers a useful framework for explaining how transition occurs and for formulating interventions.

1.7.6 Conclusion. It is acknowledged that other models have been useful for understanding transitions e.g. Schlossberg's (1981) model of transition and adaptation and Ruble's (1994) phase model of transitions. Additionally, it is apparent that these models relate to similar concepts within the context of *normative* experiences. Given that young people with severe intellectual disabilities and their parents may experience the transition into adulthood as a difficult time, and indeed experience it differently to normative populations (on which existing models are based), the application of such models to an intellectual disabilities population should be done with caution. In light of the absence of any transition theories developed from the perspective of parents of a child with a severe intellectual disability, there is a need to develop a more contemporary and psychologically informed theory to address this gap (see section 1.8).

1.8 Why are Parents' Views Important?

Exploring parents' views is important because it remains a neglected area within the intellectual disabilities field (Beresford, 2004). Research suggests that generally caring for a child with an intellectual disability can place pressure on partner relationships (Shapiro, 2003) and that there is a higher risk of parent separation when compared with families without a disabled child (Clarke & McKay, 2008). This indicates that transitions into adulthood coupled with the general care for an individual with an intellectual disability may induce further stress and ruptures in relationships. Cummins (2001) concluded that parents' quality of life when caring for their child with a severe intellectual disability is low as it may reduce opportunities for other activities and present various stressors such as financial problems or difficulties in coping with their child's challenging behaviour, thus leading to depression. However, social issues such

as a lack of service support, low financial income and poor living arrangements may also negatively impact upon the young individual and their families (Kenny & McGilloway, 2007).

By contrast, and as stated in the journal paper, research suggests that some parents may obtain rewards and satisfaction from caregiving for their child with an intellectual disability (Grant, Ramcharan, McGrath, Nolan & Keady, 1998). Thus, not all parents may view their child's transition into adulthood as a stressful time. Moreover, "Family matters: Counting families in" (DoH, 2001b) considered that parents may be the only people who have a longstanding relationship with their child with an intellectual disability from childhood to adulthood. Thus, gaining parents' views would prove to be valuable and insightful to service providers, in terms of improving service support around the time of transition.

1.9 What do we already know about Parents' Views?

For their child's transition into adulthood, pertinent issues for parents appear to be related to their child's risk and their own interactions with professional systems. Thus, key literature related to these issues are elaborated upon below.

1.9.1 Risk. For parents of a young person with a severe intellectual disability, tensions may arise when trying to balance risk and overprotection when entering adulthood. Previous research highlighted that parents feared that an increase in independence would heighten their child's vulnerability to greater risks; namely exploitation and abuse (Heslop et al., 2002). This fear is unsurprising given the recent abuse scandals (e.g., at Winterbourne View) that have occurred despite the vast number of governmental policies and practices aiming to protect vulnerable individuals (e.g., DoH, 2001a; 2001b; 2001c; 2009).

Few studies have explored parental views of their child's risk of abuse. Of those that have, samples have typically included parents of adults with mild to moderate intellectual disabilities. For example, Heyman and Huckle (1993) explored parent views of hazards in their child's lives such as crossing the road, getting lost and experiencing assault (physical and sexual). The study identified two types of adjustments that parents used to cope with their child's vulnerability to such hazards: minimising the likelihood of risk or avoiding it

completely. However, given the increased dependency that young people with severe intellectual disabilities may present with, it may be that parental fears concerning their child's risk of abuse (and subsequent adjustments made) may differ or indeed be heightened.

1.9.2 Interactions with professional systems. Some of the difficulties experienced by parents during their child's transition into adulthood may be related to issues with professional agencies or services. Research suggests that professional systems have a potential to be invasive due to their level of power (e.g., in decision making) (Fidell, 2000). As a result, parents may feel somewhat helpless with little control over transition planning. This can be problematic especially if parents have expectations to be at the heart of supporting their child's needs. Knox (2000) explored parental views of the level of control or empowerment they had over their family's lives in general, and their interactions with intellectual disabilities services. The findings indicated that having input into decisions was critical to parents' sense of control over their lifestyle. Some parents reported that being encouraged by professionals to make decisions about their child with intellectual disabilities made them feel like an integral part of the team. As such, these parents advocated for parents and professionals to be equal partners in service provision (Knox, 2000). However, other parents expressed a need to "be assertive", suggesting that control or partnership had to be fought for. Arguably, during the time of their child's transition into adulthood, having to fight for control may provide parents with additional stress or frustrations.

Knox's (2000) study provides implications for professional systems to work collaboratively with parents to foster a partnership approach. However, this study, along with general intellectual disabilities literature around parent views have not necessarily focused upon the transition into adulthood for individuals with severe intellectual disabilities. Instead, a majority of research explored parents' views at either a broad level (e.g., the impact of having a child with an intellectual disability upon family lifestyle) or at a service level (e.g., experiences of interactions with intellectual disabilities adult services). Thus, there is little known about parent experiences of crucial time-points for their child such as the transition into adulthood – this is timely as it may have implications for professionals to understand (1) how parents needs may differ at particular

stages of their child's development and (2) how to support parents' needs during these times.

1.10 What don't we know about Parents' Views?

To date, there are no retrospective qualitative studies that have explored the transition into adulthood for individuals with a severe intellectual disability within a developmental context. Research has generally focused upon transitions between services. There are also no transition theories based upon the perspective of parents. Given that individuals with a severe intellectual disability may not be able to share their experiences (e.g., if they are non-verbal or cannot express their thoughts and feelings), it is imperative to seek the views of parents who are involved in (and are primary witnesses to) their child's transition into adulthood to inform developing theories. We particularly don't know how parents make sense of their child's transition into adulthood or how they make adjustments for it i.e. the psychological processes involved.

Additionally, current transition research is biased towards individuals with mild learning disabilities (Clegg et al., 2001) and therefore further research for those with complex needs is warranted (Beresford, 2004). Furthermore, research states that a sense of the family voice has been "lost" (Rolph, Atkinson, Nind & Welsham, 2005). It is argued that gaining parents' understanding may provide valuable insights and enlighten existing psychological theories to fully appreciate the role of parents. Thus, there is a strong need to develop a psychologically informed theory at a level that can be understood by both clinicians and parents. This will contrast from existing general transition and family lifecycle theories, which are not widely applicable to this client group or understandable for significant others such as parents.

1.11 Chapter Summary

The literature reviewed in this introduction has outlined the evolution of "intellectual disability" and the current government policies and strategies employed to ease the process of the transition into adulthood for young people with intellectual disabilities and their families. Studies within an intellectual disabilities field that have explored parental views of their child's transition into adulthood have identified various markers (e.g., legal, social and physical changes) similar to individuals without an intellectual disability. However, it is

argued that these studies, along with most of the intellectual disabilities transition literature in general, have focused upon young people with mild to moderate intellectual disabilities. Similarly, a common limitation amongst existing transition theories includes that they are based upon normative experiences. Thus, there is an absence of any current theory specifically developed for an intellectual disabilities population. With this in mind, I aimed to develop a theory that would be idiosyncratic for parents of a child with a severe intellectual disability. Additionally, I hoped that this study would add a new (and more focused) perspective to existing concepts of "transition" by specifically exploring the processes that parents engage in when they view their child to become an adult, and the adjustments made, if they do so at all. Thus, the research questions of this study were:

(1) How do parents view the transition into adulthood for their child with a severe intellectual disability?
(2) What processes (if any) do parents engage in to make psychological adjustments for this transition (e.g., in terms of coping or emotional regulation)?

Chapter 2. Methodology

2.1 Chapter Introduction

Researchers argue that a clear understanding of the research paradigm is vital when choosing the "right" methodology to answer the research question (Holloway & Todres, 2003). Munhall (2001) emphasises the importance of exploring the underpinning assumptions and beliefs of the main paradigms when undertaking qualitative research. I begin this chapter by providing an overview of the qualitative methodology used to meet the aims, namely grounded theory (Corbin & Strauss, 2008). I offer a discussion around research paradigms and the critical realist framework underpinning our study. My rationale for using grounded theory is considered followed by a description of its different versions. An outline of the methods employed, procedure used and ethical considerations are then provided. Finally, I end the chapter with a discussion of the evidence-based guidelines used to assess the quality of our study.

2.2 Research Paradigms

Research paradigms "define for inquirers what it is they are about, and what falls within and outside the limits of legitimate inquiry" (Guba & Lincoln, 1994, p. 108). The parameters of such paradigms are largely based upon three interconnected questions, namely ontological (what is the form and nature of reality?); epistemological (what is the relationship between the researcher and the phenomenon under investigation?); and methodology (what are the methods used to find out what can be known?) (Guba & Lincoln, 1994).

Existing literature focusing upon research paradigms is complex with considerable overlap between paradigms and their related concepts. Some researchers identify four paradigms for guiding qualitative inquiry (positivism, post-positivism, critical theory and constructivism; Guba & Lincoln, 1994). Alternatively, others use categories to group various perspectives together (positivism, interpretivism and criticalist research; Hallebone & Priest, 2009). Indeed, more recent literature highlights a degree of integration within paradigms (e.g., the participatory paradigm; Lincoln, Lynham & Guba, 2011).

2.2.1 Critical realism*.* Within the research paradigm spectrum, critical realism is suggested to be the bridge between the positivist ideas of a reality external to humans and the insistence of socially constructed meanings within reality (Oliver, 2011). Critical realists emphasise the importance of structures and processes as a point of reference against which theories can be tested

(Bhaskar, 1978). They argue that our reality is only "imperfectably apprehendable" because of flawed human intellectual mechanisms (e.g., theoretical resources and researcher interests; Guba & Lincoln, 1994). Thus, critical realists accept that reality exists but we can never identify it or understand it with certainty (Sims-Schouten, Riley & Willig, 2007). Moreover, what we believe to be true about the world is constantly being shaped through the discourses around us, together with empirical feedback from "accessible" aspects of the world (Sayer, 2004).

Critical realism suggests that reality is stratified into three distinct ontological domains of reality: the empirical (what is observed or experienced); the actual (what occurs but may not be necessarily experienced); and the real (underlying structures and mechanisms that generate phenomena) (Bhaskar, 1978; Delorme, 1999). These domains are not open to observation but can be inferred through empirical investigation or theory construction (McEvoy & Richards, 2006). In summary, goals of critical realism are to develop deeper levels of explanation; understand individual or social processes; and identify structures at the core of events to provide an understanding of the forces at work (Miles & Huberman, 1994). These aims provide an accurate description of the perspective underpinning our study and therefore I adopted a critical realist framework.

2.3 Design

I adopted a retrospective cross-sectional exploratory qualitative design using grounded theory (Corbin & Strauss, 2008). A total of 12 participants were interviewed using semi-structured interview schedules.

2.3.1 Rationale for qualitative methodology. I aimed to inductively investigate personal accounts in order to generate a broad understanding of parents' experiences of the transition into adulthood of their child with a severe intellectual disability, and the pertinent processes involved. Research argues that individual experiences, patterns and meanings are difficult to investigate quantitatively (Strauss & Corbin, 1998). By contrast, qualitative methods are suggested to be helpful for illuminating complex concepts and relationships that are unlikely to be captured by pre-determined response categories or quantitative measures (McEvoy & Richards, 2006). I decided to adopt a

qualitative research methodology for this study for a number of reasons outlined below.

Qualitative methodology lends itself well to exploratory and discovery-oriented research (Barker, Pistrang & Elliot, 2002) because it enables new theories to be developed in areas where there is limited existing knowledge (Herzog, 1993). Qualitative methodology encourages participants to introduce ideas that they believe are pertinent to the topic of interest. Thus, a qualitative approach allowed for new concepts to develop that were not constrained by my own preconceptions around the topic. Additionally, it facilitates knowledge around processes, patterns and meanings (Thompson & Harper, 2012). Thus, as the research aims were to explore parents' inner processes in an attempt to gain new understandings of their views of their child's transition into adulthood within an intellectual disabilities context (as opposed to measuring variables or testing hypotheses), a qualitative methodological approach to data collection and analysis was deemed to be most appropriate.

2.3.2 Rationale for grounded theory. Four different qualitative methods of analysis were considered in the process of designing this study: discursive, thematic, interpretative phenomenological analysis (IPA) and grounded theory. A discursive approach aims to explore identity, subjectivity, and how people construct versions of themselves and justify their actions (Burr, 2003). Discourse analysis is thereby more concerned with the functional use of language and does not make inferences about *how* people feel or think (Payne, 2007). The current study aims were less interested in how parents produce or construct accounts of their child's transition into adulthood, but more curious about parents' understanding and perceptions of it. Therefore discourse analysis was not the most appropriate methodology to study the research aims.

Thematic analysis aims to identify concepts with similar meanings in order to understand the phenomenon under investigation (Madill & Gough, 2008). It is largely used when the researcher is seeking to descriptively summarise an individual's account into thematic categories (Harper, 2012). Thematic analysis is argued to be the "building block" of any qualitative analysis (Braun & Clarke, 2006). However, it remains unique in its theoretical flexibility in comparison to IPA or grounded theory, which some may view as being "theoretically bounded" (Braun & Clark, 2006).

Similarly, IPA has a primary intent to describe lived experiences through identifying common meanings underlying a given phenomenon (Cohen, Kahn & Steeves, 2000). This is a key difference to grounded theory, which goes beyond description in order to understand and explain experiences, and internal or external processes. Instead, IPA seeks to produce a single account of the researcher's interpretations of participant experiences. However, this was considered to largely run the risk of minimising parent views. Therefore a phenomenological approach was not considered as being appropriate for meeting the research aims.

By comparison, a unique characteristic of grounded theory is that of theory development. Grounded theory enables the researcher to move beyond description to a level of understanding what is happening, and the processes that are occurring (Corbin & Strauss, 2008; Strauss & Corbin, 1998). It is argued to be the best method of analysis when investigating social events or situations to which people may have to adapt (Corbin & Strauss, 2008; Schreiber & Stern, 2001); when there is a need to challenge existing theories; or when the research field has relied on other forms of study or inquiry (Charmaz, 2006). This is evident in the (small but growing) intellectual disabilities literature where parent perceptions of their child's transition into adulthood have typically focused upon the transition into adult services (e.g., Clegg et al., 2001) or employed alternative methods of analysis such as narrative approaches (e.g., Almack et al., 2008). As stated previously (see section 1.7.6), it is unclear whether existing transition frameworks fit with parental experiences within the context of intellectual disabilities.

In order to address this gap, grounded theory was deemed to be the most appropriate methodology to meet the research aims. In particular, it was considered to be useful for exploring the inner processes that parents experience, for understanding the multiplicity of interactions that produce variation within these processes and was considered to be compatible with my critical realist stance.

2.3.3 The history of grounded theory. Grounded theory was originally developed as an attempt to "close the embarrassing gap between theory and empirical research" (Glaser & Strauss, 1967, p. vii). Grounded theory aims to analyse rich descriptions of individual experiences and identify patterns and

relationships between them (Glaser & Strauss, 1967). It is an inductive approach whereby the theory evolves during the research process as a product of continuous interplay between data collection and analysis (Goulding, 1999). This contrasts with other qualitative methodologies where the search for meaning commences after all data has been collected (Corbin & Strauss, 1990; Glaser & Strauss, 1967).

Glaser and Strauss first presented grounded theory in their seminal book "The Discovery of Grounded Theory", published in 1967. This was written in part as a protest against the positivist paradigm that was dominating research during the 1960s[33]. Glaser's ideas were influenced by positivist researchers such as Lazarsfeld, Sewell & Wilensky (1967) who used both qualitative and quantitative methods (e.g., factor analysis). As such, similarities between factor analysis and grounded theory became apparent such as "categories" and "variables". However, Strauss' ideas originated from a social pragmatist stance. These different viewpoints held by Glaser and Strauss eventually led to alternative forms of grounded theory (Tweed & Charmaz, 2012).

2.3.4 Versions of grounded theory. Glaser and Strauss reached a diacritical crossroad over the aims, principles and procedures associated with the methodology of grounded theory (Goulding, 1999). As a result, competing grounded theory methodologies, designs and constructs were built from different ontological foundations (Hunter, Murphy, Grealish, Casey & Keady, 2011). The different versions included classic grounded theory, stemming from the original work of Glaser and Strauss (1967); Straussarian grounded theory, which offered a more rigorous process of systematic coding techniques (Corbin & Strauss, 2008; 1990; Strauss & Corbin, 1998) and constructivist grounded theory (Charmaz, 2000; 2006).

Strauss argued that the data analysis procedure within classic grounded theory (Glaser & Strauss, 1967) was too vague. As a result, they published two books (Corbin & Strauss, 1990; Strauss & Corbin, 1998) that provided detailed guidance to the grounded theory process. However, these modifications were criticised for being "programmatic", "overformulaic" and "forceful" (Glaser, 1992; Melia, 1996 p. 370). To counter-argue these criticisms, Strauss and

[33] Glaser and Strauss (1967) protested against the positivist view that all "great" theories had been discovered and that the role of research lay in testing these theories through quantitative "scientific" procedures (Charmaz, 1983).

Corbin (1998) described their modifications of the analytic procedure as "guidelines, suggested techniques and not commandments" (p.4). Furthermore, in their third edition, Corbin and Strauss (2008) encouraged researchers to "use the procedures in their own way" (p.ix-x), thereby embracing further flexibility.

Another contrast to Glaser's work included that Strauss began to employ abductive reasoning[34] when interpreting the data (Bryant & Charmaz, 2007), indicative of a further shift in Strauss's thinking. Strauss acknowledged the broader contextual factors that impact upon a situation, which is more in line with contemporary constructivist thinking. By contrast, Glaser remained faithful to the classic grounded theory approach and stood by his beliefs that theory simply "emerges" from the data (Boychuk, Duchscher & Morgan, 2004; Bryant & Charmaz, 2007).

2.3.5 Rationale for using a Straussian approach. Cutcliffe (2000) recommends that researchers need to use one method of grounded theory. I decided to use Corbin and Strauss's (2008) guidelines. This was based upon a number of reasons including that it was in line with my critical realist stance; it emphasises the role of broader environmental and contextual processes which were considered to be important when understanding the processes involved in parental adjustments; and it was a pragmatic approach that would facilitate the development of a theory that was both relevant and useful to parents of a child with a severe intellectual disability transitioning (or has already made the transition) into adulthood, as well as their clinicians.

Moreover, research suggests that a Straussian approach is generally more attractive for novice researchers (Heath & Cowley, 2004; McCallin, 2003). Whilst there have been criticisms around the Straussian approach being too rigid and clouding the analysis (see Kendall, 1999; Robrecht, 1995), Corbin and Strauss (2008) clearly state that researchers should trust their instincts and not become too fixated upon the analytic procedures[35]. I considered their explicit guidelines

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[34] Abduction is defined as "a type of reasoning that begins by examining data and after scrutiny of these data, entertains all possible explanation for the observed data, and then forms a hypothesis to confirm or disconfirm until the researcher arrives at the most plausible interpretation of the observed data" (Bryant & Charmaz, 2007, p. 603).

[35] "One has to use common sense and not get caught up in worrying about what is the right or wrong way. The important thing is to trust oneself and the process. Students should stay within the general guidelines…and use the procedures and techniques flexibly according to their abilities and the realities of their studies." (Strauss & Corbin, 1998, p.295).

for analytic tools to be helpful as a novice researcher rather than restrictive. Lastly, a fully constructivist approach was not appealing given that it has been criticised for its lack of applicability (Hunter et al., 2011).

2.4 Study Sample

2.4.1 Sample size and justification. Research highlights that the labour-intensive nature of studies that focus on a research question in depth (such as grounded theory), justifies the case for a small sample-size (Crouch & McKenzie, 2006). The nature of such studies include cross-case comparisons, intuitive judgements and reference to existing theoretical knowledge. Within grounded theory, the labour involved in the conceptualisation of data for theory development is an integral part of the research process. Arguably, the intensity of the analysis and persuasive nature of the theoretical concepts and categories are deemed to be more important than aiming to be convincing through enumeration (Crouch & McKenzie, 2006). Additionally, published grounded theory studies have incorporated sample sizes that range from as few as eight or nine participants (e.g., Beart, Hardy and Buchan, 2004; Clegg, et al., 2001) to more than 30 (e.g., Todd & Shearn, 1996). However, none of these studies provided rationales for their choice of sample size.

In grounded theory studies, sampling is described as "theoretical" where the sample is driven by the emerging theory (Glaser & Strauss, 1967). Thus, in general, grounded theory sets no limits on the number of participants and continues to select interviewees until the point of "theoretical saturation" (Cutcliffe, 2000). This occurs when the researcher is no longer receiving new information about the concepts being explored (Glaser & Strauss, 1967). By contrast, research suggests that theoretical saturation is probably never achieved (Corbin & Strauss, 2008). Instead, Dey (1999) proposed the concept of "theoretical sufficiency" where the researcher acknowledges that there are enough themes to generate a coherent theory.

Based upon the existing literature and the time constraints of this project, I predicted that approximately between 10-20 participants would be required for this study. This is consistent with the suggestion that 8-20 participants is an appropriate sample number for a Doctorate of Clinical Psychology qualitative study (Turpin et al., 1997). More importantly, I chose to utilise Dey's (1999) pragmatic approach of "theoretical sufficiency" as opposed to "theoretical

saturation". I anticipated theoretical sufficiency when I determined categories or concepts as offering considerable depth and breadth, with relationships to other categories made clear (Corbin & Strauss, 2008).

2.4.2 Eligibility criteria. Morse (1991) highlights that it is essential for the researcher to discover who will be the most appropriate participant before beginning interviews and that they should be carefully chosen according to specific qualities. The eligibility criteria for our study was provided in the journal paper.

2.4.3 Sample recruitment. After gaining ethics approval (see section 2.5), I advertised the study through charitable organisations including the IRIS project (Nottingham) website and in Mencap's (Kirklees) newsletter (see Appendix B). I also received permission to advertise the study on the Facebook page of MIND and within the "Choice Forum" of the Foundation for People with Learning Disabilities (FPLD). This is an online discussion forum for parents, carers and professionals working with people with intellectual disabilities living in the UK. Additionally, I emailed the study advertisement with a brief message to Mencap (Leeds) staff members asking them to hand out the study advertisement to participants who may be interested (see Appendix C:1 for confirmation email and Appendix C:2 for brief email message to staff members).

It was anticipated that recruiting from various locations and organisations would maximise sample variation. Recruiting from the National Health Service (e.g., community or specialist intellectual disability teams) was decided against, as services do not always have contact with parents. Thus, well-known charitable organisations that provide parental support were deemed to be more appropriate and accessible for recruiting parents directly.

2.4.4 Sample and theoretical sufficiency. Our sample consisted of 12 parents (of 11 children). Initially, the study adopted a non-probabilistic purposive sample with nine participants being chosen on a first come first served basis. Given that the data for the first nine participants largely included parents of children between the ages of 18-29 years, I felt that the final three participants should be selected with respect to age to maintain consistency in the data. Thus, the final three participants were chosen if their child was aged between 18-29 years.

I had considered theoretical sufficiency to be reached by the end of analysing nine transcripts. The data appeared to support the developing

concepts and categories. Additionally, each category was considered to be well developed in terms of their properties and dimensions. I thought that interviewing a further three participants would be helpful for explicitly examining the developing theory in terms of its categories; properties and dimensions; existing relationships between categories; and any outstanding concepts to further develop the theory. I considered sharing the grounded theory model with the final three participants. Disadvantages of this included that participants may not have understood it fully given that they requested to be interviewed via telephone. However, I decided to share the model with them as a way to validate or disconfirm the theory.

Grounded theory and critical realism both emphasise the importance of delineating the context under which something happens. In grounded theory, context helps to ground concepts but also minimises chances of misrepresenting or misunderstanding meaning (Corbin & Strauss, 2008). It was therefore important to consider participants within their broader context to acknowledge potential influences on their experiences: all participants were White British; none of the participants had other children with any form of disability; and all but one participant stated that their child had additional physical or sensory disabilities. These included "double incontinence", "dyslexia", "epilepsy", "poor minor motor movement" and being diagnosed with additional syndromes (e.g., Wooster-Drought syndrome and Hornes syndrome). Additionally, some parents reported that their child had additional physical care needs. Two participants explained that their child needed mobility support but the remaining participants did not elaborate upon this variable. Further key participant demographics extracted from the "personal details form" (see Appendix D) are presented in Table 6. In terms of characterising sampled experiences of the transition into adulthood, although it was difficult to discriminate the *relative* difficulty of these experiences (and this was not a specific focus of our questioning) it was notable that (1) all parents shared difficult experiences in relation to their child's transition but (2) three parents (Louise, Carla and Sarah) also explicitly discussed positive experiences, which mainly related to the support received from their family and friends.

Table 6. Participant demographics

Participant pseudonym	Age	Relationship to child	Sole carer?	Child pseudonym (Age)	Physical or sensory disability?	Physical care needs?	Number of siblings	Accessed support system(s)?
Carla	44	Mother	No	Joanne (21)	No	No	1	College one day a week
Tina	63	Mother	No	John (29)	Yes	Yes	3	Adult care
Sarah	55	Mother	Yes	Peter (20)	Yes	Yes	1	Adult care
Rebecca	55	Mother	No	Kyle (22)	Yes	Yes	1	Specialist residential college
Rick	78	Father	No	Tom (57)	Yes	No	1	Yes
Amanda	49	Mother	No	Teresa (19)	Yes	Yes	1	Post-16 education
Paul	46	Step-father	No	Henry (20)	Yes	Yes	3	College
Jack*	55	Father	No	Stacey (26)	Yes	Yes	2	Yes
Amy*	57	Mother	No	Stacey (26)	Yes	Yes	2	Yes
Samantha	62	Mother	No	Jane (28)	Yes	No	1	Adult care
Roger	77	Father	No	Luke (24)	Yes	Yes	1	Adult care
Louise	50	Step-mother	Yes	Joseph (19)	Yes	Yes	5	College and Adult care

N.B. * denotes parents of same child.

2.5 Ethical Considerations and Approval

This study was conducted in accordance with the ethical principles of the University of Nottingham Code of Research Conduct and Research Ethics (2010), the British Psychological Society Code of Human Research Ethics (2010) and the Department of Health Research Governance Framework for Health and Social Care (DoH, 2005). I obtained ethical approval to conduct this study from the Institute of Work, Health and Organisations at the University of Nottingham on the 18th October 2013 (see Appendix E for ethics approval documents).

2.5.1 Distress or harm to participants. The occurrence of adverse events from participating within our study was not expected. I was aware that some questions were of a personal nature, however, none of the questions were experienced as uncomfortable or upsetting by parents. Additionally, some parents reported that they had not thought about certain questions before. This was interesting given that some questions probed participants to think about particular aspects of their child's transition in a different light, thereby facilitating new insights.

2.5.2 Withdrawal. Participants were informed via the information sheet (Appendix F) and consent form (Appendix G) that they would be able to withdraw from the research, including from the interview discussion without reason at any time. Participants were also informed that they could request to have any of their data destroyed within three days after the interview. None of the participants withdrew from the interview nor requested for their data to be destroyed.

2.5.3 Confidentiality. All participants were assigned a participant code at the time of consent to maintain anonymity of the data. The code was assigned numerically. For example, the first interviewee was assigned as "participant 1" or "ppt.1". During the transcription process (see section 2.7.3) pseudonyms were used and any references to personal information were changed to ensure confidentiality. All audio-recordings of interviews and computerised transcripts were identified by the participant code. The final six interviews were transcribed by a professional service who signed a confidentiality agreement prior to transcribing (see Appendix H). This information was made clear to participants on the information sheet and consent form.

2.5.4 Debriefing. All participants were offered the opportunity to ask questions related to the study prior and subsequent to their participation. Nine participants asked questions about the practicalities of the study (e.g., when it will be completed), which were answered accordingly.

2.5.5 Data Protection. This study was conducted in accordance with the Data Protection Act (1998). Access to the data was limited to the researcher, research supervisors and professional transcriber. All identifiable and anonymised data were stored in a locked filing cabinet in the administrators office at the University of Nottingham. All interview recordings and computerised transcripts were stored on an encrypted data stick and password protected to restrict access. All data will be stored for seven years in accordance with University storage policy and then destroyed.

2.6 Interviews

Research methods compatible with a critical realist perspective highlight the importance of focusing upon "who is doing what, with whom and for which reasons to explain properties of structure, as well as to understand agency within the context of the structures" (Scott, 2005 p. 640). Critical realism aims to reunite the subjective nature of knowledge with the existence of "real" underlying mechanisms and structures in a social world (Dobson, 1999). In light of this, grounded theory was deemed to be compatible with a number of data collection techniques including individual interviews, observations, life histories and focus groups (Goulding, 1999).

I chose individual interviews as a method of data collection as they allowed for an in-depth exploration of participant experiences. The aims of my study were to elicit parent views of the transition into adulthood of their child with a severe intellectual disability and to explore whether and how parents make any adjustments for it. This is an area that participants may not have felt comfortable to discuss if a different data collection method had been employed (e.g., focus groups).

Both unstructured and semi-structured interviews are congruent with a grounded theory approach (Duffy, Ferguson & Watson, 2004). Unstructured interviews enable participants to use their own experiences to define the world with no fixed interview schedule (Fielding, 1994). This allows for greater flexibility, which would otherwise be curtailed if using more structured

interviewing methods. Conversely, semi-structured interviews involve the use of prompts specific to the research question. It also allows the researcher to use prior knowledge during the interview process (Rose, 1994). Thus, the use of semi-structured interviews is congruent with Corbin and Strauss's (2008) grounded theory methodology as it allows the researcher to remain mindful of related literature whilst encouraging participants to expand upon their experiences.

Whilst unstructured interviews would have been advantageous for providing flexibility for exploring new ground, it was felt that little guidance on a broad research area would run the risk of participant confusion and incoherence, resulting in potentially meaningless data. Additionally, I anticipated that having prompts would help me to remain focused on the research aims as a novice researcher. On this basis, semi-structured interviews were deemed to be the most appropriate method for data collection.

Consistent with a critical realist framework, interview data was not regarded as being "certain" or as a "God's eye view" that was independent of any viewpoint (Putnam, 1999). Instead, data was regarded as being alternative legitimate accounts of how the world may be. Critical realism accepts that the world is structured by our own concepts, which are (to a considerable extent) expressed through language (Maxwell, 2012). Thus, whilst I perceived myself to be a *part* of the world that I wanted to learn more about as an interviewer[36], my questions and prompts were intentionally kept to a minimum to avoid taking away participants' experiences or views. Participants were therefore seen as the experiential expert on the phenomenon and were given maximum opportunity to verbalise their views (Smith & Osborn, 2003).

2.6.1 Types of interviews. Face-to-face interviews are a common method for data collection within qualitative research. However, when participants are located at a distance from the researcher, face-to-face interviews can become expensive and time-consuming. To overcome such barriers and accommodate participants' schedules, the use of telephones and videoconference software (e.g., Skype) are considered to be an increasingly utilised method for data collection (Cater, 2011; Thomas & Purdon, 1994).

[36] Critical realists argue that our perceptions are shaped by our theoretical resources and investigative interests (McEvoy & Richards, 2006).

Methodological literature has traditionally advised against the use of telephone interviews following concerns of the loss of non-verbal cues that are thought to convey subtle layers of meaning (Irvine, 2010) and the limited scope to establish working relationships with participants (Ivey & Ivey, 2003). However, research highlights that there is little difference in the resulting data of telephone and face-to-face interviews (Irvine, 2010). In fact, some advantages of using telephone interviews include that it allows participants to remain more anonymous if desired and the interview process may feel less emotionally demanding. In contrast to face-to-face interviews, the absence of non-verbal cues means that everything needs to be articulated through the participant and researcher, thereby potentially providing richer text for analysis (Holt, 2010).

Similarly, whilst it is possible to see some body language via videoconference software (typically a "head shot"), cues such as nervousness and other non-verbal characteristics may not be observable. However, body language was not necessarily critical to our study therefore such drawbacks were not viewed as being detrimental to the data collection process. Instead, telephone and Skype interviews were deemed to be cost-effective, productive and valid methodological tools for maximising diversity within the sample.

2.6.2 Interview materials.

2.6.2.1 Interview schedule. The semi-structured interview questions were designed to be open-ended, free of complex jargon and did not include any leading questions. The initial interview schedule covered four broad areas related to the research aims. This enabled participants to expand upon their discussions and introduce new concepts to the study. The four areas included participants' understanding of the term "adulthood"; participants' understanding of their child's transition into adulthood; participants' perceptions of their son or daughter as an adult; and the adjustments that participants had made in light of the transition (see Appendix I for initial interview schedule). As concepts (e.g., about sexuality development) emerged, questions in relation to this were incorporated into the interview schedule. Thus, in line with the principles of theoretical sampling (Corbin & Strauss, 2008), I revised the initial interview schedule three times and it became more focused according to the developing concepts and categories (see Appendix J for the final interview schedule).

2.6.2.2 Personal details form. Hutchinson (1993) argues that a wide and diverse sample may provide extensive data that covers a range of

experiences in varied situations, which contributes towards generating a wider substantive theory. Additionally, the American Psychological Association (1994) argues that appropriate identification of research participants is critical to the science and practice of psychology, particularly for assessing the results and making comparisons to replicable studies. Based upon this (and in line with my critical realist position), demographic information was collected to help me remain mindful towards the context of each participant's experiences. This included details about the participant (e.g., date of birth, relationship to child and ethnicity) and details about the adult with a severe intellectual disability (e.g., age, siblings, additional disabilities, accessing support) (see section 2.4.4).

2.6.2.3 Recording equipment. All 12 interviews were recorded on an Olympus DS-30 digital audio recorder and stored onto a personal computer.

2.7 Procedure (see Appendix K for study process)

2.7.1 Interview preparation. Participants who made initial contact after viewing the study advertisements were sent the information sheet, which provided further information about the study. All participants requested for the information sheet to be sent via email. Participants who showed a further interest in the study were then emailed information regarding the details of the interview. This included the date, time and location of the interview if it was face to face (see Appendix L).

Prior to the interview, I sent participants a consent form via email to sign either electronically or handwritten. I then offered all participants the opportunity to receive a summary of the study findings at the end of the research process. The information sheet and consent form outlined that this would require their contact details to be retained. Participants were entered into a prize draw for their chance to win up to £50 worth of Amazon vouchers as a result of their involvement. They were also offered the opportunity to ask any questions related to the study. I also asked participants to complete the personal details form prior to the interview. Both consent and personal details forms were anonymised using the unique identification codes outlined earlier (see section 2.5.3).

2.7.2 Semi-structured interviews. All participants were interviewed individually (including the parents of the same child). I reminded participants of the research aims and the equipment used to record the interview. During each

interview, I employed active listening skills and empathic reflections to validate understanding. At the end of the interview, I stopped the audio-recorder and asked participants if they had any questions related to what had been discussed.

2.7.3 Transcription. Willig (2008) suggests that the process of transcription will nevertheless transform the data and can never be an exact representation of the interview held. Based upon this, I transcribed the first six interviews. This enabled me to become immersed in the data and encouraged me to develop analytical insight during the initial stages of the analysis process (Potter, 2003). Due to time constraints, the remaining six interviews were transcribed using a professional transcription service. Each transcript was read thoroughly whilst listening to the audio recording to check the quality and accuracy of them. This enabled me to remain immersed in the data and helped to refine the interview schedules for subsequent interviews. Thus, data collection and data analysis occurred simultaneously to orient further data collection (Backman & Kyngäs, 1999).

2.7.4 Using NVivo software. NVivo is a computer-assisted qualitative data analysis software (CAQDAS) that can be used in conjunction with a grounded theory approach (Hutchinson, Johnston & Breckon, 2009). Different functions of NVivo may be helpful for the initial design and early sampling stages, through to the analysis and presentation of findings (Hutchinson et al., 2009). Whilst CAQDAS takes qualitative analysis further than is possible with manual techniques (Bazeley, 2006), researchers argue that it may have the potential to transform qualitative analysis into a rigid automated process that neglects the role of human interpretation and reflection (Kelle, 1995). Another limitation of using CAQDAS is that researchers may be tempted to use all the different program functions rather than those appropriate for the research question and methodology (Mangabeira, Lee & Fielding, 2004).

For this study, I decided to use NVivo in conjunction with the guidelines provided by Corbin and Strauss (2008) to enhance the analysis process. Moreover, NVivo was used for organising and storing data, concepts, categories and constructing memos. NVivo enabled me to instantly access original data behind each concept with memos being linked at any level of the hierarchy (code, concept or category). Thus, NVivo helped to keep the analysis process systematic, facilitated detailed comparisons within the data and encouraged theory development. Despite using computer software, I continued to ask

questions of the data to help make interpretations and decide what to code. This encouraged me to remain close to the data.

2.7.5 Analysis process. Data was transcribed and analysed after every three participants had been interviewed. Through a cyclical process of data collection and analysis, I refined the interview schedule in response to the data collected. Transcripts were imported into NVivo. Software tools were used to assign open codes to the data. This involved breaking data down to identify important words or concepts that were pertinent to the participant (Corbin & Strauss, 2008) (see Appendix M for transcript excerpt and open-coding). Open codes were purely descriptive at this stage. Some quotes were "in vivo" whereby verbatim quotes from participants were used to label the codes (Birks & Mills, 2011). Line by line coding encouraged me to ask a range of questions suggested by Corbin and Strauss (2008) to grasp what was being highlighted from the data. This included asking questions that were sensitising to the data (e.g., "what is going on here?"); theoretical (e.g., "what is the relationship between these categories?"); and practical in terms of theory development (e.g., "have I reached theoretical sufficiency?"). These codes were then grouped together to form concepts (see Appendix N for examples of concepts).

The constant comparison method was used to identify similarities and differences between the concepts within each batch of transcript data when grouping them into themes (see Appendix O). Related themes across all transcripts were then merged into categories (see Appendix P). Categories were labelled at a more abstract level at the final stages of theory development. In order to determine the central core category[37], visual conceptualisations of the developing theory were designed and stored using Microsoft Powerpoint (Version 14.0). Diagrams were used to work with concepts rather than details of data (Strauss & Corbin, 1998) (see Appendix Q for theory development). Diagrams were helpful for considering the nature behind relationships amongst concepts and categories. Additionally, I used criteria set out by Corbin and Strauss (1990) to decide upon the core category (see Appendix R). As outlined earlier (see section 2.4.4 and journal paper), the final three interviews were used to share the model of inter-related categories. Ways in which these interviews were

[37] A central core category evolves out of existing categories (Corbin & Strauss, 2008; Strauss & Corbin, 1998). It is suggested to account for considerable variation within categories to form an "explanatory whole" (Strauss & Corbin, 1998).

similar and different to the previous nine interviews were outlined in the journal paper.

Throughout the analytic process, I was mindful of negative cases i.e. data that did not fit the developing concepts. This enabled me to maximise the dimensions of concepts and categories, and offer alternative explanations for particular patterns in the data. I also focused upon participants' emotional responses as this helped to consider the potential meanings behind what was being discussed.

2.7.6 Memos. Corbin and Strauss (2008) suggest that memos are written from the first analytic session through to the end of the analytic process. I used memos as an organisational tool to log my thoughts. Corbin and Strauss (2008) consider memos to be useful for opening data exploration; identifying properties and dimensions of concepts and categories; making comparisons; asking questions; and elaborating upon the relationships between concepts and categories. Thus, writing memos was a key part of the analytic process (see Appendix S for memo examples). Additionally, memos helped me to keep track of decisions I had made before, during and after the analytic process. Early memos were exploratory with later memos becoming more focused upon the developing concepts and categories. Memos were written and stored using NVivo.

2.8 Reflexivity

Critical realism encourages researchers to articulate the perspective from which the material is approached (Madill, Jordan & Shirley, 2000). Before I started the research process, I was aware that the data collection and analysis would be influenced by my own conceptions and previous experiences. Thus, I was particularly mindful of how my analytical style influenced the nature of the psychological knowledge produced (Madill et al., 2000).

Corbin and Strauss (2008) emphasise the importance of reflexivity during data collection and analysis in qualitative research. They argue that participants undoubtedly react to the researcher's own emotions, thereby continually adjusting their stances throughout the interview process. Thus, it is recommended that researchers explicitly acknowledge their relationship with the research topic and remain open to the potential influences of their own values, assumptions and interests throughout the research process (Elliot, Fischer &

Rennie, 1999). I perceived myself to be the research instrument for data collection and analysis in order to represent parent views of their child's transition into adulthood (Strauss & Corbin, 1998). I acknowledged that through myself, as the researcher, a correct balance between objectivity and sensitivity had to be achieved.

2.8.1 Consideration of the role of the researcher. I am a 28-year-old British Indian female employed as a trainee clinical psychologist at the University of Nottingham. My previous clinical experiences have been largely within intellectual disabilities services. I have worked within community and forensic intellectual disabilities services as a trainee clinical psychologist in England and as an assistant clinical psychologist in England and India (Kolkata). All experiences included working with adults with intellectual disabilities (mild to profound) and their carers (e.g., parents or staff). I was made aware of the stark cultural differences that existed between eastern and western society, particularly around service provision and the notion of "adulthood". Given that all participants in this study were White British, I was unable to fully explore the cultural diversity that may exist in the assumptions and beliefs held by families of different ethnicities residing in the UK. However, I still found myself comparing their beliefs and assumptions of adulthood to my own (see section 4.10).

My interest in intellectual disabilities was borne out of my clinical experiences of working within this field. Specifically, I was particularly interested in the systemic nature of the transition process, thinking about the role of parents and any adjustments in their patterns of behaviour or relationships with others, and how these were managed. I was aware of my own assumptions e.g. that parents may report mainly negative views of their child's transition into adulthood. This belief was developed from my previous work experiences. For example, I witnessed the frustrations and challenges being experienced by adults with an intellectual disability and their families (or carers), particularly around transitional periods. I have also been involved in discussions with adults with intellectual disabilities, their families and staff around their experiences of transitions which were largely negatively narrated. As a result of these experiences, I strived to remain mindful of my assumptions throughout the research process to minimise potential bias in my interpretations of the data.

This involved keeping a reflective diary and using supervision frequently to reflect upon how I may have influenced the study.

Although I have had some experience of working with adults with an intellectual disability and their families during common transitional periods, I did not have experience of supporting parents who explicitly perceived their child with a severe intellectual disability transitioning into adulthood. Given that this transition process is under-researched within intellectual disabilities research, the focus of this study was driven by a desire to offer parents a voice and a platform for others to hear their experiences of their child's transition into adulthood, whether positive or negative.

2.9 Evaluating Quality

Evaluating the quality of research involves making a judgment about how well the study has been conducted, and whether the findings are useful (Yardley, 2008). Silverman (2005) suggested that an evaluation should seek to assess the reliability and validity of the research process. He proposed that research validity may be enhanced by refuting assumptions against the data; using a constant comparative method; and searching for deviant cases. Morse, Barret, Mayan, Olson and Spiers (2002) suggested that an evaluation judges for "methodological rigor". Strategies to achieve this included "methodological coherence", "theoretical sampling" and taking an "active analytic stance" (Morse et al., 2002, p.9). Further research has developed criteria for assessing "credibility" within research (e.g., Chiovotti & Piran, 2003). This relates to how trustworthy the findings are. Thus, there are some inconsistencies around what an evaluation should consist of (Corbin & Strauss, 2008).

It is difficult to identify a set of criteria that is applicable to all qualitative studies. This is due to the different approaches used in qualitative research and an array of assumptions that they could be based upon. A further problem is that quantitative methods have historically dominated the field of psychology (Yardley, 2008). There is a tendency to assume that the criteria for trustworthiness of data in quantitative studies (e.g., objectivity, reliability and generalisability) can be applied to qualitative research. Quantitative researchers seek to minimise error through using methods to reduce the influence of the researcher e.g. standardised questionnaires and statistical analyses. By contrast, qualitative researchers seek to maximise an active role with participants e.g.

through asking open-ended questions and being transparent. In doing so, it is hoped that researchers can gain insight into the phenomenon under investigation. Thus, it is essential for qualitative research to be credible, rigorous and yield valuable findings.

Several evaluation criteria were considered when thinking about how best to judge the trustworthiness of this study. These included Corbin and Strauss (2008); Yardley (2008); Chiovitti and Piran (2003); Charmaz (2006); and Cooney (2011). I decided to use Corbin and Strauss's (2008) guidelines to evaluate the "credibility" of the research. They highlight that "credibility" refers to the findings as being believable and reflecting the participant, and researcher experiences, whilst providing one of many possible "plausible" interpretations from the data. Judging for "credibility" was deemed to be in line with the epistemological stance and aims of our study i.e. to provide a trustworthy, plausible and applicable interpretation of the data.

Corbin and Strauss (2008) identify specific research conditions that foster the construction of "credibility" in research. This includes "methodological consistency" (Morse et al., 2002) i.e. following relevant procedures as designed; clarity of purpose i.e. being clear whether the study aims are for theory building or theory description; having self-awareness (Hall & Callery, 2001) i.e. remaining aware of researcher bias; being sensitive to the topic area i.e. getting close to the data; and a willlingness to be creative e.g. when comparing data. Throughout the research process, I ensured to meet these conditions (see Appendix T).

The set of criteria used by Corbin and Strauss (2008) to judge the quality of research are outlined below. They highlight that this is general criteria and is not applicable to all research methods or other versions of grounded theory. Additional criteria for evaluating the "credibility" of the research published by Corbin and Strauss (1990) were integrated. The criteria used to evaluate this study are presented below in question form:

- Do the findings fit with the researcher and participants?
- Do the findings ring "true" to participants? (Lomberg & Kirkevold, 2003)
- Do the findings offer new insight or explanations?
- Can the findings be used to develop policy, change practice, and add to the knowledge base of clinical psychology?

- Are the concepts developed in terms of their properties and dimensions?
- Is there density and variation within the concepts?
- Are the findings contextualised?
- Is there a logical flow of ideas?
- Do the findings make sense?
- Are methodological decisions made clear?
- Do the concepts have depth?
- Are the findings rich in description?
- Is there variation within the findings?
- Are there examples of cases that do not fit the patterns?
- Are the findings presented in a creative and innovative manner?
- Does the research say something new or put old ideas together in a new way?
- Was sensitivity demonstrated to the participants and data?
- Were the questions driving the data collection arrived at through analysis?
- Were the concepts and questions generated before the data was collected?
- Is there any evidence of using memos throughout the research process?
- How was the original sample selected?
- How did later sampling occur?
- What major categories developed?
- What were some of the events, incidents, and actions that pointed to some of these major categories?
- How did theoretical formulations guide the data collection?
- How representative were the categories of the data?
- What were some of the statements of relationships made during the analysis? On what grounds were they formulated and validated?
- Were there instances when statements of relationships did not explain the data i.e. negative cases? How were these discrepencies accounted for?
- Were statements of relationships modified?
- How and why was the core category selected?
- On what grounds is the final analytic decisions made?
- Are the concepts systematically related?
- Are the conditions and consequences built into the study and explained?
- Has process been taken into account?

Chapter 3. Extended Results

3.1 Chapter Introduction

The aim of this section is to outline and describe some of the processes that parents engaged in when understanding their child's transition into adulthood, and how they made adjustments for it. I begin this section by presenting the over-arching core category of the developing theory[38]. This is followed by a description of the five categories that developed from the analysis, evidenced by participant quotes. I am not suggesting that this section offers the only possible interpretation of the data as a different researcher may have noticed different concepts within the data, and produced a different analysis. This section offers a conceptual overview of some of the contextual and processual elements, grounded in parental perspectives.

3.2 Making Comparisons with Perceived "Norms"[39]

As stated in the journal paper, this process was salient throughout all participant interviews and evolved throughout all existing categories. The core category encapsulated five related categories. These were viewed as being processes that parents engaged in and were hypothesised to interact with one another (see Figures 2, 3 & 4 in journal paper). Although the sub-categories of "Noticing sexuality development" and "Responding to sexuality development" seemed to be important issues in relation to the transition into adulthood, they were not salient throughout all participant interviews (n=5). However, they were inextricably linked to "Noticing adult development" and as such will be explored under this category.

3.3 Defining Adulthood

Defining what it meant to become an adult seemed to be an initial process that all parents engaged in for understanding their child's transition into adulthood. This was considered to be an implicit process. Most parents defined adulthood at a broad level, i.e. definitions were not specific to individuals with intellectual disabilities. Ten participants made sense of adulthood by naturally drawing upon the "obvious" physical changes, for example:

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[38] I have used the term "developing theory" as it is deemed to be a foundation for further research to build upon. Thus, our theory is not viewed as being a fully developed representation of parents' experiences.
[39] Please refer to journal paper for definition.

"I think obviously there are physical changes, in terms of becoming a woman, so developing breasts, growing taller, growing bigger, periods starting, all those normal things" – Jack

Parents' understanding of "adulthood" was influenced by conceptual factors including the legal and social aspects of becoming an adult. Four parents assigned a cut-off age of 18 years as a marker of adulthood. In particular, Sarah defined adulthood in terms of what an adult could access. She reflected upon her own personal experiences, making references to statutory notions of adulthood:

"When I hit 18 there were certain things that I could access that I wasn't allowed to access before like legally drinking, legally buying cigarettes, you know, the legalness of adulthood I suppose" – Sarah

Two parents questioned whether celebrating 18th birthdays were symbolic of becoming an adult. They drew upon their own experiences of celebrating their 18th birthdays, possibly as a way to rationalise age as being a marker of adulthood:

"I think I just wanted him to celebrate his 18th because that's what everybody does to mark that they're an adult don't they? They have occasions for 18ths, I did when I was that age and so did my siblings" - Carla

"At 18th birthdays, these days are a big thing and you sort of think you should be doing something to celebrate that you're an adult now shouldn't you? Back in the day I celebrated my 18th by going to the pub with my friends…" - Sarah

Whilst most parents considered the age of 18 years to be legally important within contemporary society, some viewed it as being meaningless for their child. Three parents described age as being irrelevant to adulthood. For example, by comparing with her own experiences of becoming an adult, Rebecca explained the importance of the social markers of adulthood and highlighted that they occurred before the age of 18:

"At the end of the day, alright, there's the age 18 but the day before they're 17, you don't change overnight. I left school when I was 15 so I started work as soon as I left school. I think I always thought of myself as an adult from the time that I actually started work, so the money that I earned was my money, I wasn't getting any pocket money from mum and dad and this was before I was even 18" - Rebecca

Tina identified further social markers of adulthood. An awareness of her own "successes" of achieving these markers led her to make comparisons with John's inabilities:

"Adulthood is about being able to make your own decisions, I was doing what I wanted to do and didn't need support to do it, I was successful at cooking my own meals, locking up the house and all sorts… and that's not something that John will ever be successful at doing. Making himself a meal, he wouldn't understand that when he goes out the door needs to be locked and the windows need to be shut, he wouldn't understand, I don't know, he wouldn't know the difference between a penny and a pound, so he wouldn't be able to manage his finance, lots and lots of things" - Tina

It seemed that parents drew upon multiple contexts when developing their understanding of adulthood. Whilst they had an awareness of the societal "norms" and legal aspects of adulthood (e.g., being aged 18 years), some did not view this as being relevant. Defining adulthood was an important process that parents engaged in and it influenced how they noticed adult development in their child (i.e., looking for specific markers; see section 3.4). The type of definition used to understand adulthood was likely to affect whether or how parents made adjustments for their child's transition.

3.4 Noticing Adult Development

This category referred to how parents noticed adult development specifically within their child with a severe intellectual disability. Drawing upon

their conceptualisations of "adulthood", all parents identified biopsychosocial[40] changes as being a "stepping-stone" (Paul) into adulthood. Biopsychosocial changes were largely related to notions of independence. Some parents noticed independence through their child's improved sense of direction since they became an adult:

"she's more independent now she's walking to the bus stop, knowing where all the bus stops are, knowing how to leave this house and being able to find a place by being told where it is, all these things she couldn't do before she became an adult"
- Amanda

Similarly, Rick explained that he had noticed Tom become more able to make connections between time and events as he entered adulthood. This suggests that adulthood may be related to being able to consider the abstract future. He also viewed Tom's transition as a continuous process. This was an interesting finding and highlighted that the transition into adulthood for individuals with a severe intellectual disability may vary in time-length, depending upon the individual's abilities:

"He seems to have more regulated memories of what has happened when and what is going to happen in the future. He used to be repetitive in his conversations but now more recently he is acquiring basic language skills at a later stage as he is 57 now…so maybe his transition into adulthood is still on-going"
- Rick

Further changes were noticed through improved social awareness and behaviours such as "going out with a friend for a drink" (Jack) or "being able to turn-take in conversations" (Paul). However, whilst parents described how they had noticed their child's development as an adult, they were mindful of the limitations of achieving independence. For example, some parents acknowledged that independence was somewhat impeded by parental concerns of risk:

[40] Please refer to journal paper for a definition.

"It's a limited amount of independence. I mean she's independent in the sense that she has her own income, so she's financially independent but she can't manage her finances by herself, she has to have the carers help her to do that. But, I can't give her total free choices that may put her in danger" - Amy

Amy further explained that whilst her daughter physically looked like an adult, her cognitive functioning was not in line with it. She described her daughter's physical and cognitive development as being "out of sync" with each other.

In order for parents to view their child with a severe intellectual disability as an adult, an important process involved noticing markers of adult development. Key markers were largely related to their child's level of abilities. Sometimes noticing adult development was difficult for parents when their child's cognitive functioning was not in line with their physical development. This may have an impact upon whether and how parents made adjustments for their child's transition. Noticing adult development was not necessarily limited to one time-point i.e. it could begin in the mid-teens and continue to develop throughout adult life. This suggests that parents may continue to engage in this process over time (see section 3.8).

3.4.1 Noticing sexuality development. This sub-category appeared to be an important link when noticing adult development. Five parents made references to their child's sexuality when discussing how they noticed their child become an adult. Parents largely focused upon the impact of having an intellectual disability on their child's sexuality development. For example, Sarah appeared to be unsure about whether her son's physical and "mental faculties" were in line with each other. She highlighted that she often had to make assumptions around her son's sexuality given that he is non-verbal:

"There is nothing coming from his mental faculties but physically his body might be telling him a different story, and I don't know how the two marry up or whether they don't marry up and he's finding it difficult, it's hard to tell. I guess when I really think about it I have always gone with what I thought, so if he has

giggled when he saw a girl walk past I just think oh he likes girls then. It's more difficult to know for certain with my son as he can't talk" – Sarah

Most parents of non-verbal children described that they noticed sexuality development through indirect ways. For example, one parent explained that he noticed his daughter's temperament and body language change around boys:

"*She just became a bit more obedient to boys. I think she felt more comfortable around men because she would laugh and giggle more around them. She would sit more forward when they were around and be more smiley. Like, there were no obvious sexual behaviours but just small things which made us aware that she liked boys rather than fancying a girl"* – Jack

Rebecca took a similar approach to Sarah by making assumptions of Kyle's sexuality development:

"I'm not sure but I think at times Kyle has masturbated by lying on the floor and rocking himself on the floor but lying flat if you understand what I am saying. He is actually really lying flat so that his head is down. It could have been a comfort thing. I think it was a way of him releasing that sort of frustrations perhaps, but I can't ask as he doesn't have a clue and doesn't have an answer" - Rebecca

Arguably, parents of a child with a severe intellectual disability and non-verbal ability may focus upon sexually related behaviours through body language given that they are unable to directly ask their child or hold discussions with them about their sexuality. It is worthwhile to note that two parents (Rebecca and Jack) explained that their child's sexuality development occurred before their child chronologically became an adult i.e. "aged 15 or 16" (Rebecca). Thus, some parents may view their child's sexuality development in line with some normative lifecycles i.e. emerging through late adolescence. Noticing sexuality development appeared to be limited to discrete forms of behaviour. This may differ to individuals without an intellectual disability in which sexuality development may be more apparent e.g. through conversation or having sexual relationships. Additionally, parents of a child with a severe

intellectual disability may struggle to notice sexuality development if they perceive their child to be functioning at a low cognitive and emotional level. This lack of synchrony between a child's physical, cognitive and emotional development may leave parents unsure of how to best support their child's sexuality development.

3.4.2 Responding to sexuality development. Some parents described feeling challenged in supporting their child with their sexuality. Three parents explained that they sought professional help due to "not knowing enough" (Amy). This was reflected in Rick's explanation whereby he viewed healthcare professionals as being more resourceful than himself in relation to managing Tom's sexual needs:

"We had no training in it or anything of that nature, it was a real dilemma, completely just like somebody asking you to do something that you have no idea about. Tom was displaying these sexual needs and I didn't have the knowledge to help. So, eventually the people at the centre suggested that Tom needed some sort of medication to manage his sexual frustrations so he was medicated to deal with it" – Rick

From Rick's quote, it seems that managing sexuality development may also be an ambiguous area for professional staff. "Not knowing enough" may lead both staff and parents to consider immediate ways of managing their child's sexual needs i.e. using medication. Whilst such strategies may help to contain an individual's sexual frustrations (and parent and staff anxieties), it could also be seen as inhibiting the child's adult development.

Another parent appeared to have little confidence in managing her son's sexuality development. This was evident in her description of being unsure whether her son would benefit from her help. Seeking professional support served to bridge the gap in her knowledge whilst avoiding "uncomfortable" feelings in herself:

"I would get some support rather than do it myself. It feels wrong and I don't think I'd be able to change my feelings, it would feel uncomfortable for me and I wouldn't know if he was understanding me and I'd definitely seek support around it" – Rebecca

Thus, none of the participants described taking an active role in helping their child understand their sexuality. One mother appeared to be unsure of how to respond to her son's sexuality development but seemed to address it in an indirect way:

"He probably doesn't understand sexuality anyway so I kind of just carry on as usual and have to come to terms with the fact that I might not ever know what some of these behaviours are about, it's more straight forward this way" – Sarah

All five parents viewed the management of their child's sexuality development as a challenging process. Responding to their child's sexuality was a process that they appeared to feel incompetent in. Arguably, parents of children without an intellectual disability may also experience similar feelings towards their child's emerging sexuality but the ways in which they respond to it may differ. For example, some parents in this study immediately sought professional help, whereas, parents of a child without an intellectual disability may initially have conversations with their child before seeking alternative strategies. Feeling unsure of how to support the sexual needs of an adult with a severe intellectual disability was deemed to be a dilemma for both parents and professionals. As a result, parents may make adjustments that impede their child's sexuality development (e.g., agreeing to use medication). This, in turn, may have a negative impact upon their child's adult development.

3.5 Perceiving Barriers to Adulthood

This category referred to the problems that parents and their children experienced around the transition process. Parents viewed barriers relating to the professional system (e.g., public and private services) and the nature of having a severe intellectual disability. As stated in the journal paper, most parents seemed to experience problems when they viewed their child's development as deviating away from the perceived "norms" of adulthood.

3.5.1 Perceiving barriers within professional systems. A common barrier experienced by parents included feeling unsupported by healthcare professionals. Some parents discussed feeling disappointed in services for

excluding their child upon turning 18, and not providing them with information about what to expect afterwards:

"They kept her there till she was 18 but we were given very little information about what could happen next so we felt fairly lost in the process. We wanted the best for Stacey but we didn't know how to go about it and we just felt hard done by the services" – Jack

Changes in services' approach as a result of an individual's age were not helpful to parents or their child. This, together with little information provided by services, led parents to feel "in the dark" (Amy). Tina highlighted the frustrations she experienced in not knowing how to plan for her son's transition. She emphasised the difference in transition process between her son and "normal" children, which possibly contributed to her frustrations i.e. having to depend upon services to know how to plan for transition as opposed to having a child who can communicate their ambitions:

"It's different for normal children, parents know where they want to go or know what they want to do. For me, I had no clue as my son can't talk, I had no clue how to plan, as I didn't have any information so I clutched at any form of help I did get in whatever form, it was irritating for me and it probably isn't as much for parents of normal kids" – Tina

Additionally, some parents felt disappointed at the contradictory nature of services with regards to parental involvement in their child's care:

"The social worker kept saying to us all the time, 'of course you're not responsible for him anymore', I sort of joked with her when she said 'you're not responsible' and I said 'oh good, does that mean I can, I can nip off to the cinema then and just leave him here?' and she says 'oh no of course not'" - Sarah

Such contradictory attitudes of healthcare professionals may be frustrating for parents and give rise to conflict i.e. parents being excluded but still expected to be responsible for their child. In particular, exclusion often led

parents to feel de-valued by services, which was detrimental to their relationships with them:

"It felt horrible, I felt like I didn't matter any more. It just felt like someone had taken us away from being his parents…there's not a lot you could do, I felt let down so I opted out of [charity] newsletters and didn't recommend them to anyone" – Sarah

Eight parents viewed services as being unhelpful when treating their son or daughter like a child. They described that services often used their child's disability as a reason for interacting with them in "child-like" ways.

This was perceived as being damaging to their child's "normal" adult development:

"Care staff still treat them like kids and it's this that has a harsh impact upon the child and slows down their chances of having a normal adult development…people perceiving that he is a child because he doesn't have the language skills, the cognitive skills and the social functioning skills like the rest of us, thinking that he won't respond to things age appropriate is disappointing considering they are the professionals" - Paul

Similarly, Amanda reflected that such an approach made it difficult for her to bond with services but left her feeling forced to accept their ways of working:

"I don't think its helpful for parents either because if [charity] keep treating her as a child then it makes it more difficult for me to reflect on any change…its tough if they're [charity] not listening to me but I'd rather get some support than none at all so you have to just carry on" – Amanda

It seems that the frustrations experienced by parents, attributable to services' approach, sometimes led parents to feel de-valued or to feel compelled to accept their approach. One interpretation may be that parents make adjustments e.g. become accommodating to professional systems' approach, to avoid feeling abandoned or "left in the dark" (Amy) at a time when support may

be needed the most. By contrast, two parents (Jack and Amy) found services unhelpful when they treated their daughter as an adult. In particular, they both believed that treating their daughter according to her chronological age was like trying to fit her into their "stereotype of normal life" (Amy). Jack noticed that removing "child-like" interests was actually detrimental to their daughter's wellbeing:

"They [staff] were very keen that everything around Stacey should be age or adult appropriate…she's been always very into Winnie the Pooh and Teletubbies, and they got rid of everything like that, and she just became really stroppy, refused to join in with others and was purely miserable there" – Jack

Generally, most parents viewed certain aspects of service delivery as unhelpful for them and their child's transition into adulthood. Services' approach for one parent may not have been a good fit for other parents, as highlighted by contrasting data. Perceived barriers were largely influenced by personal views of how their child's adult development "should be" (e.g., encouraging "age appropriateness" or not). Subsequently, there is a general lack of negotiation between parents and professionals, which makes it difficult to offer a consistent approach around the child's transition process.

3.5.2 Perceiving barriers within the individual. Whilst there were barriers identified within professional systems, another shared view related to the challenges of having a severe intellectual disability. Parents appeared to make frequent comparisons with perceived normative lifecycles. Some parents believed that being non-verbal prevented their child from engaging in activities that were considered to be facilitators of a "normal" adulthood:

"He can't talk really because of his disability and so he isn't like normal adults. His transition into adulthood is slower in terms of achieving those mile stones that normal children establish like going to normal schools, having friends, going out on their own…" - Rebecca

It could be inferred that making comparisons was a way for parents to rationalise the barriers that they perceived. However, three parents of children

that had verbal ability raised concerns of their child's intellectual disability being masked:

"She's pretty verbal but it's very misleading because her verbal skills are quite good but, it sort of covers the severity of her learning disability" – Samantha

As such, parents may view the discrepancy between their child's "normal" physical and verbal development, and limited cognitive abilities as problematic when interacting with society. Indeed, such discrepancies may lead parents to worry about their child's needs being overlooked:

"He looks very normal and so you find that people speak to him as if he's a normal adult. They'll say to him, what's your date of birth? Well he doesn't know that and they sort of look at him all expectantly and I'll have to say things like, well I'm really sorry, he's got a learning disability so he doesn't know that" – Louise

In order to manage these difficulties (and parent anxieties), children with a severe intellectual disability often need support to go out into the community. However, some viewed this as being a barrier towards their child achieving independence or a "normal" adulthood:

"In an appointment, I will answer the questions for him because he's got a learning disability. If he was a normal young man, he'd be doing all these things on his own and I wouldn't be speaking for him as he wouldn't need to depend on me" - Sarah

Seven parents illustrated ways in which their child's behaviour may prevent others from viewing and treating them as an adult, as outlined by Paul:

"Its difficult for people to actually treat him like an adult if he's making odd noises and waving him arms about. They actually might feel a little bit uncomfortable about that. He definitely won't be able to make or even keep

relationships with other people like we can, probably because of his LD like his difficulty in understanding how to be in social settings" - Paul

Most parents highlighted characteristics of their child which prevented or slowed down the process of becoming an adult or being viewed as an adult. Given the severity of their child's intellectual disability, it is unlikely that barriers (e.g., behavioural or cognitive) could be completely overcome. This is a constant reality for parents and their child i.e. that they are not going to experience adulthood in the same way as individuals without an intellectual disability. Most parents explained that these challenges often led them to worry about their child's wellbeing. One parent seemed to take control over the decision-making process in order to manage her worries about her son's future:

"There was a chance of him going to college or just sitting at home or going to daycentres. I wanted to make that choice with the right support to make sure it was right and safe for him" – Rebecca

Notably, different parents identified different types of barriers to their child's transition into adulthood. These were largely related to the challenges within professional systems and within the nature of their child's intellectual disability. Interestingly, parents did not view their own actions or assumptions as barriers to their child's adult development. For example, whilst parental control may be seen as a form of protection against danger (e.g., abuse), it could also be a barrier e.g. inhibiting their child's ability to learn how to make decisions. Thus, it could be argued that the adjustments that some parents make for overcoming the perceived barriers may inadvertently provide further blocks to their child's transition into adulthood (see section 3.7).

3.6 Worrying – The "black hole" of Transition

This process included parents worrying about being over-ruled by healthcare professionals; worrying about their child's vulnerability in society; and worrying about the future of their child's adult life. Being excluded or ignored by healthcare professionals was a worry shared by most parents. They reflected that these worries occurred before their child left school; during the transition process; or both as highlighted by Louise:

"My major concern was to not be part of decisions being made, not being invited to meetings or kept up to date. I was worried about all these things whilst the transition was happening but then I suppose there were also times when these worries came when she was planning to leave school, I was just worried that anything that I said would be over ruled" – Louise

Five parents expected to have been "kept in the loop more frequently" (Jack). Sarah shared several anxious thoughts that she experienced before her son left school. She viewed her son's transition into adulthood as being a move from a position of knowledge and predictability to an unknown territory that she described as being a "black hole":

"Before he left school I knew where I was with it all but I wasn't sure what would happen after he left, it was like a black hole…what the hell is going to happen? Where is he going to go? What about the funding? Will there be enough money in the budget to pay? Are the council going to give me enough money to cover the cost because it's very expensive. Nobody gave me the answers that I needed at that time but if they had then perhaps I wouldn't have panicked as much" – Sarah

Sarah's quote highlighted that it might be helpful for services to proactively work with some parents to anticipate or pre-empt "peaks" of worry. As such, services may be able to help parents to make adjustments for their child's transition whilst managing their anxieties.

Additionally, for most parents, independence was a double-edged sword; they desired for their child to "develop independence like normal adults" (Amy) but this was also viewed as increasing their child's vulnerability to abuse (as discussed in our journal paper). This, together with worrying about how much involvement they would have, left parents feeling uncertain about their child's future. Two fathers (Rick and Jack) perceived "worrying" as a "natural" process:

"I think it's natural though when you are getting older, you start worrying about your health and you start worrying about your children's future. It's

natural. Because of my son who is mentally handicapped, things are different because he will always need a lot of support unlike the rest of us and so we have to put plans in place for that" - Rick

Rick's quote highlighted some differences in the ways parents viewed feelings of worry. This is important because the way in which parents appraise worry may influence their decisions around adjustments. For example, parents who considered worrying to be a "natural process" may have been less inclined to make adjustments in comparison to those who viewed worrying as a "black hole". Some parents worried about the future beyond the transition into adulthood. For example, thinking into the future influenced Amy's decisions for the transition process. She recognised that her daughter was not going to have a "normal" life and therefore planned for this accordingly:

"If we'd had her living with us, as we got older into our sixties and seventies, and she's in her thirties, forties, fifties, we become old and frail, we can't care for her, we're not going to be around forever. I didn't want her to become a burden on her sisters when we can't care for her anymore because let's face it she isn't going to have a normal life. So, I wanted her to learn to live independently, albeit limited, that was best for her" - Amy

Generally, worrying was an on-going process. Most parents worried about being excluded or ignored by healthcare professionals once their child became an adult. This highlighted the importance for services to work closely with parents to manage their worries (and stress), but to acknowledge that parents would not all experience their child's transition in the same way. Additionally, most parents experienced dilemmas when thinking about their child's independence but worrying about risk of abuse. These worries were viewed as being problematic as it left parents unsure of how to manage, especially if they viewed services as being unhelpful. There were some differences in the ways parents appraised feelings of worry. This appeared to influence whether parents made adjustments and how they did it. Furthermore, worrying was not limited to the transition into adulthood. Some parents worried about the future of their child's adulthood, which appeared to influence the decisions made at the time of transition.

3.7 Making Adjustments

All parents made adjustments to manage their worries and overcome some of the perceived barriers to their child's adult development. This included encouraging "age appropriateness" (Tina) in their child, accepting "child-like" interests, making changes in their interactions with their child and finding strategies to manage their anxieties. Encouraging "age appropriateness" was a common adjustment for parents. Some encouraged their child to engage in activities that they viewed as being symbolic of "normal" adulthood such as drinking alcohol:

"He has adult rights, if he was a normal adult he would have at least tried a beer, so, he has had a bit of lager, he didn't like it, spat it out and that's it. I have tried him with a bit of wine, he wasn't keen on that either, so he has tried things, it's not like I have denied him of those things that normal adults would do" - Sarah

Further examples of encouraging "age appropriateness" included "buying adult clothes" (Paul); "going to the golfing range instead of sitting on the floor playing the triangle in music therapy" (Louise); "going to watch a football match rather than taking him to the aquarium" (Rick); and "getting her interested in current music bands to move away from nursery rhymes" (Carla). Upon exploration, some parents explained that encouraging "age appropriateness" was important for reducing their child's vulnerability within society:

"If he's behaving in an inappropriate way or doing inappropriate things for what people would perceive as abnormal, then he's more open to comments or bullying, and I think that's why I want him to fit in as much as possible" – Louise

However, there were contrasting views towards encouraging "age appropriateness". For example, two parents perceived a need to accept interests which were important to their child but incongruent to their chronological age. These parents had considered their child's chronological age to be meaningless when defining adulthood (see section 3.3 and journal paper):

"I felt happy for him that Shrek was there because he loves Shrek so I wouldn't have said no and robbed him from his wishes or things like that. Thinking back now it just sounded strange when I was telling you because you don't usually associate Shrek with a 21 year old, it was like a kids party although it was an adult party" – Rebecca.

Networking with other parents was a common strategy used by most to cope with their worries or adjustments being made:

"I have been really lucky because I have found other parents who share similar views with me and are on similar wavelengths to me so it's reassuring as it makes you realise that other people are in the same situation as you" – Amanda

Some parents found support within their own families:

"It wouldn't have taken much for me to say he's not going, I was really in two minds. Alice [daughter without a disability] did go with me to take him [son] to the college and in a way it was nice to have a voice telling me it was going to be okay. I think if Alice hadn't have been there, then I certainly would have burst into tears" - Tina

By contrast, two fathers felt reluctant to share their worries with family members:

"I am very close to my sisters but they have their own families and I don't want to put my worries on to them" – Roger

"I live on my own, I have friends and my own siblings, but everyone is too busy with their own lives so I rarely get a chance to actually sit down and chat with them. So when I do, I'd rather talk about positive things" - Rick

It could be inferred that fathers may be less inclined to make adjustments that involve seeking support from others. It seemed that seeking support from their family would make them feel like a burden. For Rick, focusing upon

"positive things" may have been his way of coping with issues that were burdensome for him. Alternative methods for seeking support were reflected through discussions of "doing a lot of research" (Carla). For most parents, knowledge was viewed as being important for various reasons. This included learning about the legalities of adulthood (e.g., adult rights); the types of professional support available (both locally and at a government level); the transition process; and how to challenge healthcare professionals if needed. That said, some parents seemed to be forced into researching information as a result of a lack of support from professional services:

"The school weren't great and they'd basically directed us to [adult service]…and then it was left to us to do all the research, so there was a lot of reading involved and asking professionals questions and things but we just did it ourselves in the end" - Jack

Other adjustments included changes in their interaction style with their child. For example, Rick noticed that he became more a guide for his son as opposed to telling him what to do:

"I probably advise him what to do now whereas before when he was younger it was more "do this do that" but I stopped dictating once he started doing adult things that he should be doing" - Rick

Similarly, Louise became more mindful of how she interacted with Joseph. She appeared to make efforts to widen Joseph's awareness to his adult-self. This was motivated by her perceptions of Joseph having the same adult rights as his non-disabled peers:

"I still go to all the hospital appointments with him but now he's an adult I'll say, 'Joseph, do you mind me answering for you if you don't understand?'. So now I make him aware that he's an adult and that he has the same rights as everyone else so I make him aware that the questions are directed at him, whereas before I'd just answer for him without asking" - Louise

Whilst parents demonstrated ways in which they made adjustments (either to themselves or their child), there were three parents who highlighted ways in which they had not made changes in light of their child's transition. This was largely related to staying involved in their child's care, as outlined by Roger:

"I wrote his person centred plan, it had all the stuff about what he does, what he's like, his needs and so on, his likes, his dislikes, what frightens him, what pleases him and all that sort of gobbledygook…and then what we felt about how to manage his future and I also wrote emergency plans...." - Roger

It could be suggested that some parents expected to stay in control in order to manage their worries of being over-ruled by healthcare professionals (see section 3.6). All parents made adjustments around their child's transition into adulthood. The types of adjustments varied according to how they defined adulthood. Parents who viewed chronological age as meaningful were likely to make adjustments that encouraged "age appropriateness" for their child. However, parents who did not view chronological age as important seemed to be more accepting of the incongruence between their child's interests and age. A common adjustment included "doing research". This appeared to be both a proactive and reactive strategy for parents to seek information. Additionally, whilst gaining family support was helpful for some, two fathers viewed this as being a burden, which could be indicative of gender differences in types of adjustments made. By contrast, some parents demonstrated ways in which they did not make any changes. This was largely related to staying involved in their child's care.

3.8 The Concept of "Time"

Through further interaction with the data, a temporal dimension developed. "Time" was a pertinent process when understanding how parents viewed their child's transition into adulthood. For example, parents drew upon words related to time (e.g., "when…", "after…", "since…", "before…") when describing their worries throughout their child's transition (see extracts in section 3.6). Additionally, one parent thought about her son's adult life from the moment he was diagnosed with a chromosomal disorder at birth:

"My son was born with a chromosomal disorder, so the first things I asked the paediatrician was you know, what does it mean? Is he going to live? What can go wrong? Will he survive into adulthood? What will it be like for him?" – Sarah

Significant childhood events (such as being diagnosed with a potentially life limiting disorder) may prompt parents to worry about the barriers that disrupt the normative lifecourse model that they may have initially anticipated for their child. Five parents referred to the concept of "time" when they reflected upon the length of their child's transition process, as highlighted below:

"…you can't predict what somebody would be like as an adult, I knew that John had brain damage, but it's just time that tells you, I had to be patient to see how his life unfolded for him, time is your evidence" - Tina

" With an ordinary child you see transitions in stages, one after the other. But with Tom, it was like evolution; a very very slow process" - Rick

Through this temporal trajectory, parents engaged in interactional processes to make sense of their child's transition and the subsequent adjustments made.

3.9 Chapter Summary

Parents viewed their child's transition into adulthood as a process over time within the context of perceived "norms" of adulthood. They all engaged in both implicit and explicit processes to understand their child's transition and make adjustments for it. In particiular, it seemed that parents' definition of adulthood was likely to influence how adjustments were made. "Worrying" was a continuous process but the ways in which is was managed was related to how parents appraised it. "Noticing sexuality development" and "Responding to sexuality development" were processes that developed in parallel with "Noticing adult development". Thus, noticing and responding to sexuality were processes that had a distinctive salience for parents, suggesting that they were somewhat separate from the broader transition into adulthood. There was some variation

throughout these processes, highlighting the diversity of parents' views and adjustments made.

Chapter 4. Extended Discussion

4.1 Chapter Introduction

I have organised this chapter into nine subsections. I begin by providing a synthesis of the findings i.e. the key parental views and adjustments made in relation to their child's transition into adulthood. I use existing psychological literature to elaborate upon possible explanations for my study findings, with clinical implications offered throughout. I then provide a brief critique of the transition model of parents' views and adjustments and offer further implications of my findings for clinical psychologists and future research. I end this chapter with a discussion of the strengths and limitations of my study, and a reflective account of this research process.

4.2 Making Comparisons with Perceived "Norms"

The social comparison theory would posit that some parents of individuals with a severe intellectual disability would make comparisons with normative lifecycles in order to learn about their child's abilities and improve them (Brickman & Bulman, 1977; Taylor & Lobel, 1989). Thus, parents might manage their worries by making adjustments in line with "norms" to improve their child's abilities e.g. encouraging "age appropriateness", as reported in the findings. By contrast, parents who do not make comparisons (or are less worried about deviating away from the perceived "norms") are more accepting of their son or daughter's "child-like" interests. Individual differences research suggests that those who do not make comparisons may be more confident or have lower levels of uncertainty (Gibbons & Buunk, 1999). Alternatively, it could be that these parents had negative experiences when making comparisons with normative lifecycles in the past (e.g., the worries or "pain" of being different; Brickman & Bulman, 1977). Research argues that this is one of the reasons why comparison activity becomes extinguished (Gibbons, Benbow & Gerrard, 1994), and thereby explains why some parents may disengage from seeking normalisation.

By contrast, where parents were actively encouraging "normality" for their child's adult life, it is more likely that these parents would rate their child's abilities (e.g., independence) as lower than their non-disabled peers. This comparison may lead to feelings of inadequacy and worry as found in my study. Alternatively, it could lead parents to feel hopeful in facilitating their child's transition into adulthood. Parents who struggle to help their child meet "normative" goals over time (due to lack of support from services or "not

knowing enough"), might abandon their attempts to adjust (e.g., agreeing with services rather than challenging them).

4.3 Conceptualising Adulthood

When noticing adult development in their child, parents' descriptions were closely in line with Western ideations of "independence" (Arnett, 2000). However, markers of "independence" varied between parent accounts. For example, parents referred to changes related to their child's behaviour (e.g., making the bed), cognitive abilities (e.g., knowing where the bus stops are) and social skills (e.g., turn-taking in conversations). Government policy documents such as Valuing people (DoH, 2001a) and Valuing people now (DoH, 2010) broadly use the term "independence" as a key aim for improving the lives of people with intellectual disabilities. The findings from my study have implications for policy makers to deconstruct the term "independence" when developing (or evaluating the outcome of) governmental strategies. Parents noticed that the nature of their child's intellectual disability slowed down their adult development. It may be that some people with a severe intellectual disability may never achieve normative constructs of independence. Indeed, it is often unclear how independence can be promoted in people with intellectual disabilities (van Hooren, Widdershoven, van den Borne & Curfs, 2002). As discussed in the journal paper, the notion of "relational autonomy" may be best suited to the care of individuals with an intellectual disability (Widdershoven & Sohl, 1999), and may have implications for clinical interventions.

4.4 Dilemmas of Sexuality Development

Responding to sexuality development appeared to be a struggle for parents. My study found that most parents sought professional help to manage their worries of "not knowing what to do" and to ensure the best approach for their child. We also highlighted parents' views of sexuality development being limited to discrete forms of behaviour. Both of these findings have clinical implications for child and adult services to (1) explore signs of sexuality in young people with a severe intellectual disability and (2) be trained in knowing how to manage sexually-related issues. In doing so, staff may feel more competent in sharing knowledge and skills with parents. Additionally, having a clear service agenda for managing sexuality issues may reduce its ambiguous nature and

lower potential stress in parents and staff. Furthermore, it seems that being unsure of how to best support their child's sexuality may result in a pull towards using a "quick-fix". This was evident in Rick's experiences of agreeing with staff to use medication to inhibit his son's sexual needs, and in turn, his adult development. In light of this, both staff and parents need to be aware of the legal background to their decisions i.e. staying mindful of the laws and rights that people with an intellectual disability have with regards to sexuality.

4.5 Further Barriers and Resources

One of the key barriers to adulthood perceived by parents was discussed in the journal paper (parents vs professionals). This section provides further barriers and resources utilised by parents.

4.5.1 Independence vs risk. My study highlighted that parents desired for their child to develop independence like "normal" adults. However, this was perceived as being unattainable given their child's vulnerability to abuse in the community or residential settings. The notion of balancing an individual's needs for independence with the need for protection is not new. In fact, early intellectual disabilities literature reflects upon the difficulties that parents had in "letting go" of their children (Richardson, 1989) verses a tendency to be over-protective (Wertheimer, 1981). Parents in my study did not display signs of being "over-protective" towards their child with a severe intellectual disability. Most parents actively encouraged independent living skills whilst being mindful of potential risks. This contrasts with earlier research that portrays parents as being reluctant to encourage independence in their children (Anderson, Clarke & Spain, 1982; Card, 1983). Possible explanations for this shift in view could be related to parents (and professionals) having an improved awareness of the abilities of individuals with a severe intellectual disability, and ways of adjusting.

4.5.2 Accessing support. My study found that some parents sought social support to help them cope with their child's transition. This involved joining parent support groups and sharing their difficulties with family members. Parents described positive experiences of accessing parent support groups. It provided them with emotional support and helped them to feel less isolated.

As discussed in the journal paper, it could be inferred that making comparisons with similar others (or in-group members) could be a form of protection from being threatened or negatively judged. Crocker and Major

(1989) argue that in-group comparisons may serve to foster (a) a "proximity" effect that develops as a result of segregated environments in which in-group members are readily available for comparison, (b) a "similarity" effect in which individuals who have been stigmatised search for similar stigmatised others to allow for more accurate self-evaluations, and (c) a "self-protective" effect where comparing with advantaged out-groups may have negative effects upon an individual's self-esteem. It could be argued that these effects encourage a sense of belongingness for parents. It might also help to reduce negative feelings associated with transitions such as anxiety or stress. This explanation is consistent with the stress-buffering hypothesis, which emphasises that providing emotional, informational or instrumental resources is central for facilitating an individual's coping skills (Cassel, 1976). Research exploring the mechanisms of the stress-buffering hypothesis emphasises that social support provides protection by intervening between the stressful event and stress reaction (i.e., by attenuating a stress appraisal); providing supportive beliefs which are suggested to dampen physiological responses to the situation; providing solutions to problems; and reducing the perceived importance of the problem (Lepore, Silver, Wortman & Wayment, 1996). In light of these mechanisms, accessing support from other parents with similar experiences may serve to bolster parents' perceived ability to adjust to stress associated with their child's transition into adulthood. This has implications for intellectual disabilities services to provide parent support groups or for clinicians to signpost parents to such resources (e.g., face-to-face groups or online forums).

My study also highlighted a potential gender difference when accessing support. This is not surprising given that existing intellectual disabilities literature suggests that fathers have different experiences from mothers and thereby different support needs (Krauss, 1993; Hastings et al., 2005; Saloviita, Italinna & Leinonen, 2003). I found that some fathers felt reluctant to share their worries with family members. It appeared that fathers did not want to be a "burden" within their family or preferred to cope through avoidance strategies. Typically, avoidant coping strategies are suggested to be associated with psychological distress (Hastings et al., 2005). Thus, for fathers who perceive their child's transition into adulthood as challenging, services should be equipped to share the "emotional burden" e.g. through offering psychological interventions to help manage distress.

4.6 Developing A Grounded Theory Model

A common critique of grounded theory studies involves the failure to move beyond a descriptive level (Charmaz, 2006). Given the assumptions held by critical realists in relation to theory development (e.g., identifying process and systematically related concepts; Corbin & Strauss, 2008), I would argue that my study offered a non-linear interpretation of understanding the processes that parents engage in for their child's transition into adulthood and the adjustments made.

A summary and visual representations of the model have already been provided in the journal paper (see Figures 2, 3 & 4). Thus, I will provide a brief critique of it here. I acknowledge that this model may be applicable to parents of children without an intellectual disability. However, I argue that the difference lies within the types of parental adjustment made. For example, parents of children with a severe intellectual disability are more likely to seek support from professional services to manage perceived barriers (e.g., difficulties in managing sexuality development). Additionally, given that the parents in my study identified some unexpected barriers within their child's transition trajectory (e.g., exclusion from services), it is likely that these parents may experience more inconsistencies between their expectations and actual experiences compared to parents of a child without an intellectual disability (see section 4.7.2 for further limitations). A strength of the model is its ability to account for the diverse experiences that parents may encounter as represented by Figure 3 and 4 in the journal paper. It may also be a valuable tool for psychological assessments, formulation and intervention (see section 4.8).

4.7 Study Strengths and Limitations

The journal paper outlined limitations of my study whilst giving a brief reference to a potential strength of shifting away from the staged idea of transition. Here, further consideration of the strengths and limitations of my study are provided.

4.7.1 Strengths. My study aimed to provide knowledge shaped and influenced by parents and their contexts[41]. Data collection included a the use of

[41] I acknowledge that there was a degree of subjectivity as a researcher that will also have shaped the findings (see section 4.10.1).

telephone, face to face and skype interviews. This allowed for greater researcher and participant flexibility, and also maximised opportunity for diversity in the sample. The analysis provided a conceptualisation of the processes and actions (grounded in research data) that parents engaged in for their child's transition into adulthood. My study findings provide a foundation for intellectual disabilities researchers to build upon e.g. further exploration of the dilemmas associated with sexuality development. My findings also provide strong implications for clinical practice and future research (see sections 4.8 & 4.9).

Throughout the interview process, information elicited from participants was reflected back to them to ensure validity of my understanding of participants' accounts. I also shared hypothesised relationships between the categories with the final three participants. Whilst I was unable to confirm the potential mechanisms of the processes that parents engaged with (i.e., *how* categories linked together, I was able to enhance the validity of the findings. Sharing a visual model provided participants with an opportunity to form their own opinions regarding the validity of the developed concepts, categories and theory. This helped to confirm or refute the pertinent processes and their influences upon one another. A further strength of my study included doing credibility checks (using the evaluation criteria set out in section 2.9 in this paper) in order to enhance the trustworthiness of the study (see Appendix U for the evaluation).

4.7.2 Limitations. First, my study related to the nature of the sample. Participants' age ranged from 44-78 years. Given that some had considered their son or daughter to become an adult several years ago (e.g., Rick), it is acknowledged that the data may not be an accurate reflection of parents' experiences. Second, whilst the female:male ratio in this study (2:1) is an improvement from existing study samples in this field, males were still under-represented. Third, due to the nature of conducting interviews, it was not possible to cover all topics within the interview schedule. Thus, some participants may have had more opportunity to elaborate upon certain topics compared to others. In light of this, the fact that my study only had five parents reporting about their child's sexuality development may have been due to limitations in the methodology as opposed to it being an ambiguous topic. Lastly, we know that in reality, the transition into adulthood is complex (for individuals with and without an intellectual disability). The current model is a

simplified representation of the transition process and could be perceived as parents holding a rather reductionist view of their experiences. However, it is argued that most lifecycle models are simplified. In this case, it is believed that a simplified model of parents' experiences would be helpful for parents of a child with a severe intellectual disability to understand how other similar parents make adjustments and the issues that they have encountered. My study explained that seeking support or making comparisons with other parents of children with intellectual disabilities might serve to function as a stress-buffer (see section 4.5.2). Thus, I would argue that my model could do the same i.e. by providing parents with information grounded in perspectives from similar others.

4.8 Further Clinical Implications and Relevance for Clinical Psychology

In addition to the clinical implications that have been interwoven throughout this chapter and journal paper already, this section provides further implications with specific relevance for clinical psychologists.

Given the variation within my findings, I highlighted the non-prescriptive nature of what "should" be happening for parents as their child becomes an adult e.g. some parents were embracing "age appropriateness" whereas others were not. One possible intervention could involve developing a booklet as a practical output to capture the differences in parents' views and adjustments. This may help other parents in similar situations to understand that there is no "right" way of experiencing this transition. On a theoretical level, the variability of how parents experienced their child's transition into adulthood helps to shift away from existing linear models that are restrictive (e.g., family life cycle model; Carter & McGoldrick, 1980). Thus, my findings may help clinicians to broaden their awareness that transitions may not occur in fixed stages.

My model may be of particular use within psychological therapy. First, aspects of my model may be used to inform psychological assessment. It would enable us to consider parent factors (e.g., content and rigidity in expectations, unhelpful coping strategies), which may be maintaining their anxieties. Second, my model provides an explanatory framework for formulation. It could be used as a tool to help normalise parents' difficulties in adjusting to their child's transition. Simplified visual diagrams may be useful for this. Third, my model

could be used to inform interventions. Following the difficulties that may arise during their child's transition into adulthood, parents may require help to re-evaluate their (and their child's) life goals. Cognitive behavioural techniques could be used to help parents to manage difficult emotions and unhelpful coping responses that may be related to their negative self-beliefs. Additionally, interpersonal therapy (IPT) could be employed to encourage parents to develop more adaptive expectations (for both their child and themselves). IPT may also be useful for helping parents to accept the reality of their child's adult development; understand the adjustment-related worry they may be experiencing; and explore new ways of coping with (or appraising) the transition process. Lastly, given the increasing leadership role for clinical psychologists within clinical teams and project development, a greater awareness of understanding parents' views of the transition process may encourage us to think about (1) how to integrate parents into transition planning and (2) how to make the transition process into adulthood more psychologically informed.

4.9 Further Implications for Intellectual Disabilities Research

The journal paper outlined brief implications of my study for future research. Here, further research implications are provided.

4.9.1 Making comparisons. Whilst there is evidence to suggest that individuals with an intellectual disability make upward comparisons with individuals without a disability (e.g., Tracey, 2002), there is no intellectual disabilities research that has specifically investigated this process with parents. My study did not find any indication of parents making downward comparisons in order to enhance their (or their child's) self-esteem or self-concept. Research has considered that establishing shared interests between parents of a child with and without an intellectual disability can be an important basis for forming "alliances for change" (Ryan & Runswick-Cole, 2008). Thus, future intellectual disabilities research could explore the types (and function) of comparisons that parents make at the time of their child's transition into adulthood. This might include identifying the similarities and differences of experiences between parents of children with and without an intellectual disability, and between different parenting contexts (e.g., biological, step or foster parents). It may also consider whether the types of comparisons change along the transition trajectory.

4.9.2 Fathers' perspectives. Gaps in existing literature include fathers' perspectives of caring for their child with an intellectual disability. Further exploration of their perspectives would illuminate specific issues or positive experiences that arise for fathers around their child's transition into adulthood. This would be helpful for contributing to the growing evidence base and for providing us with a broader understanding of fathers' needs.

4.9.3 Sexuality. My study highlighted that parents struggled to support their child's sexuality development. This was largely underpinned by parents and professionals "not knowing" what to do. There is little intellectual disabilities research documenting parents' views of their child's sexuality development, and related responses. Further research could thereby explore how parents adjust to their child's sexuality development, if at all. This could be achieved through using quantitative (e.g., questionnaires or surveys), qualitative or mixed methods and would contribute towards the little evidence base, whilst providing valuable insight for parents and professionals.

4.9.4 Design and influencing factors. Further research could approach data collection using a longitudinal design e.g. in the form of a family case study where parents are interviewed frequently over time to gain a more dynamic account of how change happens. This would enable researchers to explore the temporal nature of salient processes that parents engage in along the transition trajectory. It is argued that such designs would allow for a "complete view of transition" (Beresford, 2004). Additionally, given the limitations with the study sample, further research could explore whether sample characteristics (e.g., age) shape parents' attitudes towards their child's transition and the processes that they engage in. Including more older parents in the sample (i.e., over 65 years) may allow for further exploration of the contextual changes over time, in terms of parents' attitudes and relationship with services. Furthermore, a question that developed from the findings was whether the type of parenting relationship (e.g., biological, step or foster parent) influenced whether parents chose to make adjustments for their child's transition, and how changes were made (see journal paper). It was beyond the scope of my study to explore this. However, future research could investigate whether parental relationship and other factors (e.g., child behavioural difficulties, ineffective parental coping strategies or a lack of family cohesion; Biswas, Tickle & Moghaddam, 2014) mediate the processes that parents engage in around their child's transition into

adulthood. This would be particularly helpful for clinicians working with parents when considering a focus for intervention.

4.9.5 Grounded theory model. My study was unable to specify the nature and location of causal mechanisms within the model. Future research could use a longitudinal design to capture these processes. For example, following a family through the transition trajectory would allow for questions such as "what is changing?", "how is that happening?" or "how are you coping with that?" to be asked. Responses to questions in the present moment (as opposed to retrospectively) would help to build upon the model by providing a more in-depth account of the pertinent processes that parents engage in for their child's transition into adulthood. It would also help to shed light upon potential causal pathways in the model e.g. between defining adulthood and making adjustments. This would be important for clinical psychologists when deciding upon the type of intervention to deliver to parents who may be struggling to make adjustments.

4.10 Critical Reflection

In line with a critical realist epistemology, it is important to critically reflect upon what I have learnt as a researcher. Corbin and Strauss (1990) argue that maintaining analytical distance whilst drawing upon past experience and theoretical knowledge to interpret what is seen, astute powers of good observation and good interactional skills. Thus, I used professional and theoretical knowledge to enhance sensitivity during the research process. Engagement with the data encouraged me to become sensitive to words and concepts pertinent to parents' views and experiences. Prior reading around the research area enabled me to grasp meaning behind data and identify theoretical connections between concepts, whilst remaining creative and flexible for theory development. Importantly, whilst I was aware that early consultation with the literature could influence the data collection and analysis process, keeping a reflective diary enabled me to remain mindful of superimposing preconceived ideas on the emerging concepts and categories.

4.10.1 Epistemology and methodology. Critical realism accepts that people's understanding of the world originate from their personal views. As such, critical realists argue that knowledge needs to be examined "inside out". Given that my study was interested in exploring parents' inner processes of their

child's transition into adulthood, a critical realist position was deemed to be the best fit for answering the research question. Adopting a critical realist position and using an inductive approach to meet the aims of this study allowed me to make a number of revisions to the model presented in the journal paper (Figure 2). This was particularly the case during the analysis stage, where relationships between concepts and categories were being explored. Grounded theory is open to modification and so I considered it to be well placed to operationalise critical realism's fallibilism (Oliver, 2011). A critical realist would argue that the participant data, concepts, categories and model developed within this study may reveal something about the reality of the processes that parents engage with, but that it does not directly mirror this reality due to the limits in human knowledge.

Moreover, other epistemological stances such as objective positivist assumptions[42] would have been difficult to apply to abstract ideations such as "adulthood". My position as a critical realist and using grounded theory (Corbin & Strauss, 2008) was helpful for highlighting the dual focus on the individual and wider society[43]. For example, I was mindful of how participants' own experiences of adulthood may have influenced their perceptions of their child's transition into adulthood. I was also able to reflect upon my own preconceptions (e.g., about my own beliefs of adulthood), and how this may have influenced the research process (see section 2.8.1). Indeed, if the data had been analysed by another researcher, it could have led to a different analysis and a different model. Similarly, given that I was a novice researcher with little knowledge of grounded theory at the beginning of the research process, it could be argued that there are more complex ways of answering the research question.

4.10.2 Interview process. During the interviews, I was able to be part of a world that I wanted to learn more about. In line with critical realism, I perceived myself to adopt a dual role of an "outsider researcher" and an "inside participant" (Nogeste, 2006). This was helpful for allowing me to provide a balanced perspective, which may not have been possible if I had adopted

[42] Positivists propose that there is a concrete single reality that is knowable and unchangeable (Clark, 2004).
[43] "To understand experience, that experience must be located within and can't be divorced from, the larger events in a social, political, cultural, racial, gender-related, informational and technological framework and therefore these are essential aspects of our analyses" (Corbin & Strauss, 2008, p.8).

another epistemological position, in which the researcher takes a single view (Stiles, 2003). During the initial interviews, I tried to keep my questions and prompts to a minimum as I wanted participants to share their experiences and views. However, this was challenging given that participant answers did not always stay focused on adulthood as a subjective concept. Instead, participants tended to relate their answers to their child's transition into adult services. Whilst my research was not specifically targeted at parental views of the transition into adult services, I was able to revise the interview schedule to incorporate it in, and explore how it may have influenced their child becoming an adult more generally. Thus, I found the ability to revise the interview schedules useful for staying focused on the research question and theoretical framework. Additionally, I initially stuck closely to the interview schedule due to my little confidence as a novice researcher coupled with my anxieties of "doing it right". As the interview process progressed, I felt more confident in being able to explore new topics that arose whilst linking them to the research aims.

A further issue that I noticed during the interview process included the differences in views between myself and the participants when defining adulthood. For example, some participants described "leaving home" as a key feature of adulthood. Whilst I understand that leaving home could be perceived as gaining independence, this is not a strong indicator of marking a shift into adulthood for me. Within my Indian culture, role transitions such as getting married would be an important sign of adulthood. In light of such contrasting views, I was prompted to think about possible cultural differences when answering the research question. Given that critical realism understands research by assembling multi-faceted views of reality (Riege, 2003), it would have been interesting to explore cultural differences. However, all participants that volunteered to take part in this study were White British and therefore there was little opportunity for me to explore this.

4.10.3 Analysis and sharing the thematic map. Critical realists aim to provide contextualised explanations by initially describing the properties and causal mechanisms, and then describing how different mechanisms manifest under certain conditions (Danermark, Ekstrom, Jakobsen & Karlsson, 2002). This fit with the grounded theory analysis process whereby the properties and dimensions of categories were developed through constant comparison of data. Through this process, I was able to develop a plausible theory of parent

experiences. However, there were a few challenges along the way. I initially felt over-whelmed with the amount of data collected from the interviews, and the number of "analytic tools" (Corbin & Strauss, 2008) that were available to analyse the data with. I sought regular supervision, which was helpful in a number of ways. This included when identifying pertinent concepts within the data; identifying relationships between categories; "letting go" of less important concepts; justifying the core category; deciding upon the best way to capture the findings in a conceptualised model; and for building my confidence in interpreting the data at a more abstract level. Additionally, memos, NVivo and the use of visual diagrams were helpful when making sense of how categories were formed and the nature of relationships between categories i.e. potential mechanisms.

Another challenging experience was during the final stages of the analysis process when I shared a thematic map of the key processes with three participants (Samantha, Roger and Louise). I decided to share the map as I hoped that it would facilitate discussions that would help to confirm or disconfirm my hypotheses of how parents understood their child's transition into adulthood. As such, sharing the map was a difficult experience. Given that parents may not naturally think about the processes they engage with (e.g., defining adulthood) and that most participants in this study responded at a more surface level during the interviews, it is understandable that the last three participants found it difficult to connect with the models. In order to manage this challenge, I prompted participants to think about the connections between examples they had provided in earlier discussions (i.e., encouraging the participant to apply the model to themselves). This strategy made it somewhat easier for the participants to understand the map. However, I acknowledge that it may have risked participants "shoe-horning" their experiences into the boxes, or even adapting their original views[44].

Additionally, explaining that parents made frequent comparisons to societal "norms" was tricky for Samantha. As could be seen from her quotes (see journal paper), Samantha was keen to develop her "norms" appropriate to her daughter's needs, rather than fitting in with what other people thought.

[44] "The act of conceptualisation is potentially transformative as a theory can alter your viewpoint and change your consciousness. Through it you can see the world from a different vantage point and create new meanings of it" (Charmaz, 2006, p.128)

Whilst sharing this concept with Samantha was challenging, I recognised that her alternative views made the data richer in terms of having a "negative case".

Despite the criticisms of Corbin and Strauss's (2008) guidelines being overly prescriptive, I found it helpful to learn about the different "tools of analysis". This provided me with a structure for approaching the analysis and enhanced my understanding of this method. Overall, the research process has not been without its challenges but it has most certainly been a worthwhile experience. I have gained knowledge and skills throughout this process and in particular from my research and field supervisors. I have also learnt how to become creative as a researcher which will be beneficial for any research that I conduct in the future.

References

Almack, K., Clegg, J., & Murphy, E. (2008). Parental negotiations of the moral terrain of risk in relation to young people with intellectual disabilities. *Journal of Community & Applied Social Psychology*, *19*(4), 286-298.

American Psychiatric Association. (2013). *Intellectual disability: American Psychiatric Publishing*. Retrieved September 3, 2013, from www.dsm5.org.

American Psychological Association. (1994). *Publication manual of the American Psychological Association* (4th ed.). Washington, DC: Author.

Anderson, E., Clarke, L., & Spain, B. (2002). *Disability in adolescence*. London: Routledge.

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, *55*(5), 469.

Backman, K., & Kyngäs, H. A. (1999). Challenges of the grounded theory approach to a novice researcher. *Nursing and Health Sciences, 1*, 147-153.

Barker, C., Pistrang, N. & Elliott, R. (2002). *Research methods in clinical psychology. An introduction for students and practitioners* (2nd ed.). Chichester: John Wiley & Sons, Ltd.

Bazeley, P. (2006). The contribution of computer software to integrating qualitative and quantitative data and analyses. *Research in the Schools, 13*(1), 64–74.

Beart, S., Hardy, G., & Buchan, L. (2004). Changing Selves: A grounded Theory Account of Belonging to a Self–advocacy Group for People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, *17*(2), 91-100.

Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child: Care, health and development*, *30*(6), 581-587.

Bhaskar, R. (1978). *A realist theory of science*. Brighton: Harvester Press.

Bigby, C., Fyffe, C., & Ozanne, E. (2008). *Planning and support for people with intellectual disabilities: Issues for case managers and other professionals*. Australia: UNAZ publishers.

Birks, M., & Mills, J. (2011). *Grounded theory: A practical guide*. Los Angeles: Sage Publications.

Biswas, S., Moghaddam, N., & Tickle, A. (2014). What are the factors that influence parental stress when caring for a child with an intellectual disability? A critical literature review. *International Journal of Developmental Disabilities*. Advance online publication.

Blair, S. E. (2000). The centrality of occupation during life transitions. *The British Journal of Occupational Therapy*, *63*(5), 231-237.

Boychuk, D. J. E., & Morgan, D. (2004). Grounded theory: Reflections on the emergence vs. forcing debate. *Journal of Advanced Nursing*, *48*(6), 605-612.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

Brennan, J. (2001). Adjustment to cancer—coping or personal transition? *Psycho-oncology*, *10*(1), 1-18.

Brett, J. (2002). The experience of disability from the perspective of parents of children with profound impairment: Is it time for an alternative model of disability? *Disability & Society*, *17*(7), 825-843.

Breunlin, D. C. (1988). Oscillation theory and family development. In C. J. Falicov (Ed.), *Family transitions: Continuity and change over the life cycle* (pp. 133–158). New York: The Guilford Press.
Brickman, P. & Bulman, R. J. (1977). Pleasure and pain in social comparisons. In J. Sulls., & R. Miller (Eds.), *Social Comparison Processes,* (pp.149-186). London: John Wiley & Sons.
Bridges, W. (1991). *Managing transitions: Making the most of change*. Reading, Mass: Addison-Wesley.
Bridges, W. (2004). *Transitions: Making sense of life's changes.* Da Capo Press: Cambridge.
British Psychological Society. (2000). *Learning disability: Definitions and contexts*. Leicester: Author.
British Psychological Society. (2010). *Code of human research ethics*. Leicester: Author.
Bryant, A. & Charmaz, K. (2007). Grounded theory research: Methods and practices. In A. Bryant & K. Charmaz (Eds.), *The sage handbook of grounded theory* (pp.1-29). London: Sage Publications Limited.
Burr, V. (2003). *Social Constructionism* (2nd ed). London: Routledge.
Card, H. (1983). What will happen when we've gone? *Community Care, 28*, 20-21.
Carter, E. A., & McGoldrick, M. (1980). *Family life cycle: A framework for family therapy.* New York: Gardner Press.
Cassel, J. (1976). The contribution of the social environment to host resistance. *American Journal of Epidemiology, 104,* 107-123.
Cater, J. K. (2011). Skype a cost-effective method for qualitative research. *Rehabilitation Counselors & Educators Journal*, *4*(2), 10-17.
Charmaz, K. (1983). The grounded theory method: An explication and interpretation. In R. Emerson (Ed*.), Contemporary field research: A collection of readings* (pp. 109-126). Boston, MA: Little brown company.
Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* London, England: Sage Publications.
Chiovitti, R. F., & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing*, *44*(4), 427-435.
Clark, L. S. (2004). *Constructivist methods in the symbolism, media and the lifecourse and the symbolism, meaning and the new media @ Home Projects.* University of Colorado: School of Journalism and Mass Communication.
Clarke, H., & McKay, S. (2008). *Exploring disability, family formation and break-up: Reviewing the evidence* (No. 514). Stationery Office.
Clegg, J., Sheard, C., Cahill, J., & Osbeck, L. (2001). Severe intellectual disability and transition to adulthood. *British Journal of Medical Psychology*, *74*(2), 151-166.
Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (2000). *Hermeneutic phenomenological research: A practical guide for nurse researchers*. Sage Publications.
Cooney, A. (2011). Rigour and grounded theory. *Nurse researcher*, *18*(4), 17-22.
Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons and evaluative criteria. *Qualitative Sociology, 13*(1)*,* 3-21.
Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed). London, England: Sage Publications.

Cote, J. (2000). *Arrested adulthood: The changing nature of maturity and identity*. Canada: NYU press.
Crocker, J., & Major, B. (1989). Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review, 96*(4)*,* 608-630.
Crouch, M., & McKenzie, H. (2006). The logic of small samples in interview-based qualitative research. *Social Science Information*, *45*(4), 483-499.
Cummins, R. A. (2001). The subjective well-being of people caring for a family member with a severe disability at home: A review. *Journal of Intellectual and Developmental Disability*, *26*(1), 83-100.
Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing, 31*(6), 1476 – 1484.
Dale, N. (1996). *Working with Families of Children with Special Needs: partnership and practice*. London: Routledge.
Danermark, B., Ekstrom, M., Jakobsen, L., & Karlsson, J. (2002). *Explaining Society: Critical Realism in the Social Sciences.* London: Routledge.
Data Protection Act (1998). *Data protection act of No. c.29*. Retrieved October 11, 2014, from http://www.legislation.gov.uk
Delorme, R. (1999). *Realism in economics: Critical or complex?* Paper presented at the XIth conference of the European Association for Evolutionary Political Economy, Charlies University, Prague, November 1999.
Department of Health. (2001a). *Valuing People: A new strategy for learning disability for the 21st century: A white paper*. UK: Author.
Department of Health. (2001b). *Family matters: Counting families in.* UK: Author.
Department of Health (2001c). *No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse.* Retrived June 4, 2014, from https://www.gov.uk/governmentguidelines/policyandguidance
Department of Health. (2005). *Research governance framework for health and social care* (3rd ed.). Retrieved September 3, 2014, from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962
Department of Health (2009). *Valuing people now: A new three year strategy for people with intellectual disabilities, making it happen for everyone.* HMSO, London.
Department of Health. (2010). *Valuing people now: The delivery plan 2010-2011.* UK: Author.
Dey, I. (1999). *Grounding grounded theory. Guidelines for qualitative inquiry.* San Diego, California: Academic Press.
Disability Discrimination Act (1995). *Disability discrimination act*. Retrieved October 2, 2014, from http://www.legislation.gov.uk
Dobson, P. J. (1999). *Approaches to theory use in interpretive case studies – a critical realist* perspective: 10th Australasian Conference on Information Systems. Wellington, New Zealand.
Duffy, K., Ferguson, C., & Watson, H. (2004). Data collecting in grounded theory-some practical issues. *Nurse Researcher*, *11*(4), 67-78.
Elliot, R., Fischer, C. T. & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-219.
Falicov, C. J. (1988). *Family transitions: Continuity and change over the life cycle.* New York: The Guilford Press.

Fidell, B. (2000). Exploring the use of family therapy with adults with a learning disability. *Journal of Family Therapy, 22*, 308– 323.
Fielding, N. (1994). Varieties of research interviews. *Nurse Researcher*, *1*(3), 4-11.
Franzblau, S., & Moore, M. (2001). Socialising efficacy: A reconstruction of self-efficacy theory within the context of inequality. *Journal of Community and Applied Social Psychology, 11,* 83–96.
Gibbons, F. X., Benbow, C. P., & Gerrard, M. (1994). From top dog to bottom half: Social comparison strategies in response to poor performance. *Journal of Personality and Social Psychology, 67,* 638-652.
Gibbons, F. X., & Buunk, B. P. (1999). Individual differences in social comparison: Development of a scale of social comparison orientation. *Journal of Personality and Social Psychology*, *76*(1), 129.
Gilson, S. F., & DePoy, E. (2002). Theoretical approaches to disability content in social work education. *Journal of Social Work Education, 38*, 153-165.
Glaser, B. G. (1992). *Basics of grounded theory analysis: Emergence vs forcing*. Mill valley, CA: Sociology press.
Glaser, B. G., & Strauss, A. (1967). *The Discovery of Grounded Theory.* Chicago, IL: Aldine.
Goffman, I. (1963). *Stigma: Notes on the management of spoiled identity*. Harmondsworth: Penguin.
Goldberg, D., Magrill, L., Hale, J., Damaskinidou, K., Paul, J., & Tham, S. (1995). Protection and loss: Working with learning disabled adults and their families. *Journal of Family Therapy,* 17(3), *263-280.*
Goulding, C. (1999). *Grounded Theory: Some reflections on paradigm, procedures and misconceptions.* Retrieved June 2, 2015, from https://www.wlv.ac.uk
Grant, G. (2005). Experiences of family care: Bridging discontinuities over the life course. In G. Grant., P. Goward., M. Richardson & P. Ramcharan (Eds.), *Learning Disability:* A *life cycle approach to valuing people.* Open University Press: Berkshire.
Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: Towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, *42*(1), 58-71.
Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). London: Sage.
Hall, W. A., & Callery, P. (2001). Enhancing the rigor of grounded theory: Incorporating reflexivity and relationality. *Qualitative Health Research*, *11*(2), 257-272.
Hallebone, E., & Priest, J. (2009). *Business and management research: Paradigms and practices.* New York: Palgrave Macmillan.
Harper, D. (2012). Choosing a qualitative research method. In D. Harper & A.R. Thompson (Eds.). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners.* Chichester, England: Wiley-Blackwell.
Hastings, R. P., Kovshoff, H., Ward, N. J., degli Espinosa F., Brown, T., & Remington, B. (2005) Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with Autism. *Journal of Autism and Developmental Disorders, 35*, 635–644.

Hatton, C., Emerson, E., & Lobb, C. (2005). *Evaluating the impact of valuing people. Report of Phase 1: A review of existing national datasets.* Lancaster: Institute for health research, Lancaster University.
Heath, H., & Cowley, S. (2004). Developing a grounded theory approach: A comparison of Glaser and Strauss. *International Journal of Nursing Studies*, *41*(2), 141-150.
Herzog, H. A. (1993). "The movement is my life": The psychology of animal rights activism. *Journal of Social Issues, 49,* 103-119.
Heslop, P., Mallett, R., Simons, K., & Ward, L. (2002). *Bridging the divide at transition: What happens for young people with learning difficulties and their families?* Plymbridge, UK: British Institute of Learning Disabilities.
Heyman, B., & Huckle, S. (1993). 'Normal' life in a hazardous world: How adults with moderate learning difficulties and their carers cope with risks and dangers. *Disability, Handicap & Society*, *8*(2), 143-160.
Holloway, I., & Todres, L. (2003). The status of method: Flexibility, consistency and coherence. *Qualitative Research*, *3*(3), 345-357.
Holt, A. (2010). Using the telephone for narrative interviewing: A research note. *Qualitative Research,* 10, 113.
Hopson, B. (1981). Response to the papers by Schlossberg, Brammer and Abrego. *The Counselling Psychologist, 9*(2), 36-39.
Hopson, B., & Adams, J. D. (1977). Towards an understanding of transition: Defining some boundaries of transition dynamics. In J. Adams, J. Hayes & B. Hopson (Eds.), *Transition: Understanding and managing personal change* (pp. 3-25). Montclair, NJ: Allenheld & Osmun.
Hunter, A., Murphy, K., Grealish, A., Casey, D., & Keady, J. (2011). Navigating the grounded theory terrain. Part 1. *Nurse researcher*, *18*(4), 6-10.
Hutchinson, S. A. (1993). Grounded theory: The method. In P. L. Munhall & C. O. Boyd (Eds.), *Nursing research: A qualitative perspective.* New York: National League for Nursing Press.
Hutchinson, A. J., Johnston, L. H., & Breckon, J. D. (2009). Using QSR-NVivo to facilitate the development of a grounded theory project: an account of a worked example. *International Journal of Social Research Methodology*. 13*(4)*, 283-302.
Irvine, A. (2010). *Realities toolkit no 14: Using phone interviews. Realities*. York: ESRC National Centre for Research Methods.
Ivey, A. E., & Ivey, M. B. (2003). *Intentional interviewing and counseling: Facilitating client development in a multicultural society* (5th ed.). Pacific Grove, CA: Thomson Brooks/Cole.
Kelle, U. (1995). *Computer aided qualitative data analysis.* London: Sage.
Kendall, J. (1999). Axial coding and the grounded theory controversy. *Western Journal of Nursing Research*, *21*(6), 743-757.
Kenny, K., & McGilloway, S. (2007). Caring for children with learning disabilities: An exploratory study of parental strain and coping. *British Journal of Learning Disabilities*, *35*(4), 221-228.
Knox, M. (2000). Family control: The views of families who have a child with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *13*(1), 17-28.
Kralik, D., Visentin, K., & Van Loon, A. (2006). Transition: A literature review. *Journal of Advanced Nursing*, *55*(3), 320-329.
Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation, 97*, 393–404.

Lazarsfeld, P. F., Sewell, P. F., & Wilensky, H. L. (1967). *The uses of sociology.* New york: Basic books.

Learning disability task force (2004). *Rights, independence, choice and inclusion.* Retrived October 2, 2014, from http://webarchive.nationalarchives.gov.uk

Lepore, S. J., Silver, R. C., Wortman, C. B., & Wayment, H. A. (1996). Social constraints, intrusive thoughts, and depressive symptoms among bereaved mothers. *Journal of Personality and Social Psychology, 70*, 271-282.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Contractions, and emerging confluences, revisited. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (4th ed., pp. 97-128). Thousand Oaks, CA: Sage Publications.

Linneman, R. D. (2001). *Idiots: Stories about mindedness and mental retardation*. New York: Peter Lang.

Lomborg, K., & Kirkevold, M. (2003). Truth and validity in grounded theory–a reconsidered realist interpretation of the criteria: Fit, work, relevance and modifiability. *Nursing Philosophy*, *4*(3), 189-200.

Madill, A., & Gough, B. (2008). Qualitative research and its place in psychological science. *Psychological Methods*, *13*(3), 254.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91(1),* 1-20.

Mangabeira, W. C., Lee, R. M., & Fielding, N. G. (2004). Computers and qualitative research: Adoption, use, and representation. *Social Science Computer Review 22*(2), 167–78.

Mason, J. (2007). The provision of psychological therapy to people with intellectual disabilities: An investigation into some of the relevant factors. *Journal of Intellectual Disability Research*, *51*(3), 244-249.

Maxwell, J. A. (2012). *Qualitative research design: An interactive approach* (3rd Ed). California: Sage publications.

McCallin, A. M. (2003). Designing a grounded theory study: Some practicalities. *Nursing in Critical Care*, *8*(5), 203-208.

McConkey, R., & Smyth, M. (2003). Parental perceptions of risks with older teenagers who have severe learning difficulties contrasted with the young people's views and experiences. *Children & Society*, *17*, 18-31.

McEvoy, P., & Richards, D. (2006). A critical realist rationale for using a combination of quantitative and qualitative methods. *Journal of Research in Nursing*, *11*(1), 66-78.

Melia, K. M. (1996). Rediscovering Glaser. *Qualitative Health Research, 6*(3), 368-378.

Miles, M. B., & Huberman, M. A. (1994). *Qualitative data analysis: A sourcebook of new methods.* (2nd ed). Newbury Park, CA: Sage.

Mills, M. (2000). Providing space for time: The impact of temporality on life course research. *Time and Society,* 9, 91-127.

Molinari, L., Everri, M., & Fruggeri, L. (2010). Family microtransitions: Observing the process of change in families with adolescent children. *Family Process*, *49*(2), 236-250.

Morse, J. M. (1991). Strategies for sampling. In J.M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 126-145), London: Sage.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). International Journal of Qualitative Methods. *Verification strategies for establishing reliability and validity in qualitative research*, *1*.

Munhall, P. (2011). *Nursing research*. Florida: Jones & Bartlett Learning.
Nogeste, K. (2006). *Development of a method to improve the definition and alignment of intangible project outcomes with tangible project outputs*. Melbourne: RMIT University.
Oliver, C. (2011). Critical realist grounded theory: A new approach for social work research. *British Journal of Social Work*, bcr064.
Oliver, M. (1996). *Understanding disability: From theory to practice.* Basingstoke: Macmillan.
Payne, S. (2007). Grounded Theory. In E. Lyons and A. Coyle (Eds.). *Analysing qualitative data in psychology: A practical and comparative guide* (pp. 65–86). London: Sage publications.
Pilnick, A., Clegg, J., Murphy, E., & Almack, K. (2010). Questioning the answer: questioning style, choice and self-determination in interactions with young people with intellectual disabilities. *Sociology of Health & Illness*, *32*(3), 415-436.
Potter, J. (2003). Discourse analysis and discursive psychology. In P. M. Camic, J. E. Rhodes & L. Yardley (Eds.), *Qualitative Research in Psychology: Expanding perspective in methodology and design* (pp. 73-95). Washington, DC: American Psychological Association.
Putnam, H. (1999). *The threefold cord: Mind, body, and world* (No. 5). New York: Columbia University Press.
Richardson, A. (1989). Letting go: A mother's view. *Disability, Handicap & Society, 4*, 81-92.
Riege, A. M. (2003). Validity and reliability tests in case study research: A literature review with "hands on" applications for each research phase. *Qualitative Market Research: An International Journal,* 6(2), 75-86.
Robrecht, L. C. (1995). Grounded theory: Evolving methods. *Qualitative Health Research*, *5*(2), 169-177.
Rolph, S., Atkinson, D., Nind, M., & Welshman, J. (2005). *Witnesses to change: Families, learning difficulties and history.* Glasgow: British Institute of Learning Disabilities.
Rose, K. (1994). Unstructured and semi-structured interviewing. *Nurse Researcher*, *1*(3), 23-30.
Royal college of psychiatrists. (2010). *Psychiatric services for children and adolescents with intellectual disabilities.* College report CR163. Author.
Ruble, D. N. (1994). A phase model of transitions: Cognitive and motivational consequences. *Advances in Experimental Social Psychology*, *26*, 163-214.
Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society*, *23*(3), 199-210.
Saloviita, T., Italinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double ABCX model. *Journal of Intellectual Disability Research, 47*, 300–312.
Sayer, A. (2004). Foreword: Why critical realism? In Fleetwood, S., & Ackroyd, S. (Eds.), *Critical realist applications in organisation and management studies*. London: Routledge.
Schalock, R. L., Verdugo, M. A., & Gomez, L. E. (2011). Evidence-based practices in the field of intellectual and developmental disabilities: An international consensus approach. *Evaluation and Program Planning*, *34*(3), 273-282.
Schlossberg, N. K. (1981). A model for analysing human adaptation to transition. *The Counseling Psychologist*, *9*(2), 2-18.

Schreiber, R. S., & Stern, P. N. (2001). *Using grounded theory in nursing*. New York: Springer Publishing Company.
Scott, D. (2005). Critical realism and empirical research methods in education. *Journal of Philosophy of Education*, *39*(4), 633-646.
Settersten, R. A., & Ray, B. (2010). What's going on with young people today? The long and twisting path to adulthood. *The future of children*, *20*(1), 19-41.
Shapiro, A. (2003). *No time for us: Relationships between parents who have a disabled child. A survey of over 2000 parents in the UK*. Contact a family: London.
Silverman, D. (2006). *Interpreting qualitative data: Methods for analyzing talk, text and interaction*. London: Sage publications.
Sims-Schouten, W., Riley, S. C., & Willig, C. (2007). Critical realism in discourse analysis: A presentation of a systematic method of analysis using women's talk of motherhood, childcare and female employment as an example. *Theory & Psychology*, *17*(1), 101-124.
Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to methods.* London: Sage publications.
Stewart, D., Freeman, M., Law, M., Healy, H., Burke-Gaffney, J., Forhan, M., Young, N., Guenther, S. (2010). Transition to adulthood for youth with disabilities: Evidence from the literature. In J.H Stone, M.Blouin (Eds.). *International Encyclopedia of Rehabilitation*. Retrieved January 4, 2015, from http://cirrie.buffalo.edu/encyclopedia/en/article/110/
Stiles, J. (2003). A philosophical justification for a realist approach to strategic alliance research. *Qualitative Market Research: An International Journal, 6*(4), 263-71.
Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed)*.* London, England: Sage Publications.
Tarleton, B., & Ward, L. (2005). Changes and choices: Finding out what young people with learning disabilities, the parents and supporters need at transition. *British Journal of Learning Disabilities, 33,* 70-76.
Taylor, S. R., & Lobel, M. (1989). Social comparison activity under threat: Downward evaluation and upward contacts. *Psychological Review, 96*, 569-575.
Taylor, G. H., Todman, J., & Broomfield, N. M. (2011). Post-stroke emotional adjustment: A modified social cognitive transition model. *Neuropsychological Rehabilitation*, *21*(6), 808-824.
Thomas, R., & Purdon, S. (1994). *Telephone methods for social surveys. Social research update issue 8*. Retrieved June 20, 2014 from www.soc.surrey.ac.uk/sru/SRU8.html.
Thompson, A. R., & Harper, D. (2012). Introduction. In D. Harper, & A.R. Thompson (Eds.). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners.* West Sussex, England: Wiley-Blackwell.
Todd, S., & Shearn, J. (1996). Struggles with time: The careers of parents with adult sons and daughters with learning disabilities. *Disability and Society, 11*(3), 379-401*.*
Tracey, D. K. (2002). Self-concepts *of preadolescents with mild intellectual disability: Multidimensionality, measurement and support for the Big-Fish-*

Little-Pond-Effect. Unpublished PhD Thesis, University of Western Sydney, Australia.
Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J. A., & Walsh, S. (1997). Standards for research projects and theses involving qualitative methods: Suggested guidelines for trainees and courses. *Clinical Psychology Forum*, *108*, 3–7.
Tweed, A. & Charmaz, K. (2012). Grounded theory methods for mental health practitioners. In D. Harper, & A. R. Thompson (Eds.). *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners.* Oxford, England: Wiley-Blackwell.
University of Nottingham (2010). *Code of Research Conduct and Ethics.* Retrieved September 10, 2014, from http://www.nottingham.ac.uk/fabs/rgs/documents/code-of-research-conduct-and-research-ethics-approved-january-2010.pdf
Van Hooren, R. H., Widdershoven, G. A. M., Van den Borne, H. W., & Curfs, L. M. G. (2002). Autonomy and intellectual disability: The case of prevention of obesity in Prader–Willi syndrome. *Journal of Intellectual Disability Research*, *46*(7), 560-568.
Walsh, F. (2006). *Strengthening family resilience*. New York: The Guilford Press.
Wertheimer, A. (1981). *Living for the present: Older parents with a mentally handicapped person living at home*. London: Campaign for People with Handicaps.
Widdershoven G., & Sohl C. (1999). Interpretation, action, and communication: Four stories about a supported employment program. In T. A. Abma *Telling Tales: On Evaluation and Narrative* (pp. 109-30). Stamford: JAI Press.
Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method.* Berkshire, England: Open University Press.
Willig, C. (2008). *Introducing Qualitative Research Methods in Psychology.* Maidenhead: Open University Press.
Yardley, L. (2008). Demonstrating validity in qualitative psychology. *Qualitative psychology: A practical guide to research methods*, *2*, 235-251.

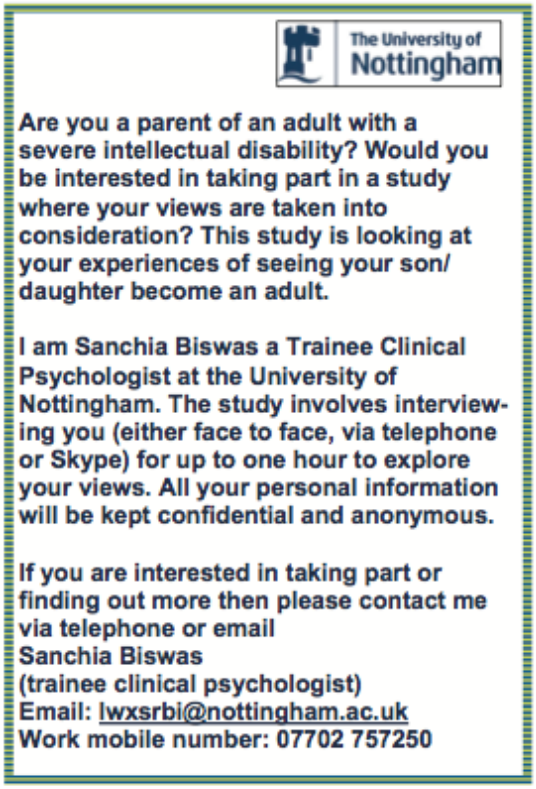
Appendices

Appendix A: Definition of a severe intellectual disability

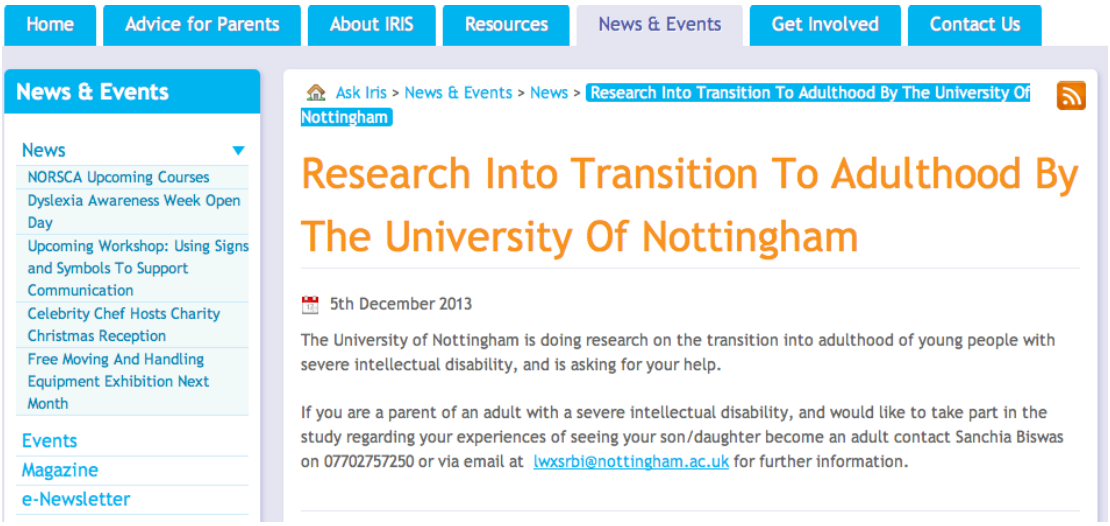
The British Psychological Society (BPS, 2000) defines a "severe intellectual disability" as having severe impairments of intellectual and adaptive/social functioning. Severe intellectual impairment requires the individual to have an IQ below 55; severe impairments in adaptive/social functioning; requires the individual to have extensive and/or pervasive support in performing daily living tasks such as eating, communicating and personal hygiene, in some or all environments (BPS, 2000).

Appendix B: Study advertisement for Mencap and IRIS project

Mencap Newsletter November 2013



IRIS Project Website (December 2013)



Appendix C:1 – Email confirmation for study advertisement from Mencap (Leeds)

study

Andrea Brough [andrea.brough@leedsmencap.org.uk]
Sent: Wednesday, February 20, 2013 10:11 AM
To: Biswas Sanchia

Hi Sanchia
I am the Family Support Coordinator here at Leeds mencap and Cath has passed on you details to me. Very recently I have just started to work with a student from the Leeds University who is coincidentally researching on the same subject, she has visited the families and set up interviews. we do have another project where they maybe some scope for approaching some of those parents if you want to send a poster/info sheet that I could pass on to the group leader giving some details of study etc. and your requirements.

Hope this of help to you

Kind Regards

Andrea

(N.B. The Leeds University student conducted a phenomenological study of parent experiences of the transition into adulthood for their child with profound and multiple learning disabilities).

Appendix C:2: Brief email to Mencap (Leeds) staff members.

I-WHO,

University of Nottingham,

YANG Fujia Building,

Jubilee Campus,

Wollaton Road,

Nottingham,

NG8 1BB.

Dear [name]

Thank you for supporting the recruitment component of my research project. I am now looking for participants. This is open to parents (male or female) who have experienced the transition into adulthood of their child with a severe intellectual disability. The parents must be able to read, write and speak English. Please provide the attached study advertisement to anyone meeting these criteria.

Kind Regards,
Sanchia Biswas (trainee clinical psychologist)
Email: lwxsrbi@nottingham.ac.uk
Work mobile number: [to be confirmed]

Appendix D: Personal details form.

I-WHO,
University of Nottingham,
YANG Fujia Building,
Jubilee Campus, Wollaton Road,
Nottingham,
NG8 1BB.

Personal details form.

[Participant ID number]

Thank you for taking part in the interview today. Before we begin, please could you complete the following details about your and your child with a severe intellectual disability:

Details about you:

Name -

Relationship to your child -

Date of birth -

Ethnicity -

Are you the sole carer for your child – yes/no *(please circle)*

Details about your child with a severe intellectual disability:

Gender -

Date of birth -

Additional physical or sensory disabilities -

Need for physical care – yes/no *(please circle)*

Number of siblings -

Number of siblings with a disability -

Accessing any support system e.g. adult care or school/college – yes/no *(please circle)*

Appendix E: Ethics approval documents

Ethics approval confirmation letter

Direct line/e-mail
+44 (0) 115 8232561
Louise.Sabir@nottingham.ac.uk

Faculty of Medicine and Health Sciences

Research Ethics Committee
Division of Respiratory Medicine
D Floor, South Block
Queen's Medical Centre
Nottingham University Hospitals
Nottingham
NG7 2UH

18th October 2013

Sanchia Biswas
Doctorate in Clinical Psychology Student
c/o Dr Anna Tickle
Division of Psychiatry and Applied Psychology
YANG Fujia Building
University of Nottingham Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

Dear Sanchia

Ethics Reference No: L10102013 SoM Psychiat & App Psychol - please always quote.
Study Title: How do parents make adjustments when they perceive their child with a severe intellectual disability transition into adulthood?
Academic Supervisors: Dr Anna Tickle, Academic Tutor, Doctorate in Clinical Psychology, Division of Psychiatry & Applied Psychology, School of Medicine, Dr Nima Moghaddam, Research Fellow, Dr Kathryn Almack Senior Research Fellow, School of Health Sciences
Student Investigator: Sanchia Biswas, Doctorate in Clinical Psychology.
Duration of Study: 09/13-09/14 12mths **No of Subjects:** 20

Thank you for your recent application which was considered by the Committee at its meeting on 10th October 2013 and the following documents were received:

1. UoN FMHS Med Sch Research Ethics Application form dated 16/09/13.
2. Parent adjustments and perceptions: Research Proposal, final version 1.0, Date 20.09.13.
3. Parent adjustments and perceptions: Appendix A-Definition of a severe intellectual disability final version 1.0, Date: 20.09.13.
4. Parent adjustments and perceptions: Appendix B – Emails from Mencap (Kirkless, Leeds) and MIND dated 20.2.13 and 13.2.13.
5. Parent adjustments and perceptions: Appendix C:1 – Brief Study advertisement, final version 1.0, Date: 20.09.13.
6. Parent adjustments and perceptions: Appendix C:2–Brief email to charity staff members, final version 1.0, Date: 20.09.13.
7. Parent adjustments and perceptions: Appendix D – Personal details form, final version 1.0, Date: 20.09.13.
8. Parent adjustments and perceptions: Appendix E-Example interview schedule, final version 1.0, Date: 20.09.13.
9. Parent adjustments and perceptions: Appendix F- Confidentiality agreement for third party transcribers, final version 1.0, Date: 20.09.13.
10. Parent adjustments and perceptions: Appendix G-Participant Information Sheet version 1.0, Date 20.09.13
11. Parent adjustments and perceptions: Appendix H-Flow diagram of study procedure, Final version 1.0, Date: 20.09.13.
12. Parent adjustments and perceptions: Appendix I-Email/postal letter to participants regarding interview details, final version 1.0, Date: 20.09.13.
13. Parent adjustments and perceptions: Appendix J-Consent Form, final version 1.0, Date: 20.09.13.
14. Parent adjustments and perceptions: Appendix K –Evaluation Criteria final version 1.0, Date: 20.09.13.

These have been reviewed and are satisfactory and the study is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).

2. You must notify the Chair of any serious or unexpected event.

3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Dr Clodagh Dugdale
Chair, Nottingham University Medical School Research Ethics Committee

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Ethical approval of amendment to transcription service agreement contract confirmation email

RE: Ethics application ref L10102013 SoM Psychiat & App Psychol approval letter

Sabir Louise

Sent: Tuesday, August 19, 2014 5:04 PM
To: Biswas Sanchia

Dear Sanchia

Thank you for submitting your revised transcribing service contract which is a minor administrative change and does not require full ethics committee review. This has been reviewed and approved.

With best wishes

Louise

Ethical approval of amendment to consent form

Direct line/e-mail
+44 (0) 115 8232561
Louise.Sabir@nottingham.ac.uk

29th September 2014

Faculty of Medicine and Health Sciences

Research Ethics Committee
School of Medicine Education Centre
B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

Sanchia Biswas
Doctorate in Clinical Psychology Student
c/o Dr Anna Tickle
Division of Psychiatry and Applied Psychology
YANG Fujia Building
University of Nottingham Jubilee Campus
Nottingham
NG8 1BB

Dear Sanchia

Ethics Reference No: L10102013 SoM Psychiat & App Psychol - please always quote.
Study Title: How do parents make adjustments when they perceive their child with a severe intellectual disability transition into adulthood?
Academic Supervisors: Dr Anna Tickle, Academic Tutor, Doctorate in Clinical Psychology, Division of Psychiatry & Applied Psychology, School of Medicine, Dr Nima Moghaddam, Research Fellow, Dr Kathryn Almack Senior Research Fellow, School of Health Sciences
Student Investigator: Sanchia Biswas, Doctorate in Clinical Psychology.
Duration of Study: 09/13-11/14 14mths **No of Subjects:** 20

Thank you for your letter dated 24th September 2014 notifying the Committee of a minor correction to the Consent form and the following revised document was received:

- Parent adjustments and perceptions: Appendix J-Consent Form, final version 1.1, Date: 24.09.14

This has been reviewed and is satisfactory and the minor correction to your consent for is noted and approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).
2. You must notify the Chair of any serious or unexpected event.
3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.
4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Dr Clodagh Dugdale
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix F: Participant information sheet

I-WHO,
University of Nottingham,
YANG Fujia Building,
Jubilee Campus, Wollaton Road,
Nottingham,
NG8 1BB.

Participant Information Sheet

Title of Study: "How do parents make adjustments when they perceive that their child with a severe intellectual disability transitions into adulthood?"

Name of Researcher(s):

Sanchia Biswas (Trainee clinical psychologist)

Supervised by: Dr Anna Tickle (Clinical psychologist), Dr Nima Moghaddam (Clinical psychologist) and Dr Kathryn Almack (Senior research fellow).

Invitation to take part in a research study on the adjustments that parents make when they perceive that their child with a severe intellectual disability transitions into adulthood.

We would like to invite you to take part in our research study. Before you decide whether you would like to be involved, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

Thank you for reading this information sheet.

Why is this study important?

Mothers and fathers of individuals with a severe intellectual disability have a life long relationship with their son or daughter. This study aims to understand how you view your son or daughter since they became an adult. We also want to find out whether your lives changed when you saw your child become an adult, and if so, how you managed those changes. Gaining your views on this would hopefully provide valuable information to relevant services and other parents who may be sharing similar experiences.

Why me?

You may have responded to one of our advertisements via:

- a newsletter from Mencap or the British Institute of Learning Disabilities (BILD).
- a member of staff from a charitable organisation for individuals with intellectual disabilities.
- an online advert on MIND's facebook page.
- an online advert within 'The Choice Forum' within the Foundation for People with Learning Disabilities website.

We are looking for parents (biological parent/step-parent/foster parent or adoptive parent) of an adult with a severe intellectual disability. The term 'severe intellectual disability' refers to whether your child requires daily support in all of the following areas:

- to communicate with others (verbally or non verbally).
- to read and write.
- to eat and drink.
- to keep himself/herself clean, warm and clothed.
- to take care of personal hygiene.

As a mother or father, you are likely to have had first hand experience of your son or daughter becoming an adult. You will need to be able to talk about your experiences and read, write, and speak English.

Do I have to take part?

No, participation in this study is entirely voluntary. If you would like to take part, you will be given this information sheet to keep and be asked to sign a consent form to say that you have agreed to take part. If you decide to take part, you are still free to change your mind at any time without giving a reason.

What will happen if I take part?

Stage 1

If you agree to take part, please contact Sanchia Biswas (Trainee clinical psychologist) via email or telephone to show your interest in the study.

Stage 2

Sanchia will ask you to attend an individual interview (either face-to-face, via telephone or Skype depending upon your preference). The interview will last up to one hour. You do not need to prepare anything for the interview.

Stage 3

Before the interview begins, you will be asked to complete a consent form. This will ask you for your consent to take part in the study and for the recorded interview to be used in our study. You will also be asked whether the researcher can keep your contact details if you indicate that you would like a copy of the study findings summary upon completion of the research study in September 2015. You will also be asked to complete a 'personal details form', which will ask for some personal information about you and your child with a severe intellectual disability. This will include details such as name, date of birth and ethnicity. If you prefer to be interviewed via telephone or Skype then the consent form and 'personal details form' can be sent to you via email or post prior to the interview date.

During the interview, you are free to refuse to answer any questions without giving an explanation and leave or terminate the interview if and when you please.

Will my interview be recorded?

Face-to-face interviews will be audio recorded using a digital device. Telephone or Skype interviews will be audio-recorded using microphone adaptors. You are free to ask to stop the recorder at any time if you wish. You will be able to ask questions related to the study before and after the interview. This will not be recorded.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice. Everything you say during the interview will be strictly confidential. The only exception to this would be if you disclose information about criminal activity or harm to yourself or others. In this case, the information would be shared with the appropriate safeguarding agencies. The audio recording will be listened to and transcribed by Sanchia. However, due to possible time constraints, Sanchia may need to use a third party transcriber from a transcription service. In this case, the third party transcriber will be asked to sign a confidentiality agreement to ensure that they agree to maintain full confidentiality of all audio-recordings.

During the transcription process, all identifiable information will be anonymised to maintain confidentiality and your anonymity. The transcripts will be stored securely and will only be shared with Sanchia's research supervisors. On request, you can have a copy of your interview transcription sent to you. Your personal data (name and contact details) will be kept until September 2015 after the end of the study so that we are able to contact you about the findings of the study unless you indicate at the consent stage that you do not want a copy of the findings. All other data will be kept securely for seven years within the University of Nottingham. After this time your data will be disposed of securely.

Are there any benefits for taking part?

Yes, as a result of your participation in this study, you will be entered into a prize draw for your chance to win one of three prizes as follows:

First prize - £50 amazon voucher
Second prize - £30 amazon voucher
Third prize - £20 amazon voucher

We will contact the winners after all participants have been interviewed.

What are the possible disadvantages and risks of taking part?

Being part of this research will involve your time to take part in an interview. Some of the questions asked may be personal to you and sometimes people can find it upsetting to talk about. You do not have to talk about anything that you don't want to and the interview process is designed to be sensitive to your feelings and concerns. You will be reminded that you can terminate the interview at any time you want. In the unlikely event that you experience strong distress, we will be able to advise you. You may also consider speaking to your GP for further support.

What are the possible benefits of taking part?

This is an area of the learning disabilities field that has yet to be explored. Therefore the information that you provide at the interview will be valuable in helping us to understand what it is like for you when your child with a severe intellectual disability becomes and adult and how you cope with any changes in your life.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to Sanchia who will do her best to answer your questions. Sanchia's contact details are given at the end of this information sheet.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason. If you withdraw during the interview, you will be asked whether the information you have provided us with so far can be used in the study. You may also contact Sanchia via telephone or email within three days after completing the interview if you decide to withdraw your data from the study.

What will happen to the results of the research study?

The results of the study will be written up into a report that will be assessed by The University of Nottingham in January 2015 as part of the Trent Doctorate in Clinical Psychology (DClinPsy). The results will also be presented to the department of Clinical Psychology at Institute of Work, Health and Organisations, University of Nottingham. The research will be submitted for publication in a journal. You will not be identified in any presentation of the data. If you would like a summary of the study findings, please indicate this on the consent form and you will be sent a copy via email or post in September 2015.

Thank you for reading this information sheet. If you would like to take part in this study please contact Sanchia Biswas via the email address or telephone number provided at the end of the information sheet. In your email, please state the following:

- Whether you prefer to attend an interview face-to-face, via telephone or Skype.

- Days and times that are convenient for you to attend an interview.

Face to Face Interview locations:

Nottingham: I-WHO, University of Nottingham, YANG Fujia Building, Jubilee Campus, Wollaton Road, Nottingham, NG8 1BB.

Lincoln: Bridge House**,** University of Lincoln, Lincoln. LN6 7TS

West Yorkshire: To be confirmed.

Contact details:

Sanchia Biswas (trainee clinical psychologist)
Work mobile number: [07702757250].
Email address: lwxsrbi@nottingham.ac.uk

Appendix G: Consent form

I-WHO,
University of Nottingham,
YANG Fujia Building,
Jubilee Campus, Wollaton Road,
Nottingham,
NG8 1BB.

CONSENT FORM

Title of Study: "How do parents make adjustments when they perceive that their child with a severe intellectual disability transitions into adulthood?".

Name of Researcher: Sanchia Biswas

REC ref: L10102013 SoM Psychiat & App Psychol

Name of Participant:

Date:

Please initial statements below to indicate that you have read them and agree:

1.	I confirm that I have read and understood the information sheet dated [date] for the above study and have had the opportunity to ask questions.	XX
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	XX
3.	I give permission for the researcher and research supervisors to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.	XX
4.	I understand that the interview will be recorded and that a transcribing service may be used to transcribe the recording. I understand that anonymous direct quotes from the interview may be used in the study reports/publications.	XX
5.	I understand that after the interview is complete, I am free to withdraw my data within the next three days, without giving any reason.	XX

6. I understand that information about me recorded during the study will be kept securely within the University of Nottingham. I understand that if the data is transferred is will be made anonymous. Data will be kept for 7 years after the study has ended. XX

7. I agree to take part in the above study. XX

8. I would like to be sent a copy of the summary of findings when it is completed. I therefore give permission for the researcher to keep my contact details on record until November 2015. XX

9. I would like to be sent a copy of this consent form. XX

If you would like a copy of this consent form and/or a copy of the summary of findings, please provide an email address or postal address in the box below:

Name of participant:
Signature:
Date:

Name of researcher: Sanchia Biswas (Trainee Clinical Psychologist)
Signature:
Date:

Appendix H: Confidentiality agreement for transcribers

APPENDIX G: CONFIDENTIALITY AGREEMENT FOR TRANSCRIBERS

The University of Nottingham

UNIVERSITY OF LINCOLN

Trent Doctorate in Clinical Psychology

I, HELEN SMITH, transcriber, agree to maintain full confidentiality in regards to any and all audiotapes/audio-files and documentation received from Sanchia Biswas related to her doctoral study on how parents make adjustments for the transition into adulthood of their child with a severe intellectual disability. Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents;
2. To not make copies of any audiotapes/audio-files or computerized files of the transcribed interview texts, unless specifically requested to do so by Sanchia Biswas;
3. To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession;
4. To return all audiotapes/audio-files and study-related documents to Sanchia Biswas in a complete and timely manner.
5. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

Transcriber's name (printed) HELEN SMITH

Transcriber's signature [signature]

Date 8/8/2014

Appendix I: Initial interview schedule

Interview schedule 1

Definition of 'adulthood'

1. What is your understanding of the term 'adulthood'?

Prompts
- What does 'adulthood' mean to you?
- When you hear the term 'adulthood', what comes to mind?
- Are there any physical (social/personality/legal) markers? If so, what are they? Are there any other markers?
- *Encourage ppt to describe any images/values/factors that might define adulthood*

NB: If ppt struggles to define adulthood:
- *How did you know when you became an adult?*
- *What changes (if any) did you notice?*
- *Were there any markers for you?*

Adulthood and their child

2. What did the idea of your child becoming an adult mean for you?

Prompts
- When your son/daughter was a child, did you think about what he/she would be like as an adult? If so, what did you envisage/what did you imagine adult life would be like for your child?
- What had you been told to expect by others, if anything?
- Did you have any preconceptions about when your son/daughter would reach 'adulthood'?
- Thinking bout your child now, how did you know that he/she became an adult? What changes happened? (physical/social/relationships with others etc) Was there a pivotal point?
- Were you surprised by these changes or were you prepared for them?
- Were these changes in line with what you had imagined/envisioned? If so, how? What was different?
- Do you always perceive your son/daughter as an adult or are there times where you still see him/her as a child? If so, please could you give an example of when they are an 'adult' and when they are a 'child'?

NB: if ppt says for e.g. "I still see my son/daughter as a child" or "adulthood didn't mean much to me":
- *Query about a significant other's perception? E.g. "how might [sig other] perceive your child – do you think they would see them as a child/adult too?" etc.*
- *How will you know when your child becomes an adult? Would there be any changes?*

- *What do you imagine adult life would be like for your child? What would be different to how things are now? What would be the same?*

Transition and parental adjustments

3. How did your child's transition into adulthood affect you?

Prompts
- Did your child's transition into adulthood affect you practically i.e. in terms of the things you needed to do?
- Did your child's transition affect you emotionally? Socially? Physically?
- Was the transition easy/difficult for you? In what way?
- What was your role as a parent to your child like before you perceived him/her transition into adulthood?
- Were there any changes in your role as a parent post transition? If so, what were they? How did you know the changes had happened? Were there any other role-shifts that you had to make?
- What was your relationship like with your child before you perceived him/her to have transitioned into adulthood?
- Were there any changes in your relationship with your child post transition? If so, what were they? How did you know the changes had happened?
- Were there any adjustments that you made in your relationship with others (e.g. family, friends, services etc)?
- Were there any other adjustments that you made in light of this transition?
- Did you plan for any adjustments/changes?
- Did the adjustments match your expectations (if you had any)?
- How did you cope with the adjustments in your life?

NB: If ppts struggle to answer questions, could ask them to give an example of a 'good' and 'bad' day pre transition and post transition to identify any similarities/differences in their roles/relationships.

Also, if ppt says "transition did not affect me…":
- *Did this fit with your expectations? In what way?*
- *Were there any aspects of the transition that you found particularly easy/difficult to manage?*

Parent perception of child

4. Were there any changes in the way you viewed your child once they had become an adult?

Prompts
- Could you describe your son/daughter to me i.e. tell me what he/she is like now?
- Could you describe your son/daughter before you perceived them as an adult? Is he/she the same? What is different?
- Did you anticipate these changes?

- Were there any changes in your relationship with your child? What were they? Did you anticipate these changes? How did you know that these changes had happened?
- Were there any changes in the relationships that your child had with others? E.g. family members, services, friends etc?

NB: If ppt says "there were no changes…":

- *Did you expect any changes? If so, what were they?*
- *Were there any changes in the relationships your child had with others?*

<u>General prompts</u>

- Please tell me more about what you're thinking
- Please can you say more about that?
- Please could you give an example if possible?
- Was that easy or difficult to answer?

Appendix J: Final interview schedule

Interview schedule 4

To explore connection between 'time', concept of adulthood and barriers

- When did you start thinking about what your child's adult life would look like?
- Tell me about some of the barriers (or challenges) you experienced when your child entered adulthood, if any.
- Were these expected or found out along the way?

To explore proactive/reactive coping strategies

- How did you manage these barriers?
- Expected therefore planned? Expected and didn't happen? Or found out as it happened and reacted straight away? Etc

To explore connection between barriers, expectations of what adulthood is and worry

- Thinking about these barriers and how you managed them, would you say there was some sort of connection between them? If so, in what way? (worry?)
- Some parents spoke about the changes that they made when their child became an adult. Some of these changes related to XYZ. Would you say that the changes you made when your child became an adult was a way to move closer to the societal 'norms' of adulthood? If so why? If not, why not?

To explore connection between barriers, norms and worries (if talks about not meeting norms)

- When parents talked about the changes that they noticed when their child became an adult, they often described changes that were in line with normative lifecycles e.g. "seeing more independent behaviours". What was it like for you to see your child as not meeting the norms or expectations of adulthood?

To explore worry and its relationship with 'time'

- When thinking about your child and his/her adulthood, when did you start to worry about it?
- When were the worries about his/her adulthood heightened and when were they less so?
- Was worry about adulthood ongoing? Or occasional?

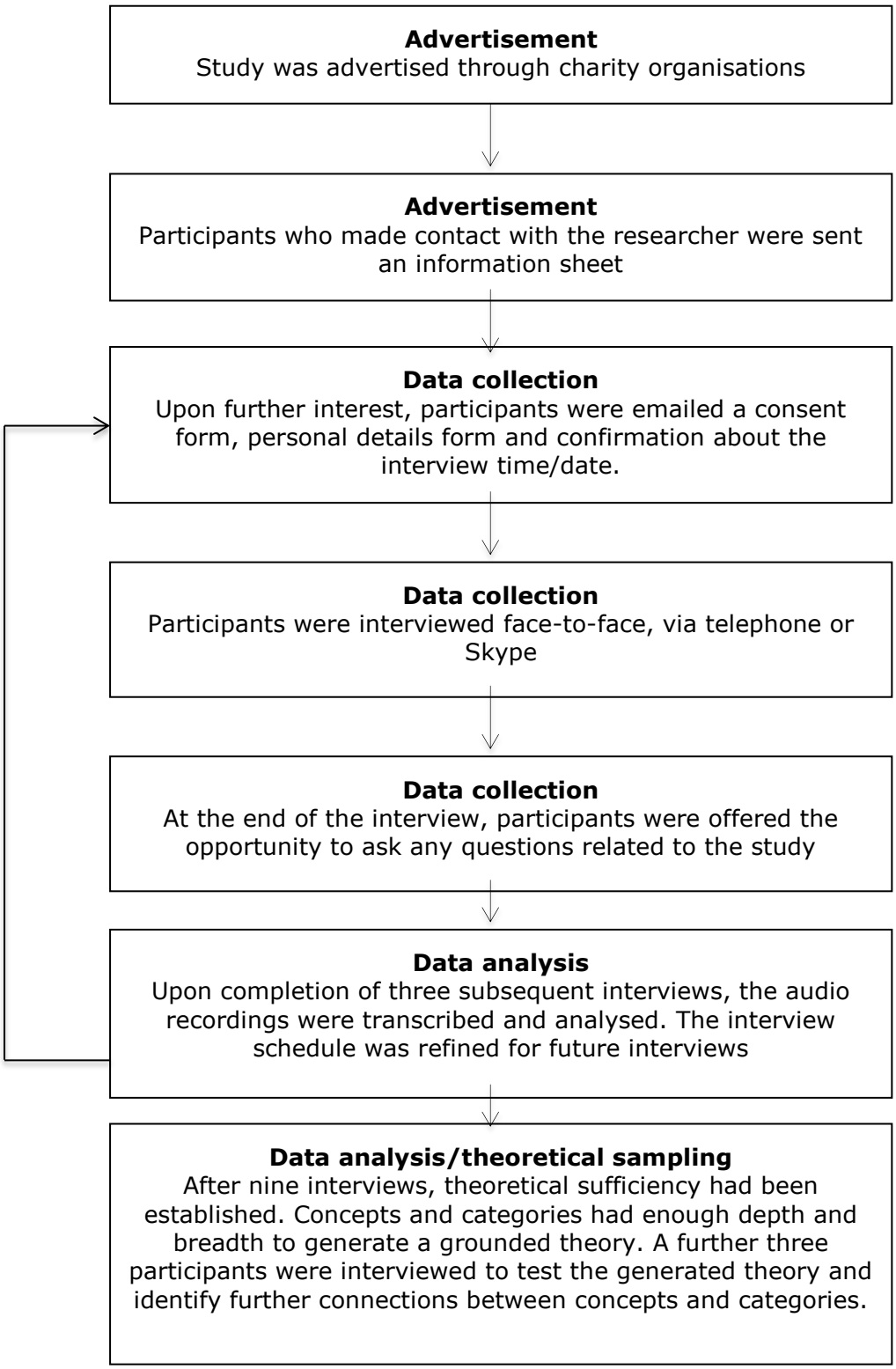
Exploring sexuality development and 'time'

- Did you notice your child's sexuality develop? If so, when did you notice it? If not, what are your thoughts about sexuality development in ID? When would you expect it to occur?
- Some parents were not sure how to respond to their child's sexuality developing, do you relate with this? If not, why not?
- What dilemmas did you face? (if didn't face any then ask what dilemmas do you think other parents face?) When?

To find out more about views on service support for the transition into adulthood (if accessed services only)

- Tell me about your experiences of services when your child entered adulthood? Helpful or not helpful? Why were they helpful/not helpful?
- What would you have liked to be different/what more would you have liked?
- If didn't access services then did they think about it?

Appendix K: Study process



Appendix L: Email to participants regarding interview details.

I-WHO,
University of Nottingham,
YANG Fujia Building,
Jubilee Campus, Wollaton Road,
Nottingham,
NG8 1BB.

Dear [participant name],

Thank you for your interest in this research project. I have provided the details of the interview below:

Date: [date]

Time: [time]

Venue: [location]

You are not required to prepare anything for this interview.

If you are unable to attend, please contact me with your concerns so that we can arrange an alternative meeting that is convenient for you.

I look forward to meeting with you.

Kind Regards,
Sanchia Biswas
Email: lwxsrbi@nottingham.ac.uk
Work mobile number: 07702757250.

(N.B. 'Venue' will not be applicable for participants who prefer to be interviewed via telephone or Skype)

Appendix M: Transcript excerpt with open codes (Transcript 4)

Transcript	Open codes
R: Thinking about your son, how did you know that he had become an adult?	Realisation of adulthood last November.
P: I only realised last November that he had become an adult.	
R: And what was it that helped you to realise that he had become an adult?	Son is at specialist residential college.
P: My son is at a special residential college	
R: Right	First Christmas at home since starting college was hell.
P: And I went last November for his review, and we discussed his progress. He has a 52 week placement at this college. The very first Christmas that he was there, his 3rd year at the college, and his very first Christmas that he was there he came home. It was 8 days and 7 nights of hell because he didn't want to be here, and I still treated him as a child. Last November I went to the review meeting again, we discussed his educational progress	He didn't want to be at home. Still treated him like a child at home during his first Christmas since starting college.

and his progress. He doesn't live at the college, he lives in a house in a village close to the college, which is shared with 3 other lads and it's residential so it's staffed adequately.	Lives in a house shared with 3 other lads. Residential house is staffed adequately.
R: Ok so at that point you treated him like a child because you viewed him as one?	
P: Yes, and we discussed his progress on the computer. They were talking about how he had come on with regards to clicking on a cross and closing the program down, which is massive, sounds probably quite small to you but that's massive.	He is now able to close a computer program down. Sounds small but that's massive.
R: No it seems as though it was a big moment for you and could you elaborate on that possibly?	He was never able to use a computer before college.
P: Well, he was never able to use a computer before college, we had one at home but he never knew how to use it and I tried to, at times show him how to turn it on and off but he never seemed to understand but I knew he loved playing on it. But going to this college,	He never knew how to use it. Tried to show him how to turn it on and off but he never understood.

staff have trained him well and he has made the changes that I wanted to help him to do but didn't. So it was a massive change for me because he was an adult and finally making decisions and showing that he wanted to do something rather than just doing it because he is told or whatever.	Staff have trained him well. Staff have made changes that I wanted to help him do but didn't. Massive change for me. He was an adult. He was finally making decisions. He wanted to do something rather than being told to do it.
R: Ok, and how did it feel for you because it sounds like you had wanted to help improve his abilities but actually you had noticed improvements since he had been at college.	
P: I felt really proud, I wasn't envious or resent staff at all. His progress on the computer showed increased maturity really.	

R: Please could you tell me more about what increased maturity is like? *P: Well, before, whilst he had never been obsessed by the computer, he loved being on the computer because he is in control and has done for a number of years. So he has actually matured enough to learn that he could go back to the computer was a massive thing during this discussion of the review process. And I had said, 'you really need to include this in the report, this is really you know, this is real progress'. This is why he was here, to improve his I.T skills and communication skills. When we left, we then went on to discuss his personal care and care issues because of the house and what support he needs. He needs full support, he needs personal care with dressing and everything. I went to sign out at the college, and when I was signing out, I looked across to this classroom, and my son was just inside the doorway and he was working on the computer. But, I mean, it's it sounds really bizarre but he was sitting there and he was focused on what he*	I felt proud. Wasn't envious or resent staff at all. Progress on the computer showed increased maturity.Was never obsessed with the computer but loved it. He is in control. Maturity=being able to learn Attended college to improve his I.T skills and communication skills. Needs full support. Needs personal care with dressing.

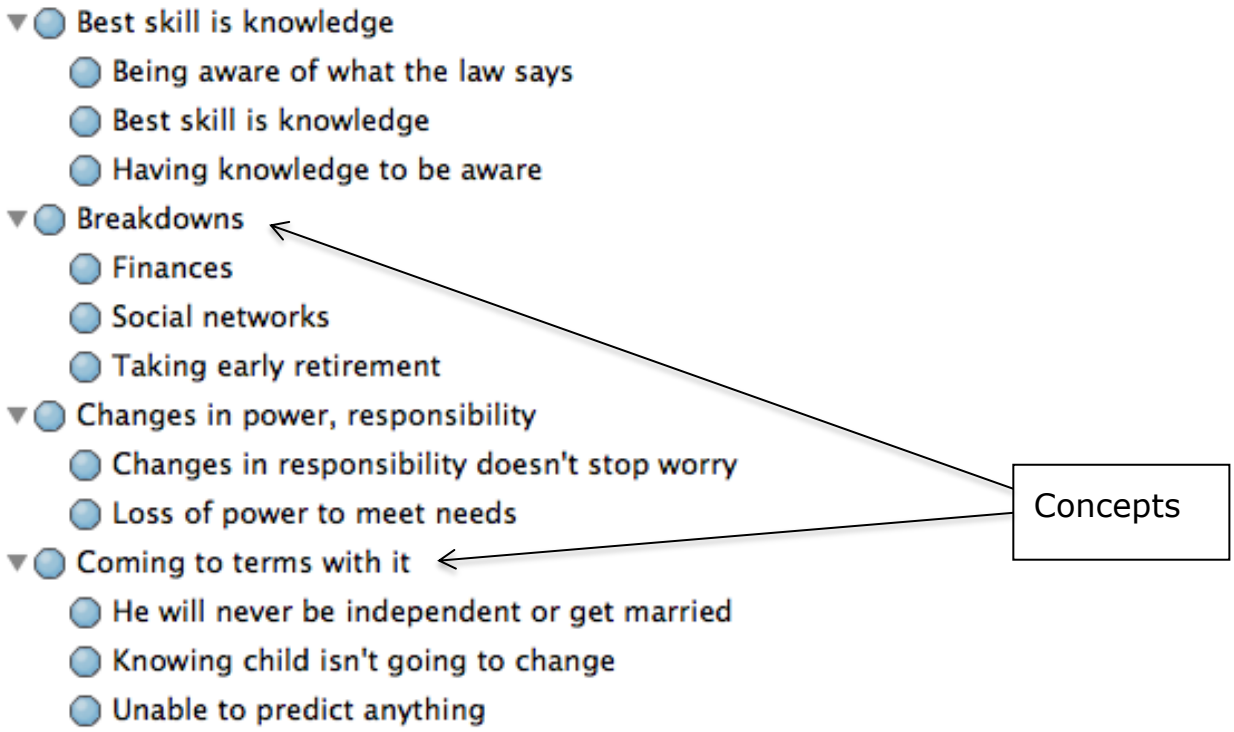
was doing, he wasn't vocalising or trying to distract his classmates, he had got supervision because obviously there was staff in the class but he wasn't having 1:1, he was sitting up straight in his wheelchair and if, it sounds ridiculous, but if I'd have been say in a block of offices and I had seen my son sitting there, he just looked like he was a young man at work, and that was the whole point. He was a young man at work, and that's when it really hit me last November that he is actually an adult now. In some ways he is not but that was the thing, he was, he was focused, he was concentrating and he would not have been out of place in any workplace, he looks the part if you understand what I'm saying you know, sounds bizarre but. R: I understand what you're saying, it sounds like for you that last November was the actual pivotal point that you actually noticed your son was an adult, a young man and – P: *Yes it was*	He was focused. Wasn't vocalising or trying to distract his classmates. Wasn't having 1:1 Looking like a young man at work. It really hit me last November that he is an adult now. Adulthood=being able to focus and concentrate.

R: But you also said that he showed increased maturity. What does maturity mean for you? *P: Just being able to make those decisions for himself really, as much as he can. It was mature because it was an ability that I had never seen him do before. It was mature because when I looked at him, he really looked the part of a young man, he's grown physically in his appearance which probably helped but that's normal male development isn't it.* R: Ok and you also said that there are some ways he is not an adult, please could you tell me a bit more about this? *P: He obviously, he has a mental age of a child so some things he does like vocalising, shouting, making odd noises is quite child-like. Its hard, its difficult to see him as a proper*	Maturity=being able to make decisions, an ability that has not been seen before, looking like a young man, growing physically in appearance. Normal male development.

adult like me or you because of his disability.	Mental age of a child. Vocalising, shouting, making odd noises is child-like. Difficult to see him as a proper adult because of his disability.

Appendix N: Example of concepts formed by grouping open codes in NVivo

Example from Transcript 2



Appendix O: Example themes developed from Batch 1 concepts

Descriptive theme	Concepts
Acquiring knowledge to inform transition	• Best skill is knowledge • Gaining knowledge from friends • Gaining knowledge to know what to do • Knowing about abuse in care
Adulthood – Comparison to Non-LD/normative lifecycle	• Adulthood = taking responsibility • Having adult rights • Reflecting upon own experience of adulthood • Thinking about non-ID adulthood • Comparing birthday experience to 'normal' family • Normalising transition into adulthood • Physical changes – normative cycle
Anxieties associated with transition	• Fears of being excluded • Worries around being over-ruled by HCPs • Worries around post-school • Worries around what society think • Worries of transition influenced by social media • Worry of abuse
Defining adulthood	• Adulthood is 'turning 18' • 18th birthday symbolic of adulthood • Accessing 'over 18' things

Appendix P: Examples of descriptive categories

Making sense of adulthood

Conceptual

(i) Legal

- Having adult rights
- Accessing 'over 18' things
- Chronological dimension (e.g. turning 18 vs age doesn't matter)

(ii) Social

- Taking responsibility
- Social markers in general
- Being employed
- Doing 'age appropriate' things
- Symbols of adulthood e.g. celebrating 18th birthday
- Thinking about own experiences of adulthood (e.g., going to pubs, drinking)

Physical

- Physical changes to body

Sexuality development

- Noticing sexuality develop through different ways (behaviour, physical, conversation)
- Difficulties noticing sexuality develop
- Understanding sexuality development

Worries involved in transition

- Worries of being excluded
- Worries around being over-ruled by HCPs
- Worries around post-school
- Worries around what society think
- Worries of abuse/vulnerability
- Worries about the future
- Worries related to sexuality development

Parental adjustments and strategies

(i) For their child

- Encouraging autonomy
- Knowing or thinking about what their child likes
- Encouraging adulthood development

(ii) For themselves

- Taking an accepting stance
- Acquiring knowledge to inform transition
- Breakdowns
- Changes in parental role and identity
- Financial adjustments
- Social isolation
- Fighting with staff/services

(iii) Strategies to cope with adjustments

- Respite provides a break
- Support from family/sibling role models
- Support from non ID peers in transition into adulthood
- Support from services
- Support from similar others

(iv) Struggling to adjust

- Not wanting to let go (not adjusting)
- Staying involved (not adjusting)
- Staying involved in child's care

Perceived barriers to adulthood

(i)Parent

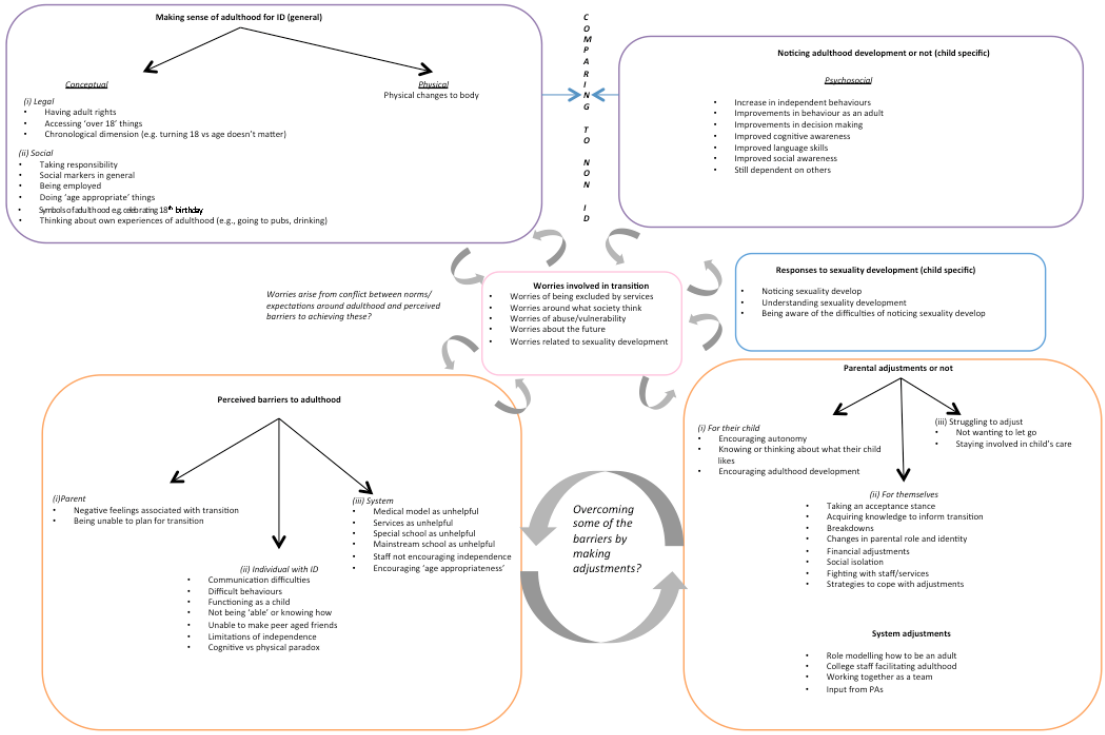
- Negative feelings associated with transition
- Being unable to plan for transition

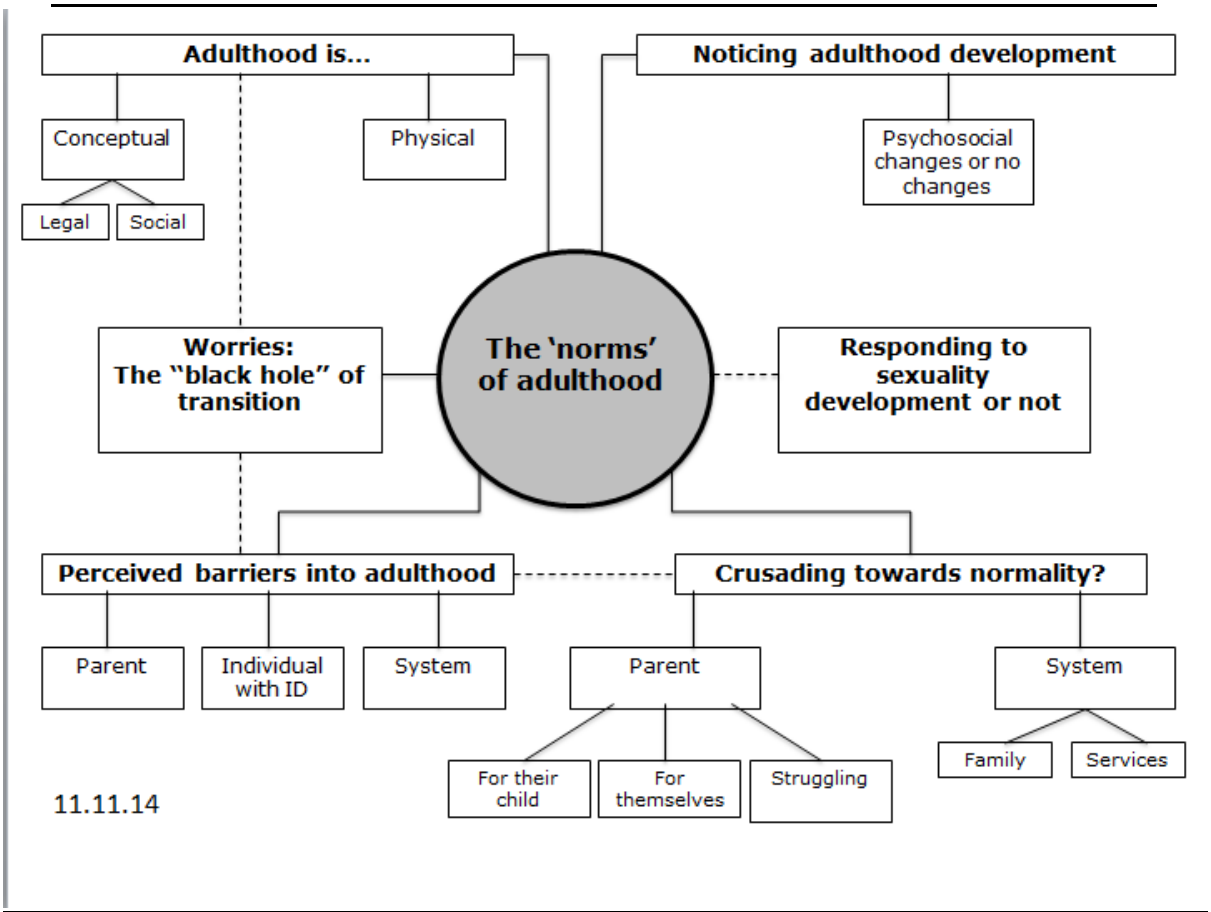
(ii)Individual with ID

- Difficult behaviours
- Communication difficulties
- Functioning as a child
- Not being 'able' or knowing how
- Unable to make peer aged friends
- Limitations of independence
- Cognitive vs physical paradox

Appendix Q: Theory development process

31.10.14





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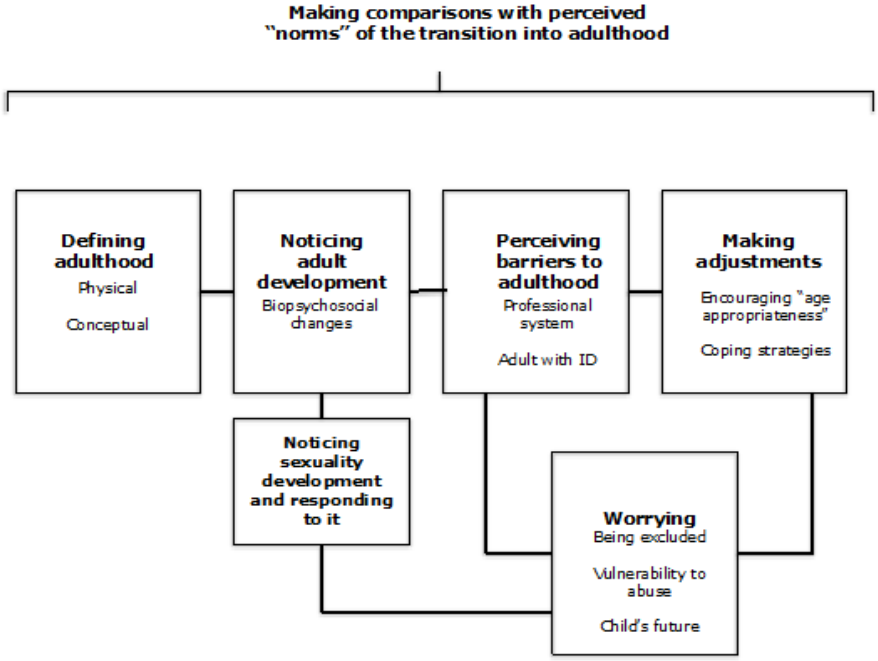
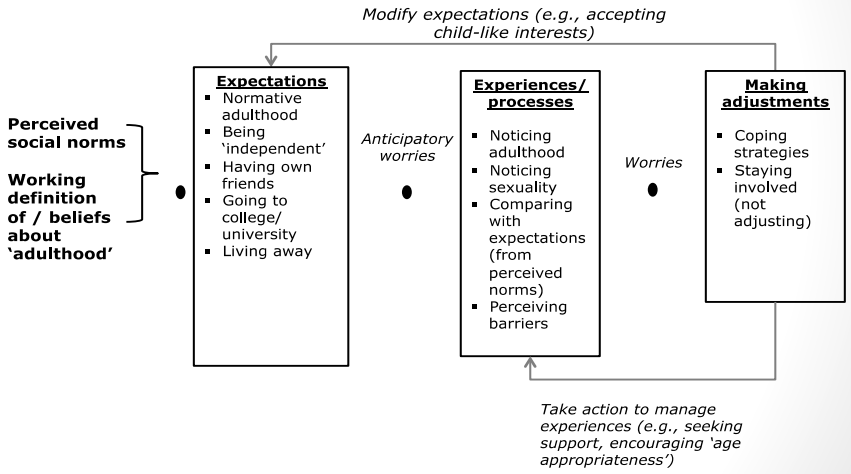


02.03.15



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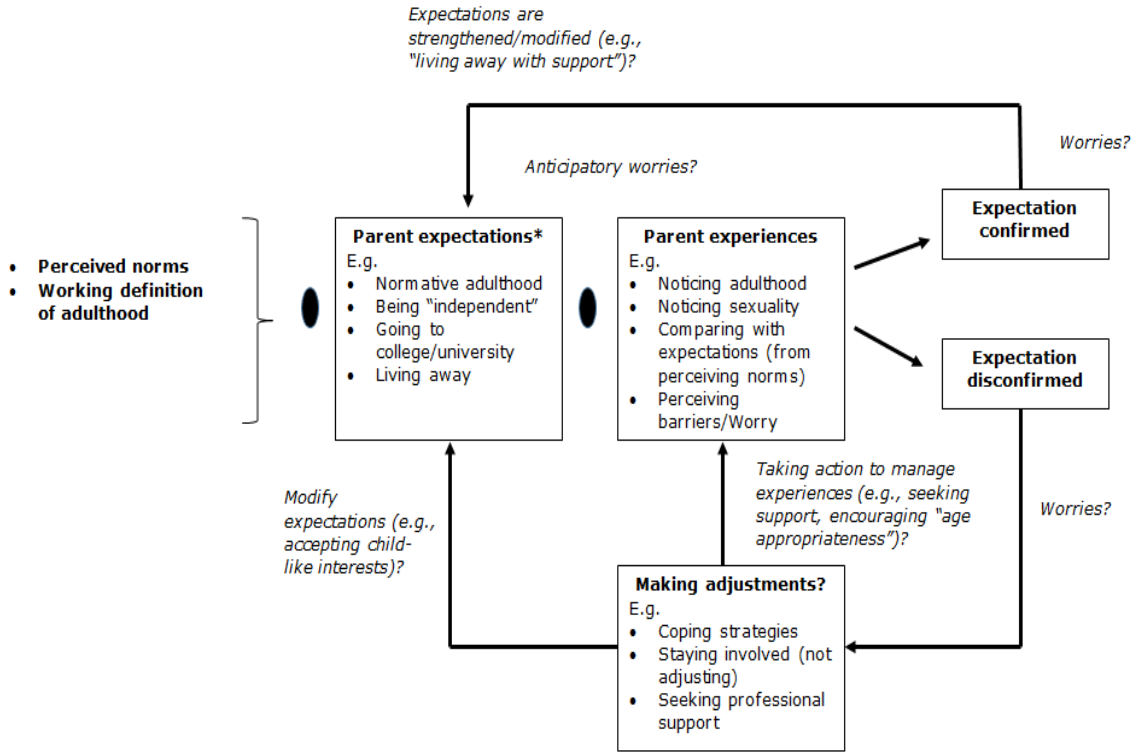
Expectations are strengthened/modified (e.g., "living away with support")?
Worries?
Anticipatory worries?
Perceived norms
Working definition of adulthood
Parent expectations*
E.g.
Normative adulthood
Being "independent"
Going to college/university
Living away
Parent experiences
E.g.
Noticing adulthood
Noticing sexuality
Comparing with expectations (from perceiving norms)
Perceiving barriers/Worry
Expectation confirmed
Expectation disconfirmed
Worries?
Taking action to manage experiences (e.g., seeking support, encouraging "age appropriateness")?
Modify expectations (e.g., accepting child-like interests)?
Making adjustments?
E.g.
Coping strategies
Staying involved (not adjusting)
Seeking professional support

Appendix R: Criteria for choosing a core category

(Adapted from Corbin & Strauss, 1990)

Criteria	Does the core category meet the criteria?
Is it central? Does it relate to all other major categories?	**Yes** – it relates to all other categories.
Does it appear frequently in the data? Within all/most cases, are there indicators pointing to that concept?	**Yes** – it was apparent in all interviews. Parents frequently reflected upon their own normative experiences or those of individuals without an intellectual disability.
Is the explanation logical and consistent?	**Yes** – it helps to understand differences in parents' definition of "adulthood" and the type of adjustments made.
Is the name/phrase used to describe the core category abstract enough? Can it be used to do research in other areas to lead to a more general theory?	**Yes** – Making comparisons to others is a common process that can be applied to other areas to understand other phenomena.
Does it have explanatory power?	**Yes** – It underpins all of the processes that parents engage in. It also helps to explain how parents define "adulthood" and how adjustments are made.
Can it explain variation in the data? Can it explain contradictory data?	**Yes** – It is able to explain why some parents chose not to adjust or the type of adjustment made (e.g., encouraging "age appropriateness" or taking an accepting stance).

Appendix S: Example memos

Revising interview schedule example

Memo 7 (January 2014)

Following the development of the concept of "independence" from the first batch of interviews (participants 1-3), additional prompts to explore this concept further were included in the interview schedule:

- How do you notice independence in your child?
- What behaviours does your child show inside/outside your home with others?
- Would you be able to notice independence in ways aside from his/her behaviour e.g. attitude?
- Any changes in emotional or intellectual development to show that he/she is independent?
- Difficulties noticing it? Difficulties encouraging it?

This will help to consider how parents notice "independence", whether it is viewed in overt and/or subtle ways, and whether is it important for all parents etc.

Developing categories example

Memo 29 (May/June 2014)

Category: "Worries- the "black hole" of transition"

The accounts provided by the first three parents suggested that "worries" was relevant for understanding parental adjustments of their child's their transition into adulthood. My understanding was not confined to these accounts; the first three transcripts provided me with the opportunity to identify some properties and dimensions before other transcripts were explored. Across nine interviews, parents described the following properties of "worry":

- Worries of being excluded
- Worries around being over-ruled by HCPs
- Worries around post-school
- Worries around what society think
- Worries of abuse/vulnerability
- Worries about the future
- Worries related to sexuality development

This category was labelled as "Worries – the "black hole" of transition" as the verbatim comment of "black hole" from a parent appeared to encapsulate the content around uncertainty. Further discussion suggested that "time" was a key dimension for this category. It was acknowledged that parents experience ongoing worry throughout their child's transition process. However, for most parents, worry appeared to peak when perceived barriers stood in the way of

their child's adulthood development (e.g. moving back home after finishing at a residential college).

Exploration of other transcripts, and subsequent discussions with the final three parents yielded no new dimensions and so this category was considered as being theoretically sufficient.

Development of a core category example

Memo 55 (October 2014)

The relationship between concepts and categories initially created a map of descriptive ideas. Reducing these ideas to the final grounded theory analysis required a central core category to pull all other categories together. This helped to form an over-arching structure for the theory.

The category "Worries" was initially considered as being a lynchpin to the developing theory. It was viewed as having a cyclical nature, feeding into each of the other categories. However, this idea was rejected because it was not deemed as being a core process of *how* parents make sense of their child's transition into adulthood or *how* adjustments were made. Additionally, Strauss and Corbin (2008) note that terms such as "uncertainty" or "worry" arise from analyses which have drifted too far from the data.

Instead, further comparisons between the properties of categories raised a key process that all parents displayed (either implicitly or explicitly); "Comparing to perceived 'norms'" of the transition into adulthood". Thus, this category was considered as being pertinent within existing categories. Theoretical sampling (deciding who else should be interviewed to structure further information-gathering) and further discussions with the final three participants demonstrated that making comparisons to normative lifecycles could well function as the nucleus of this developing theory.

Development of grounded theory model example

Memo 64 (February 2015)

As it stands, the current model incorporates the old oscillation theory (Breunlin, 1988). I've rotated the dual process model for grief by 90 degrees to try and capture how parents might oscillate between their ideas of "perceived norms" being disconfirmed and making adjustments. This diagram does depict the "peaks" and "troughs" of worry that parents experience but it doesn't really explain much more than that. It seems too basic.

Memo 68 (March 2015)

Further research around existing process/transition models, I came across Brennan's (2001) social cognitive transition model of adjustment. This seems to be broadly applicable (i.e., not cancer specific) and I have tried to modify it to suit my findings. I think I will definitely need to emphasise its initial basis within the data (i.e., that it is grounded in parent views) but that I have been able to

relate it to an extant process model. The social cognitive model seems a much better fit especially since parents appeared to be processing their experiences in relation to implicit/explicit expectations and social comparisons. There still might be a better way to capture the data, I will present it at the RVP panel in April to get some feedback. Otherwise, I think I might be nearing the final representation of the model…19 slides later! What a journey!

Appendix T: A table to show how the research conditions were met.

(Adapted from Corbin & Strauss, 2008)

Research condition	Was the condition met?
Methodological consistency *(i.e., has the method of analysis been used consistently?)*	**Yes –** I used procedures consistent with grounded theory e.g. constant comparisons, axial coding and theoretical sampling. Corbin & Strauss's (2008) guidelines were used throughout the analytic process.
Clarity of purpose *(i.e., has the aim of the study been made clear e.g. for theory building or theory description?)*	**Yes –** The aim of developing a theory grounded in parents' views was provided at the outset of the study. A further purpose was to ensure that the theory was substantial enough (i.e., in variation, depth and innovation) to address the research question/aims, which was achieved through using "analytic tools" (Corbin & Strauss, 2008).
Self-awareness *(i.e., has the researcher been aware of her own influences upon the data and vice versa?)*	**Yes –** I have kept a reflective diary and used memos throughout the research process. This has helped to identify how I may have influenced the research through my own biases/assumptions. It has also helped to remain aware of the implications/limitations of decisions made. I have also been aware of my feelings/reactions during the data collection and analysis, which has helped me to recognise the influence of the research upon me.
Sensitivity *(i.e., does the researcher have sensitivity towards the topic, participants and research?)*	**Yes –** I held respect and empathy for all participants with the aim to accurately capture their views. I am passionate about this client group (i.e. intellectual disabilities) and was driven to contribute to the evidence base from my experiences of working within this field.
Creativity *(i.e., has the researcher been able*	**Yes –** I designed visual diagrams to help make links between

to think innovatively and use strategies flexibly?)	concepts/categories. I also used tools such as axial coding and theoretical comparisons to identify variation within the data.

Appendix U: Evaluation of quality

Criteria	Example of how was it was met
Fit	• After sharing the map, all three parents agreed with the developed categories and relationships between them. • The findings were "true" for most parents. One did not agree with the category of "making comparisons to societal norms" (Samantha)
Applicability	• The findings offer new explanations using a social comparisons theory to understand why parents may make adjustments (e.g., encouraging "age appropriateness" in their child). • The findings offer new insight into how parents make sense of their child's adult development.
Concepts	• Concepts were developed in terms of their properties and dimensions to facilitate density/variation within the data. E.g. the "conceptual" notion of adulthood was developed in terms of its "legal" and "social" properties.
Contextualisation of concepts	• All concepts were grounded in parents' perspectives. • All participants provided contextual details (e.g., about themselves/their child) by completing a "personal details form".
Logic	• The methodological decisions for using a grounded theory approach were made clear. • The final results followed a logical flow of ideas and were brought together by a core process of "making comparisons".
Depth	• The descriptive details of each concept provided depth/richness. E.g. when identifying *how* parents encouraged "age appropriateness" or the types of perceived barriers.
Variation	• Contrasting data within some categories helped to identify variation within the findings. • A negative case analysis emerged when sharing the thematic map (see "*fit")*
Creativity	• The findings were visually presented in a creative manner. • A new understanding of how parents make sense of their child's transition and make adjustments was provided.

	• Analytic tools were used flexibly as opposed to in a dogmatic fashion.
Sensitivity	• The interview schedule was revised three times in order to further explore concepts that had emerged from previous interviews. As such, the interview schedule became grounded in parents' views. • Data analysis shaped the research although I was aware of my own pre-conceived ideas/assumptions
Memos	• Reflective memos were written throughout the research process.

7. Poster