THE UNIVERSITY OF HULL

The Transition to Adulthood and Adult Services for Young People with Intellectual Disabilities: Multiple Perspectives

being a Thesis submitted in partial fulfilment
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by

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Overview

This portfolio thesis consists of three parts:

Part one - Systematic Literature Review

The systematic literature explores and conceptualises the existing empirical literature relating to parent's experiences of the transition to adulthood for their child with intellectual disabilities. A systematic search identified 16 studies relevant for this review. The transition process to adulthood is often accompanied by a number of processes, includes parental involvement and has psychological and financial impact on parents. The data was synthesised using a narrative synthesis approach, including the methodological critique of the studies. Conclusions from the evidence base are drawn, and implications for future research are considered.

Part two - Empirical Paper

The empirical paper explored the experiences of residential staff and healthcare professionals that have worked with young adults with intellectual disabilities who have been in the care of the Local Authority and transitioned to adult services. A qualitative approach was adopted, primarily a thematic analysis. Three superordinate and nine subordinate themes were identified. Participants' experiences of the transition to adult services included what adulthood meant for young adults with intellectual disabilities once they departed from the care system, how transitions to adult services begin, and an absence of person-centred care occurs in adult services. The findings are discussed in the context of relevant theoretical and empirical literature, and the implications for services and future research are discussed.

Part three - Appendices

The appendices section provides a set of appendices relating to both the systematic literature review and the empirical paper. Also included in the appendices is an epistemological statement and a reflective statement, which consider the researcher's experiences of conducting the empirical paper research.

Total word count (excluding tables, figures and appendices): 15,336

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Part one: Systematic Literature Review

Parents of Children with Intellectual Disability and their Experiences of the Transition to Adulthood: A Systematic Literature Review

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Abstract

Background: The transition from childhood to adulthood for people with intellectual disabilities (PwID) and their families can be accompanied by many changes and challenges. Parents often experience a number of negative outcomes during the transition process for their child with intellectual disabilities (ID).

Method: This systematic review explores and conceptualises the existing empirical literature relating to parent's experiences of the transition to adulthood for their child with ID. 16 studies were identified for this review through systematically searching electronic databases.

Results: This review highlights the challenges and obstacles parents encounter during the transition process and planning, the impact of parental involvement during the transition planning, and the affect this can have on parents psychologically and financially. Parents also experienced positive factors that were associated with the transition to adulthood for their child with ID.

Conclusions: The current available literature is conceptualised and framed within this review. Furthermore, recommendations and solutions are also provided to facilitate smoother transitions to adulthood for PwID and their families. Future research identifying what strategies and services are helpful for parents and young adults with ID during the transition process in the UK is suggested.

Key words: Parent; carer; intellectual disability; transition; adulthood

Introduction

The transition from childhood to adulthood is described as one of the most important in the lifespan (Konstam, 2007). The movement from the protected life of a child to the autonomous and independent life of an adult can be extensively varied for young adults in which this status is attained (Arnett, 2000). Furthermore, cultural assumptions and social opportunities can also influence the timing and patterning of role entries and exits during the transition to adulthood (Berzin, 2010). Arnett (2000) suggests the transition to adulthood is a stage of life that is culturally constructed, and not one that is universal and immutable.

The transition to adulthood is a developmental period that is associated with extensive demographic variability, reflecting the wide scope of individual volition during these years (Arnett, 2000). As the transition period can appear markedly different for each individual, a number of theoretical considerations have conceptualised the notion of adulthood within the literature (Arnett, 2000; Shanahan, 2000). Some researchers note the extension of leaving school and entering employment regulates the transition to adulthood (Pollock, 2002; Côté, 2006). Whilst more holistic approaches of transition suggest the attainment of personal factors, including leaving the family home, becoming more responsible and independent, moving into a home with a partner, and for some getting married, are defining markers of adulthood (Biehal & Wade, 1996; Worth, 2009).

Many changes and challenges can occur during the transition to adulthood, which can be accompanied by stress, uncertainty and instability for young adults (Goodman, Henderson, Peterson-Badali & Goldstein, 2016). This can be particularly so for people with intellectual disabilities (PwID) as they face additional complexities and challenges during this life-cycle than for typically young adults (Ward, Heslop, Mallett & Simons, 2003; Chambers, Hughes & Carter, 2004). Research suggests that PwID experience adversity during the transition to adulthood, as they encounter difficulties with accessing vocational training programmes to integrate into the labour market (Beresford, 2004; Clarke et al, 2011), struggle to maintain and build a social network (Shelden & Storey, 2014), and find it challenging to live independently (Mill, Mayes & McConnell, 2010). Consequently, these changes during the transition to adulthood can also have a significant impact on the organisation of the family as alterations begin to arise in areas of independence, employment, responsibilities and family roles (Neece, Kraemer & Blacher, 2009; Ferguson, Ferguson & Jones, 1988).

In the past 30 years, research has produced a number of findings associated with the transition process and post-school life for young adults with intellectual disabilities (ID) and their families (Ferguson et al, 1988; Keogh, Bernheimer & Guthrie, 2004). PwID begin to lose extra support from specialist professionals, social services, and formal support in education settings during the childhood years (Young-Southward, Rydzewska, Philo & Cooper, 2017). Studies have also reported that parents have strong concerns about losing educational services and the support they provide prior to their child leaving school (Hanley-Maxwell, Whitney-Thomas & Pogoloff, 1995; Rehm, Fuentes-Afflick, Fisher & Chesla, 2012). Whilst another study found that the loss of educational provisions and support contributes to an increase in distress felt by families, as caregivers are forced to fill the void that continues to exist (West & Fuller, 2006). Thus, families experience a number of losses once their child turns 18, the age of termination of educational services in England as proposed by the Education and Skills Act 2008 (Stohler et al, 2008).

Unsurprisingly, parents often perceive the transition period as stressful and uncertain (McKenzie, Ouellette-Kuntz, Blinkhorn & Démoré, 2017), and are not always prepared for the level of support needed to care for their child (Bianco, Garrison-Wade, Tobin & Lehmann, 2009). Other studies have found that parents often fear the outcome for their child’s future, but also have expectations for their child’s life after they leave school which are often not always fulfilled (Hanley-Maxwell et al, 1995). Family involvement is therefore considered to be an essential factor in navigating complex pathways and systems for PwID during the transition to adulthood (Kohler & Field, 2003; Forte, Jahoda & Dagnan, 2011). Being a parent or carer of a child with ID implies ongoing responsibility beyond the attainment of chronological adulthood (Willingham-Storr, 2014).

As families of PwID play a central role in the transition process, it is unsurprising that they are also affected by the significant changes that occur during this process (McKenzie et al, 2017). Arnett (2000) suggests parents often experience significant psychological transformations within their lives during the process of adaption when their child transitions from the status of a “child” to an “adult”. Parents of PwID have reported an increase in distress following the transition to adulthood (McKenzie et al, 2017). Neece et al (2009) found that parents of children with severe ID reported an increase in depression and a reduction in well-being when unsatisfied with the transition process for their child. Other studies have also identified high levels of stress is often experienced by parents (McKenzie et al, 2017), with some researchers describing the stress associated with the transition process being similar to the stress parents experience when their child is first diagnosed with a disability (Wikler, 1986).

Theoretical models within the transition literature focus predominately on parental adaption to the stresses of caregiving (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986; McCubbin & Patterson, 1983). Although these cognitive models of stress and coping emphasise the role of subject appraisal of potential stressors, it has been suggested by some authors these models “overpathologise” the family (Hassall, Rose & McDonald, 2005). Parental stress during the transition period has specifically been conceptualised in the family-life cycle framework (Carr, 1994; Moghaddam, 2014). When families of children with disabilities often experience problems with the high demands of caregiving during transitions, it is suggested that sometimes parents encounter adjustment difficulties arising from grief and mourning processes (Carr, 1994). Carr (1994) further elaborates that during each transition of the offspring’s life cycle, the family begins to remember the loss of the typically developing child that was originally anticipated and the grief process reoccurs, although in a gradually attenuated form.

Currently there is no review that solely focuses on the parental experiences of the transition to adulthood for their child with ID. An existing review by Willingham-Storr (2014) aimed to explore parental experiences of caring for a child with ID in the United Kingdom (UK); however, this review did not primarily focus on parent’s experiences of the transition to adulthood. Furthermore, the review only encompassed research that had been conducted in the UK, therefore neglecting global research. Research emphasises the importance of parental involvement during the transition from childhood to adulthood for young adults for ID. The relevant literature, research findings and associated conceptual issues highlight the need for a broader understanding of the experiences of parents when their child with ID transitions to adulthood. Due to the limited research that primarily focuses on parent’s experiences of the transition to adulthood for their child with ID, this review included international research to conceptualise and understand these experiences. Building on previous literature, the current review aimed to synthesise research that has explored parental experiences of the transition to adulthood for their child with ID. The main question underpinning this review was:

1. How do parents perceive and experience the transition to adulthood for their child with ID?

Method

Search Strategy

A systematic search was conducted between December 2017 and March 2018 using the following electronic databases: PsycINFO, PsycARTICLES, CINAHL, MEDLINE, ERIC and Academic Search Premier. This included subject-specific and generic databases to ensure a thorough selection process.

The following search strategy was utilised to ensure a comprehensive review of the literature was covered. The following key terms used for ID currently and in the past were generated from initial database searches with a near operator to ensure that young adults with an ID were the focal point of the review. Key terms around caregivers were developed through scoping of abstracts and keywords within the literature to identify relevant references. The researcher consulted with a fellow academic for guidance on developing the following key search terms. It was decided that the term 'parent' would not be utilised within the search terms as the relevant papers used key words such as 'mum', 'mother', 'dad' and 'father' to refer to parents. Finally, due to the broad definitions of the transition to adulthood, the following search terms relating to transition were developed from previous studies that sought to explore the parent's experiences of the transition to adulthood for their child with ID."

Search terms used were as follows:

((adult* or "young person*" or "young people" or youth or teen* or adolescen* or juvenile*) N3 ("learning disabili*" or "intellectual disabili*" or "learning diffi*" or "intellectual diffi*" or "mental retard*" or "mental handicap" or "mental subnormalit*" or "mental deficienc*" or "mental disab*")

AND

(carer* or famil* or mother* or father* or mum* or mam* or dad*)

AND

(transition* or move* or moving or "independent liv*" or "supported living")

Initially, papers were screened by title and abstract to identify their relevance for the review. The relevant papers were then fully read, and the inclusion and exclusion criteria below were applied to conceptualise the finalised set of papers. The reference lists of all the included articles were hand-searched and the same process of reviewing the title and abstract to the full paper was employed.

Inclusion and Exclusion Criteria

Articles were included if they:

1. Explicitly focused on parent experiences of the transition to adulthood for their child with ID, as it is reported that it is particularly the parents who provide the most support to their child with ID (Willingham-Storr, 2014).
2. The paper was empirical, and not presented as autobiographical, a commentary, reflection, dissertation, book or literature review, as the review sought primary sources of research.
3. Were peer-reviewed to ensure high quality research.

Articles were excluded if they:

1. Were not published in the English language because of the time and financial constraints around translation.
2. Were published before 1990 as The National Health Service and Community Care Act 1990 (Killaspy, 2006) legislation advocated for vulnerable adults and

their carers to remain in the community after the closure of the asylums (Killaspy, 2006). The UK legislation was used as an exclusion criterion as there is no international policy that encourages community care for individuals with ID.

3. Focused on transitions that were not specifically associated with adulthood. For example, poverty transitions (Emerson, Shahtahmasebi, Lancaster & Berridge, 2010) and transitions occurring in childhood (McIntyre, Blacher, & Baker, 2006).
4. Did not explicitly focus on ID and included other disabilities and difficulties where ID was not always clearly present. Examples include Autism Spectrum Conditions (Taylor & Henninger, 2015), physical aggression (Tyrer et al, 2006) and developmental disabilities such as cerebral palsy and head injury (Bhaumik et al, 2011).

Quality Assessment

A bespoke checklist was generated by the author in order to assess the quality of each study, given the heterogeneity of the methodologies included. The utilised tools were generated from the National Institute for Health and Care Excellence (NICE) qualitative checklist (NICE, 2012), NICE quantitative checklist (NICE, 2012), and the Mixed Methods Assessment Tool (MMAT) (Pluye, Gagnon, Griffiths & Jonhnson-Lafleur, 2009) (Appendix B). Incorporating the items from the various complimentary tools permitted an adequate assessment of the various aspects of quality for each study. In the case of studies that employed a qualitative methodology, mixed method and quantitative questions of the quality assessment checklist were not included in the overall total score. For quantitative studies, the mixed method questions were also not incorporated into the overall score. Therefore, qualitative studies could only receive a total score of 17, quantitative studies obtained a total score of 18, and mixed methods included a total score of 22. The quality of each study produced a percentage score that ranged from 0% being of the lowest quality to 100% the highest based on the overall score of the study (Appendix C).

Five articles were checked by a peer reviewer to assess the quality of the studies to determine inter-rater reliability. If discrepancies occurred in ratings, both reviewers discussed their rationale for the rating and a final decision was collaboratively reached.

Articles were not excluded based upon the quality rating, as the review aimed to include the experiences of all parents in the studies, and any limitations within methodologies would be highlighted.

Data Extraction and Synthesis

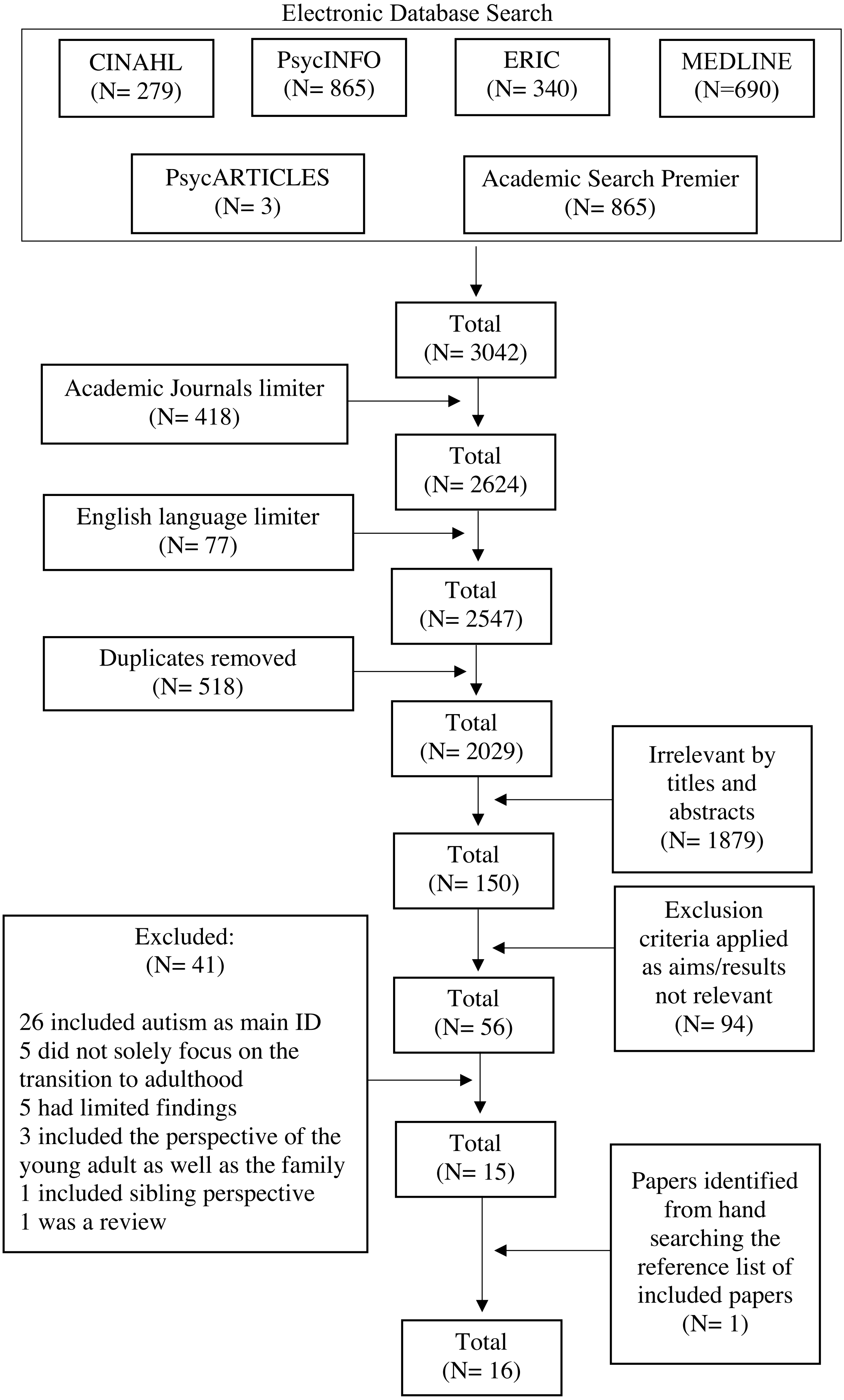
A bespoke data extraction form was created to specifically derive the data and summarise the relevant information to the review (Appendix D). Narrative synthesis was used to analyse the results of the studies included, given the heterogeneity in designs and outcome in the data. The process of the narrative synthesis comprised of four main stages, as proposed by Popay et al. (2006):

1. Relevant search terms were developed to ensure suitable research articles were retrieved. The exclusion criteria was used to finalise the relevant papers.
2. The data from the final set of papers were extracted using the bespoke data extraction form (Appendix D), which includes information that is necessary for synthesis.
3. Common themes and patterns, as well as similarities and contradictions, across the included studies were identified and grouped.
4. The robustness and trustworthiness of the synthesis of the existing literature based upon the methodological quality ratings were assessed using the bespoke quality assessment checklist (Appendix B).

Results

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher, Liberati, Tetzlaff & Altman, 2009) procedure was used to identify relevant papers for the review. From the electronic databases, 15 papers met the inclusion criteria, and one more paper was included through hand-searching the reference lists of the included articles. A final total of 16 papers were suitable for the inclusion of this review. The selection procedure is outlined in Figure 1.

Figure 1: Flowchart identifying the article selection process.



Some studies used different terminologies to describe ID, however for the purpose of this review ID will be used throughout to reflect the internationally accepted term (BPS, 2015).

The studies were conducted across five countries (USA, UK, Australia, Ireland, and Czech Republic), although Strnadová & Evans (2013) was the only study that conducted the research over two countries, Australia and Czech Republic. Most studies aimed to explore the parent experiences and perceptions of the transition process to adulthood for their child with ID. Whilst two other studies aimed to specifically focus on providing an understanding to professionals of the dilemmas experienced by parents during the transition process (Thorin, Yovanoff & Irvin, 1996) and the influence of ethnicity on the transition (Raghavan, Pawson & Small, 2013). One study (Heslop & Abbott, 2007) included the perspectives of professionals and parents, however the findings from the professionals were separated from those of parents, and therefore not included in the findings of this review.

Sample sizes ranged from eight (Unwin, LeMesurier, Bathia & Deb, 2008; Docherty & Reid, 2009) to 571 (Black, Molaison & Smull, 1990). Participants across the studies mainly included mothers, though some did include fathers as well (Black et al, 1990; Foley et al, 2013; Gauthier-Boudreault, Gallagher, & Couture, 2017a; Gauthier-Boudreault, Couture, & Gallagher, 2017b; McNair & Rusch, 1991; Rapanaro, Bartu & Lee, 2008; Gillan & Coughlan, 2010). However, no studies included father participants only. There were also some studies (Heslop & Abbott, 2007; Leonard et al, 2016; Martinez, Conroy, Cerreto, 2012; Raghavan et al, 2013; Thorin et al, 1996; Unwin et al, 2008) that did not specifically identify the gender of the participants. All studies included the child's ID. However, the majority of the studies (Black et al, 1990; Gauthier-Boudreault et al, 2017a; Gauthier-Boudreault et al, 2017b; Martinez et al, 2012; McNair & Rusch, 1991; Raghavan et al, 2013; Rapanaro et al, 2008; Thorin et al, 1996; Unwin et al, 2008) did not clarify whether the child was given a medical diagnosis of an ID or whether it was how parents defined their child's difficulty. Some studies included a sample that was diverse in culture (Raghavan et al, 2013; Strnadová & Evans, 2013).

The majority of studies employed a qualitative methodology (N=11), whilst the remaining studies used a quantitative methodology (N=3) and a mixed methodology (N=2). The main methodological approach used during the studies was the use of semi-structured interviews (N=8), followed by questionnaires (N=7) and a focus group (N=1). Table 1 provides a detailed overview of the included studies.

Table 1. An overview of included studies.

Author(s), Year & Location	**Study Aims**	**Participants**	**Design**	**Methodological Approach**	**Key Findings**
Black, Molaison & Smull (1990) (USA)	To identify the service needs of families with a child with ID.	Parents: 571 participants (412 females, 150 males, 9 unknown). Child: All had ID and were aged between 20 to 24 years.	Quantitative, regression analysis.	Idiosyncratic questionnaire.	Financial and personal concerns. Families requested day services. Services were more desirable if they provided support for parents and assistance for psychological and behavioural difficulties.
Docherty & Reid (2009) (Scotland, UK)	To explore the values and beliefs of mothers with a child with Downs Syndrome and supporting the transition from dependence to independence.	Parents: 8 mothers, average age was 56 years. Child: All had a diagnosis of Downs Syndrome. Mean age 23 years.	Qualitative, Interpretative Phenomenological Analysis	Semi-structured interviews.	Mothers discussed the importance of social activities, social interaction, child with ID being aware of their diagnosis, and independence for their child. Mother's expressed an active involvement in identifying resources for their child. Mothers also cited their own concerns about their ageing and ability to deal with the transition.
Dyke, Bourke,	To investigate the outcomes of young	Parents: 18 mothers.	Qualitative, content analysis.	Semi-structured interviews.	Transition success is associated with parent advocacy. Limited

Llewellyn & Leonard (2013) (Australia)	adults with ID transitioning from school to adult life from a parental perspective.	Child: 11 had a diagnosis of Rett Syndrome (mean age 24 years) and 7 had Down Syndrome (mean age 21 years).			information regarding the transition process, loss of support from services, child with ID having limited involvement in transition process were highlighted issues by parents. Mother's expressed fear of outliving child with ID and had difficulties achieving supported accommodation for their child. Mother's expressed feeling anxious about losing familiar services.
Foley et al, (2013) (Australia)	To investigate the relationship between activities of daily living (ADL) and post school day occupations for young adults with Downs Syndrome.	Parents: 164 parents, mothers ranged in age from 37 to 80 years, fathers ranged from 39 to 80 years. Child: All had a diagnosis of Downs Syndrome and were aged between 15 to 29 years (mean age 22.9 years).	Quantitative, analysis of variance and chi-squared tests.	Idiosyncratic questionnaire.	Strong relationship between parent involvement during the transition process and their child with ID participation in open employment and/or training post-school. Parents of young adults with ID had higher ratings on depression and anxiety stress scales when their child was not in employment.
Gauthier-Boudreault, Gallagher &	To explore family experiences of the transition from	Parents: 14 parents (12 female, 2 male), 5 parents	Qualitative, descriptive	2 semi-structured interviews.	Parents expressed late transition planning, a lack of communication and collaboration

Couture (2017a) (Quebec, Canada)	school and paediatric services to other services, and to describe the factors that may influence their experience of transition.	were 49 years of age or less, 9 were 50 years or over. Child: The children had profound ID's and were aged between 18 and 26 years.	interpretative approach.		between services, and a lack of understanding of the roles and responsibilities of professionals. Parents highlighted difficulties accessing information for the transition and the options available after school. They also expressed feelings of insecurity and uncertainty because of the lack of information provided to them. Parents described mourning the loss of school and grieving the fact that their child's disability will be permanent.
Gauthier-Boudreault, Couture & Gallagher (2017b) (Quebec, Canada)	To investigate the perspectives of families with a young adult with ID and to propose realistic solutions for the transition to adulthood.	Parents: 14 parents (12 female, 2 male), 5 parents were 49 years of age or less, 9 were 50 years or over. Child: The children had profound ID's and were between 18 and 26 years of age.	Qualitative, descriptive interpretative approach.	2 semi-structured interviews.	Solutions included the need for transition plans to begin three years prior to leaving school and transitions to be coordinated by a navigator. To have conferences on transition issues, annual presentations and visit days to available provisions. Transition plans to include important details. Create a discussion group for parents to discuss emotional difficulties.
Gillan & Coughlan (2010) (Ireland)	The study aimed to address the gaps in knowledge of the transition process,	Parents: 12 parents aged between 42 and 65 years.	Qualitative, grounded theory.	Semi-structured interviews.	Psychological impact of transition experience: transition from school was experienced as stressful,

	as well as the impact of transition from high-school to mainstream settings from a parental perspective.	Child: All diagnosed in the mild range of ID's, age ranged from 19 to 24 years.			uncertain, frustrating, and disempowering. Barriers and facilitators of the transition process: Negative emotional impact was associated with an overwhelming sense of dissatisfaction with the formal service systems. Parents experienced anxiety and frustration due to the loss of highly supported and highly structured schools.
Heslop & Abbott (2007) (Bristol, UK).	To explore family perspectives on what contributes to a satisfactory pathway and transition outcomes for their child with ID from an out-of-area residential school or college.	Parents: 16 parents. Child: All had a diagnosis of ID.	Qualitative.	Semi-structured interviews.	Being well-connected with people who provided information, practical and emotional support were highlighted as a need. Parents being proactive and advocating for their child. Allowing adequate time to prepare for the transition.

Leonard et al. (2016) (Western Australia (WA) and Queensland, Australia)	To understand the factors associated with transition and to explore parental and student engagement in transition planning.	Parents: 340 parents. Child: All young people from WA had a diagnosis of Downs Syndrome, only 20% of Queensland population had a diagnosis of Downs Syndrome and the rest were unknown. Child with ID were aged between 15 to 29 years.	Qualitative, content analysis & quantitative, descriptive analysis and Pearson's Chi squared tests.	Idiosyncratic questionnaire.	Parent had concerns about their child's capacity to adapt and change to life in adulthood, difficulties in accessing services and programs, strain on finances, and worrying about the long-term future. The majority of the parents stated that they were involved in the transition plan but about one-third wanted to be more involved in the planning. Only about half of the young adults with ID were involved in their transition planning and finding a job for the future.
Martinez, Conroy & Cerreto (2012), (Virginia, USA)	To explore parental involvement in transition planning, their desires and expectations for the future goals of their child with ID.	Parent: 61 parents. Child: Child was aged between 14 and 22 years. 11 parents reported their child as "low functioning", "profoundly retarded" or required "24/7 care".	Quantitative, descriptive statistical measures & qualitative, priori coding and grounded theory method.	Idiosyncratic questionnaire.	Parents reported that they did not have or were unaware of transition plan for their child. Parents reported feeling overwhelmed and confused about the process. Parents involved in the transition planning activities correlated with the amount of time their child was included in social activities.

McNair & Rusch (1991) (USA)	To explore parental involvement during the transition process, the type of involvement they desire, and the responsibilities they are willing to assume in order to be involved.	Parent: 85 parents, mothers mean age was 47 and fathers mean age was 49. Child: All had an ID. All aged between 14 and 25 years	Quantitative, t tests and analyses of variance.	Idiosyncratic questionnaire.	A significant number of parents were unaware of transition plans but virtually all parents desired some involvement. Parents also reported a preference for their child living away from home post-school but not living in institutional services.
Raghavan, Pawson, & Small (2013) (West Yorkshire, UK)	To explore the influence of ethnicity on the transition experience.	Parents: 43 families (White British (n = 16), Pakistani (n=24), Bangladeshi (n=2), Black African (n=1)). Child: All had an ID and were aged between 14 to 22 years.	Qualitative, framework analysis.	2 semi-structured interviews.	Parents were generally unaware of the transition plan until their child was about to leave school. Parents were often confused and had limited information about the options available for their offspring. A lack of information about services and a sense of being excluded were reported by families. South Asian families experienced a greater difficulty with language and accessing information about services.

Rapanaro, Bartu & Lee (2008). (Australia)	To explore and describe parent perceptions of the negative and positive outcomes relating to the stressful events reported and the caregiving demands during their child's transition into adulthood.	Parents: 119 parents, mean age was 48.05 years. 90% of the participants were female. Child: All had mild to severe ID and were aged between 16 and 21 years.	Qualitative, content analysis.	Idiosyncratic questionnaire.	Parents identified a number of negative outcomes such as chronic demands of their child during transition, parent's loss of freedom and independence, and requiring more mental and emotional energy than previously. Positive outcomes included personal growth and enhanced personal resources.
Strnadová & Evans (2013) (New South Wales, Australia & Czech Republic)	To explore mother's experiences of the transitions their offspring with ID has made.	Parents: 20 mothers, mean age was 61.7 years. Child: All had a diagnosis of ID and were aged between 19 to 56 years.	Qualitative, constant comparative analytic approach.	Semi-structured interview.	Limited access and opportunities post school were reported. Behavioural issues were reported as a complicating factor for successful transition, as well as difficulties in accessing ongoing care.
Thorin, Yovanoff Irvin (1996) (Washington & Oregon, USA)	To provide professionals with an understanding of the potential dilemmas faced by parents.	Parent: 103 families. Child: Primary disability ID and the average age was 24 years.	Qualitative.	Idiosyncratic questionnaire.	Dilemmas included creating opportunities for independence, child with ID to have a social life, avoiding burn-out, and maximising the young adult's growth potential.

Unwin, LeMesurier, Bathia, & Deb (2008) (West Midlands, UK)	To explore parent perspectives of transition for their young adult with learning disabilities and mental health problems/challenging behaviours	Parent: 8 parents. Child: ID	Qualitative, thematic analysis.	Focus group	Feelings of conflict between parents and professionals during the transition process. Parents felt as if they were regarded as a barrier and a hindrance but that they actually strived for opportunities for their child. Parents felt powerless in accessing relevant information.

Methodological Quality

Table 2 provides the ratings of methodological quality for each paper within this review. Majority of the studies attained a quality rating above 50%, suggesting that they scored on almost half of the quality criteria. Two studies (Thorin et al, 1996; Unwin et al, 2008) scored below 12%, meaning that they did not fill the majority of the quality criteria. A more detailed overview of the methodological quality assessment is outlined in Appendix C.

Table 2: Summary of the methodological quality ratings of included studies based on the NICE qualitative checklist (NICE, 2012), NICE quantitative checklist (NICE, 2012), and the MMAT (Pluye et al, 2009), strengths and limitations of each study are also presented.

Study (authors and year of publication)	**Quality rating**	**Strengths and limitations of studies**
Black et al (1990)	56%	Likert-scale and multiple-choice answers on the questionnaire provided the participants with a fixed choice response, therefore restricting the true representation of how parents experience the transition process. However, the study included a large sample, suggesting the findings may be representative of the target population.
Docherty & Reid (2009) /	88%	Using interpretative phenomenological analysis (IPA) provides an in-depth phenomenological account of the participant's experiences. However, this study reported limited information on how the analysis was conducted, therefore questioning the reliability of the findings.
Dyke et al (2013)	71%	This study explored the experiences of mothers when their offspring transitioned from school to adult life, however some of the young adults had left school five years previous to the study, questioning the reliability of the data. However, the experiences of 18 participants were included, suggesting in-depth and rich data.

Foley et al (2013)	94%	The study conducted data at one point in time, therefore overlooking other outcomes that could be experienced during the transition process for parents. However, the study received 75% of the questionnaires that were initially distributed, suggesting the findings may be representative of the population.
Gauthier-Boudreault et al (2017a)	82%	The interviews within this study were analysed by two researchers, which reduces researcher bias and ensures the credibility of the results. However, some participants were more proactive than others, which suggests that the findings may not be a reflection of all the parents within the study.
Gauthier-Boudreault et al (2017b)	82%	Same as above Gauthier-Boudreault et al (2017a).
Gillan & Coughlan (2010)	76%	The interview method provided rich in-depth data about parents' experiences of the transition process for young adults with Rett Syndrome and Downs Syndrome. However, the study did not include any information on the role of the researcher, therefore questioning whether researcher bias could have influenced the findings of the study.
Heslop & Abbott (2007)	47%	The demographics of the participants and the setting are not clearly defined within this study; therefore, it is unclear whether context bias was considered in this study. However, the data analysis of the study was clearly defined, suggesting that the procedure of the study is reliable.

Leonard et al (2016)	82%	The findings were derived from two states, however the differences between the two cohorts were not considered in relation to the findings. On the other hand, the consistency of the findings provided triangulation to support the validity of the study.
Martinez et al (2012)	86%	The participants within this study were all from one organisation increasing parent bias. However, using a mixed method provided triangulation to support the validity of the study.
McNair & Rusch (1991)	61%	The small response rate of the questionnaires highlights the issue of representativeness, although the questionnaire was distributed across the USA. The closed-ended questions within the questionnaire also restricted the responses participants can provide, therefore a true reflection of how parents experienced the transition process is not captured within the study. However, the study included characteristics of participants and the settings which reduces context bias.
Raghavan et al (2013)	82%	This study included interviews with 43 families from different ethnicities and cultural backgrounds, which provided rich-in-depth qualitative data. However, the study used purposive sampling which can be prone to researcher bias.
Rapanaro et al (2008)	82%	The questionnaire response rate was 29%, questioning the generalisability of the findings to the target population. However, the data was analysed by more than one researcher, suggesting that the analysis was reliable.
Strnadová & Evans (2013)	71%	The participants from this study were recruited across two countries. The characteristics and cultural settings were considered in relation to the findings, which reduces context bias. However, the role of the researcher was not reported in the study which questions researcher bias.

Thorin et al (1996)	12%	The demographics and findings in this study were unclear, which question the reliability and validity of the study. The questionnaire also included a Likert scale, therefore restricting participant response. However, the findings presented were relevant to the study aims.
Unwin et al (2008)	6%	It is unclear how the study was conducted, and the context of the data has not been described, therefore questioning the reliability of the study. However, the study did include a theoretical approach that underpinned the research.

All studies, apart from one (Thorin et al, 1996), provided a clear description of their background and research aims. The majority of the studies obtained high quality ratings of their findings and interpretations, although studies by Thorin et al (1996) and Unwin et al (2008) did not attain any scores on the analyses of the results.

The reliability of the analysis for majority of the studies was questioned, apart from five studies (Foley et al, 2013; Leonard et al, 2016; Martinez et al, 2012; Raghavan et al, 2013; Rapanaro et al, 2008) due to the limited reporting of quality assurance. Across the included studies, there was limited evidence of reflexivity in relation to both the role and influence of the researcher and/or study context on the results, suggesting difficulties with evaluating whether these factors may have influenced the original findings of the studies. This issue was weighted more heavily by three studies (Heslop & Abbott, 2007; Thorin et al, 1996; Unwin et al, 2008) due to their limited ability of assessing the representativeness of the sample. Four studies (McNair & Rusch, 1991; Strnadová & Evans, 2013; Thorin et al, 1996; Unwin et al, 2008) scored zero on the generalisability of the findings because of the lack of description of the findings.

Of the 16 studies, three (Black et al, 1990; Heslop & Abbott, 2007; Rapanaro et al, 2008) either did not report or inadequately reported on the justification of its study design. However, Unwin et al (2008) was the only study considered ‘not defensible’ in justifying its study design. Nonetheless, all four studies provided limited reasoning for the use of the study design. The quality and richness of the data in the studies by Heslop and Abbott (2007) and Rapanaro et al (2008) were not affected by the limited reasoning given to justify their study design. When reviewing the findings from this study, it is important to cautiously weigh up the methodological quality of each study before drawing upon conclusions.

The main findings from this study were synthesised into four main themes; the transition process, parent involvement in the transition, the impact of the transition on families, and moving forward.

The Transition Process

Preparing & Timeframe

Studies reported on parent's experiences of the transition plan mainly from educational services. Transition planning and preparation was described as occurring during the last year of school by parents (Gauthier-Boudreault, 2017a), and if there was a transition plan at all it was just before their child with ID finished school (Raghavan et al, 2013). Other parents revealed having no plan or being unaware of a transition plan for their child after leaving school (Martinez et al, 2012; Raghavan et al, 2013). Black et al (1990) found that parents reported being more satisfied when they were aware of the transition plan.

Leonard et al (2016) found that most parents (268/334, 80.2 %) reported attending a meeting or having a discussion with teachers about the transition plan for their child with ID and felt involved in decision making during the transition plan. Although, some parents thought a definite plan was not put in place during these conversations with school (Raghavan et al, 2013). Furthermore, when these meetings occurred young people were found to be less consulted (Raghavan et al, 2013; Dyke et al, 2013) and were less involved in the transition planning process (Leonard et al, 2016). Differences have also been found amongst parents whose first language is not English. Raghavan et al (2013) found that South Asian parents, who did not speak English as their first language, reported being less aware of the transition process: "*I don't know but maybe the teacher will guide us as to what he would do*." (CO23 Pakistani Father). Although it has been found that parents claim they initiated the transition step themselves to ensure the follow up from professionals (Gauthier-Boudreault et al, 2017a).

Heslop and Abbott (2007) highlighted parents perceive forward planning and having adequate time as an important factor in preparing the child for the next move in their lives. Furthermore, Docherty and Reid (2009) found that parents wanted enough time to organise the transition so that they were physically and mentally prepared to manage any difficulties that persisted. Parents wanted the transition plan to begin a few years, specifically three years by some parents (Gauthier- Boudreault et al, 2017b; Docherty & Reid, 2009), prior to when the child would transition from school to adulthood (Gauthier- Boudreault et al, 2017b). Parents further viewed good forward planning as a shared responsibility between professionals and themselves (Heslop & Abbott, 2007).

Communication & Information

The majority of parents expressed the need for better communication and information about service options post-school. Even when information is available, parents are provided with little information (Dyke et al, 2013; Martinez et al, 2012). Parents accessing relevant information about services for their child with ID is often perceived as a challenging and difficult process (Raghavan et al, 2013; Rapanaro et al, 2008). When parents did access information, they highlighted the lack of collaboration and communication between the services involved in the transition (Gauthier-Boudreault et al, 2017a). Parents were found to often repeat their child's history to professionals because of the lack of communication sharing between services, which was described as frustrating by some parents (Gauthier-Boudreault et al, 2017a; Raghavan et al, 2013). Parents also experienced feeling dissatisfied by adult services during the transition period (Unwin et al, 2008; Rapanaro et al, 2008), whilst others have reported that professionals seemed to know little about their role during the transition (Gauthier-Boudreault et al, 2017a). Differences of opinion and perspective between parents and professionals has been clearly outlined in the literature (Unwin et al, 2008), which could potentially be a result of the lack of communication between services.

Research suggests that parents want to be provided with more information during the transition process (Martinez et al, 2012; Raghavan et al, 2013; McNair & Rusch, 1991), which is something that parents thought would contribute to a satisfactory transition (Heslop & Abbott, 2007). McNair and Rusch (1991) found that parents wanted more information about their child's skills and the work options available after the child left school, as well as more information about community living arrangements and adult service agencies. Accessing information for their child post-school was found to be even more challenging for South Asian families whose first language was not English as they reported a greater sense of confusion and lack of awareness of options for their child: "*I haven't looked into it (future options), I have not tried to look for any activities. I don't know how to approach it because of my language problems.*" (CO40 Bangladeshi Mother) (Raghavan et al, 2013). A solution to this difficulty, as proposed by parents, is to have a key worker during the transition period that would help them with accessing information and choosing the most appropriate options for their child (Gauthier-Boudreault et al, 2017a; Raghavan et al, 2013). Heslop and Abbott (2007) also found a similar finding whereby parents mentioned having a key worker, potentially a social worker, that would be helpful in providing them with support, advice and information. Other solutions proposed by parents for services to provide information included creating a document that incorporates the steps of the transition and providing conferences and presentations on transition difficulties and post school options (Gauthier-Boudreault et al, 2017b).

Where to?

Parents described a service gap after their child leaves school: *"There is like a gap. Nothing happens anymore at age 21" (Case 8)* (Gauthier-Boudreault et al, 2017a). Leonard et al (2016) highlighted the loss of the structured support from school was a worrying factor for parents as they reported having concerns about how their child would emotionally manage the disruption to old routines and long-standing friendships. Parents were also fearful of whether their child's next stage of life would include different daytime occupations, and for some independent living (Leonard et al, 2016; Docherty & Reid, 2009).

The lack of availability of provision after school has also been indicated by a number of studies (Gauthier-Boudreault et al, 2017a; Strnadová & Evans, 2013; Raghavan et al, 2013). Raghavan et al (2013) found that when accommodation placements were available for young adults with ID after they left school, there was limited choice and the available options were often inappropriate. Furthermore, some parents find navigating appropriate accommodation as extremely time consuming and stressful (Leonard et al, 2016), whilst others express a fear for their child's future living arrangements (Dyke et al, 2013). A child's level of ID also influences their chances of accessing accommodation provision, as those with more complex needs receive greater support and have greater access to services, such as respite services (Raghavan et al, 2013). In contrast, Gauthier-Boudreault et al (2017a) found that respite services were often not applicable to young adults with profound ID. Interestingly, Raghavan et al (2013) also found that South Asian parents were less likely than White British parents to suggest that their child moves to supported accommodation or residential homes. These findings are similar to McNair and Rusch (1991) whereby none of the parents in their study wanted an institutional placement for their child with ID.

Parents also reported on employment options for their child after school (Leonard et al, 2016; McNair & Rusch, 1991; Strnadová & Evans, 2013). McNair and Rusch (1991) found 50% of the parents in their study imagined their child obtaining a job, whilst other parents reported young adults with ID had limited opportunities for employment once they transitioned from school (Strnadová & Evans, 2013; Leonard et al, 2016). PwID often tend to experience difficulties with aggressive, inappropriate or sexual behaviours once they leave school which parents associate with adjusting to post-school life (Rapanaro et al, 2008), however some parents report these behaviours influence their child's employment options (Strnadová & Evans, 2013). Due to limited employment options during adulthood, Black et al (1990) found 39% of parents reported their child had no regular daytime activity. Unsurprisingly, PwID often experience social isolation during adulthood as a result of the limited opportunities they have during this phase of their lives (Strnadová & Evans, 2013; Docherty & Reid, 2009).

Access to formal support services (Strnadová & Evans, 2013) and daily activity centres (Gauthier-Boudreault et al, 2017b) have been suggested as possible solutions to these problems. Furthermore, developing social and personal skills for use beyond school were perceived to be a priority for mothers (Strnadová & Evans, 2013; Docherty & Reid, 2009).

Parent involvement in the transition

Parental Involvement

Parent involvement in transition planning has been highlighted by a number of studies (Martinez et al, 2012; Foley et al, 2013; McNair & Rusch, 1991; Docherty & Reid, 2009). Studies have highlighted parent involvement in the transition planning is correlated with greater employment opportunities (Foley et al, 2013) and social activities (Martinez et al, 2012) during adulthood for their child with ID. Other studies have found that parents are often actively involved at navigating and identifying resources and activities for their child during the transition process (Docherty & Reid, 2009; Gauthier-Boudreault et al, 2017b; Rapanaro et al, 2008). However, this active involvement during the transition process has been described as exhausting by some parents (Gauthier-Boudreault et al, 2017b).

Being involved in the transition process was also described as a positive factor by some parents (Leonard et al, 2016). They often felt proud about participating in the development of a plan for their child to foster a successful transition to adulthood: *"very excited that we had organised a plan in which she would be happy and could develop."* (Leonard et al, 2016). Rapanaro et al (2008) also found that parents reported positive outcomes in relation to their child's transition to adulthood, which included feelings of pride and fulfilment, greater acceptance of their child's abilities and development of their own positive personal characteristics (Rapanaro et al, 2008).

Parents as Advocators

Researchers have highlighted that parental advocacy is associated with successful transitions (Dyke et al, 2013; Martinez et al, 2012; Heslop & Abbott, 2007). Parents have reported their advocacy and involvement in accessing information is necessary in order to *"carry on the good fight!"* (Martinez et al, 2012). Accessing services has also been described as a battlefield by Gauthier-Boudreault et al (2017a) as parents are often fighting for services by writing letters or repeatedly contacting professionals: *"I often tell moms I meet: Learn to fight my friends. Because me, I have many examples in the system that I fought, and it worked. You have to be a fighter, that's for sure" (Case 4).* However, the role of an advocate can also be difficult and stressful for some parents (Heslop & Abbott, 2007).

Impact of the transition on families

Psychological Impact

Research suggests that some parents often feel great anxiety when their child leaves school (Martinez et al, 2012; Gauthier-Boudreault et al, 2017a; Dyke et al, 2013), whilst other parents often felt worried and fearful of what will happen after school (Leonard et al, 2016): "*Well, the greatest concern was the gap. You know, when you are in limbo, you feel insecure and anxious, that's for sure"* (Gauthier-Boudreault et al, 2017a).

Parental anxiety often reflected the limited information parents had about post-school options (Martinez et al, 2012; Unwin et al, 2008), which has been described as a powerlessness feeling by some parents (Unwin et al, 2008; Gillan & Coughlan, 2010). When parents are provided with the opportunity to make decisions on behalf of their child about their transition to adulthood, parents report feeling concerned about making the wrong decisions (Leonard et al, 2016). Parental anxiety was also associated with the loss of support received from schools (Gillian & Coughlan, 2010; Dyke et al, 2013). Furthermore, some researchers suggest that parents mourn the loss of the education system as it provides them with freedom and independence in their daily lives (Gauthier-Boudreault et al, 2017a; Rapanaro et al, 2008). Research also suggests parents begin to grieve the fact that their child's disability will be permanent (Gauthier-Boudreault et al, 2017a) which can often result in feelings sadness and restfulness when witnessing other parents with children that do not have an ID (Rapanaro et al, 2008). Despite the psychological impact the transition has on parents, research has found that transition issues do not significantly impact the daily life and wellbeing of the rest of the family (Leonard et al, 2016; Black et al, 1990).

A number of studies found the dual role of a parent and a caregiver also influenced their psychological wellbeing (Black et al, 1990; Dyke et al, 2013; Heslop & Abbott, 2007; Leonard et al, 2016; Gillan & Coughlan, 2010): *"I stress and worry about him all the time, I have been sick and a few months ago they diagnosed me with depression."* (Leonard et al, 2016). Similarly, Foley et al (2013) also found that parents experienced greater depression and anxiety when their child was not employment and lived at home.

Raghavan et al (2013) reported the family belief system and religion provided comfort to Pakistani family parents. For some parents, being well-connected with key professionals or other parents provided them with practical and emotional support which contributed to satisfactory transitions (Heslop & Abbott, 2007). To help parents with psychological support, Gauthier-Boudreault et al (2017b) propose creating a parent's discussion group that is supervised by professionals to provide emotional support to families. Likewise, Heslop and Abbott (2007) also highlighted the importance of having dedicated events or contact lists that would enable parents to meet other parents.

Financial Impact

Financial difficulties on the family were highlighted in some studies (Gauthier-Boudreault et al, 2017a; Leonard et al, 2016; Black et al. 1990). Black et al (1990) found financial problems to be the most frequently identified problem. Identified concerns by parents included being worse off financially and that funding was not sufficient enough to cover necessary therapy services after their child with ID transitioned into adulthood (Leonard et al, 2016). Parents often reported leaving employment to care for their child (Leonard et al, 2016; Gauthier-Boudreault et al, 2017a): *".... had to give up work so I could look after and plan for future employment."* (Leonard et al, 2016). Parents identified having increased financial support would be helpful during their child's transition to adulthood (McNair & Rusch, 1991).

Moving Forward

Personal Growth

Leonard et al (2016) found that some parents perceived the transition period to adulthood as a positive experience. Parents described the process as part of continued growth and development for their child: *"It's a natural progression of life, all children have to leave the school system whether they have a disability or not."* (Leonard et al, 2016). Gillian and Coughlan (2010) further highlighted that parents perceive the transition to adulthood as a positive experience for their child as they begin to adjust to new roles and settings. However, parents can often have difficulties with keeping a balance between encouraging change and being aware of their child's abilities although this is an important factor in facilitating independence for the young adult (Docherty & Reid, 2009; Thorin et al, 1996). Parents have also highlighted the importance of their offspring being aware of their intellectual disability diagnosis, but that this does not prevent them from accomplishing their goals in life (Docherty & Reid, 2009). Parents perceived the transition to adulthood as successful when their child with ID was happy and content, had a social life, was able to engage in activities and had confidence in doing what they wanted (Heslop & Abbott, 2007).

The Future

Some studies found parents often reflected on their child's future (Leonard et al, 2016; Raghavan et al, 2013; McNair & Rusch, 1991; Thorin et al, 1996). The findings from Leonard et al (2016) suggest that parents recognise the critical role they perform in helping their child during the transition period, as they provide love and practical to ensure their child has a good life. However, parents also acknowledged their own ageing and the implications this may have on providing the care and support their child needs (Leonard et al, 2016; Docherty & Reid, 2009). Whilst the parents in Raghavan et al (2013) study also discussed future expectations for their child, they envisaged the siblings in the family taking on the responsibilities of caring for the child with intellectual disabilities when they were no longer able to do so. Furthermore, Pakistani and Bangladeshi parents also expressed expectations of marriage for their child and anticipated that the married wife or husband would take over the caring duties (Raghavan et al, 2013).

Discussion

This review aimed to gather and explore data relating to how parents perceived and experienced the transition to adulthood for their child with ID. This review indicates that a number of challenges and obstacles persist in facilitating smooth transitions to adulthood for young adults with ID. The main factors identified within this review relate to the transition process and planning, the impact of the parent involvement during the transition planning, and the affect this can have on parents psychologically and financially. These findings mirror those of previous research that highlight the difficulties parents experience in accessing information and services post-school, the lack of support available for families during the transition plan, and the limited access to social activities for PwID (Chambers et al, 2004; Hudson, 2003). However, positive factors associated with the transition to adulthood also emerged within this review, which further support the growing evidence base of satisfaction in relation to caregiving for PwID (Grant & Ramcharan, 2001).

The majority of the studies included in this review focused on the transition from school to adulthood, further suggesting this continues to be one of the most significant movements in a young adult's life-cycle (Arnett, 2000). Despite the importance of this momentous change, this review highlighted that parents are often unaware of the transition plan, and when they were, it was during the last moments before their child was leaving school. Although these findings are consistent with research from over a decade ago (Kraemer & Blacher, 2001), research since the 1980s has continued to demand that educational providers enhance the current transition practice (Lindstrom, Doren & Miesch, 2011; Gauthier-Boudreault et al, 2017a; Leonard et al, 2016). In the UK, The Department of Health (2001) identified the transition to adulthood as a difficult process to manage by families and services, although it was recommended as an essential period to reduce stress and anxiety for families. It was therefore suggested that services need to take a long-term view of the transition planning for PwID (Department of Health, 2001). Although this review synthesised research that was conducted nationally, studies carried out in the UK (Raghavan et al, 2013; Heslop & Abbott, 2007; Docherty & Reid, 2009) indicate a gap between policy and practice as transition timing and planning continues to be problematic issue for parents. From this review, it is evident that transition timing and planning is a global issue for parents rather than one that is bound and informed by policy.

The studies within this review also indicated that there has been limited transformation and change internationally from 1990 to 2018, as certain difficulties have continued to reside during the transition process to adulthood for individuals with ID. Examples include parents experiencing psychological difficulties (Thorin et al, 1996; Rapanaro et al, 2007), parents wanting more involvement in the transition process (Thorin et al, 1996; Gauthier-Boudreault et al, 2017a), and parents requesting for more daytime activities for their child with ID once they have left educational services (Black et al, 1990; Strnadová & Evans, 2013). Despite the time frame of the studies in this review, the findings suggest that parents of children with ID continue to experience the same challenges that were highlighted in the 1990s. These findings therefore imply that there has been limited change to support families during the transition process to adulthood for their child with ID.

This review highlighted that parents express the need for better communication and information about services during the transition process, another identified recurrent problem within literature (Dean, 2003; Beresford, 2004). Due to the complexities and challenges associated with the transition process, parents may be unaware of adult service providers and must rely on others for information (Kraemer & Blacher, 2001). This review found that some parents wanted a key worker to help them during the transition, however research suggests that professionals are often unable to cope with the demands of these services for PwID (Cope, 2003). Due to the limited availability of formal support provided by services, this review found that parents often take on the role of a caregiver and navigator during the transition process. However, the young adults' personal involvement in the transition planning from school to adulthood was reported as an issue by some parents. Research suggests the involvement of young adults with ID during the transition process is an important factor in facilitating successful transitions, as it often helps them achieve their desired outcomes and is often associated with positive results, such as better quality of life (Wehmeyer, 1998; Laragy, 2004). This review found that some parents experience feelings of anxiety and uncertainty in relation to making choices on behalf of their child with ID, although involving young adults in the decision-making process may alleviate some of these feelings parents experience. However, some young adults with ID may lack capacity in making these decisions (Bartlett, 2012), which further highlights that PwID may continue to dependent on their families during adulthood.

The work of some authors such as Arnett (2000) have been criticised in overly focusing on concepts such as individualism which are associated with Western cultural bias, and therefore fail to consider collectivist values of other cultures (Docherty & Reid, 2009). Other researchers view the dichotomy between individualism and collectivism as overly simplistic, with evidence of complexity existing in different cultures which impact on their expression of independence and interdependence (Schulze, 2004). Within this review, the parental role often reflected these complex concepts of both independence and interdependence. A majority of the parents in the included studies reported a need for some sort of support from professionals or services to help them facilitate the transition to adulthood, however they expressed an ideal account of independence in adulthood for their child with ID. Furthermore, parents also expressed that their child with ID remained dependent on them and their caregiving duties. Thus, parents may conceptualise independence and interdependence not as concepts occupying conflicting ends of a continuum but rather as constructs that form component parts of an adult identity for their child with ID.

In this review, parents often perceived the transition to adulthood as a stressful and uncertain time and they often felt sad, anxious, and resentful, similar to key themes reported in the literature (Beresford, 2004; Kraemer & Blacher, 2001; Chambers et al, 2004). The negative emotional impact experienced by parents was often associated with the loss of the school provision and the lack of opportunities for their child. Furthermore, the lack of available accommodation provision and employment options post-school transition was also salient issue for parents, as highlighted by previous research (Chambers et al, 2004; Kraemer & Blacher, 2001). However, the need for these services may reflect the limited post-school options that are in fact available to families and PwID.

For some parents the stress they experience during the transition process may be accompanied by their own fear of the future for their child and their own reluctance of the young adult moving out of the family home. These parental perceptions may derive from an attachment base that may be experienced by parents of young adults with ID (e.g., an anxious-ambivalent attachment between caregiver and child) (Liddle & Schwartz, 2002). However, the differing attachment experiences of parents with a child with ID and those without an ID during the transition to adulthood have not yet been studied, which would yield interesting findings for this field of research. The stress experienced by parents may also perhaps be influenced by an underlying sense of unresolved grief from when the child was initially diagnosed that is perpetuated by this period in the life-cycle, which Carr (1994) suggests occurs during the family life cycle.

Strengths and Limitations

This is the first review that synthesises a wide range of research that specifically considers parental experiences of the transition to adulthood for their child with ID. The findings could perhaps provide supplementary information to services and professionals in determining how best to help families of PwID during the transition to adulthood. Although a comprehensive process was facilitated to identify relevant papers, only 16 articles met the inclusion criteria. This highlights the limited research on PwID and their families, further suggesting they are a marginalised group within society (Hall, 2010). On the other hand, despite conducting a thorough search of the studies, some articles may have potentially been overlooked as it is not completely possible to conduct an objective or replicable review. Consequently, increasing the trustworthiness of findings through transparency is considered to be an important part of the review process (Bearman & Dawson, 2013). The methodological quality assessment of the included studies highlighted limited reflexivity of the researcher in the studies, further suggesting limitations for trustworthiness across findings. Furthermore, the first author's characteristics may have also potentially influenced the synthesis of the findings highlighted in this review. A reflective diary and the use of supervision were used to mitigate the impact the first authors assumptions and values on the review.

There are common design and methodological limitations across the included studies in the review. The samples in the studies were generally small and unrepresentative, questioning the generalisability of the findings. Furthermore, studies used different diagnoses and definitions of ID, which further question whether these findings are representative of the ID population. Moreover, most of the studies relied on parent volunteer sampling, with a number of studies only focusing on the perspective of mothers. When fathers were included in the studies, this was in conjunction with their partners, which may have led to sample biases. Within literature, it has highlighted that it is predominately mothers that support their child with ID (Willingham-Storr, 2014), which may have perhaps led to researcher bias when recruiting and approaching fathers for the studies. Furthermore, there is little published research that focuses on the experiences of fathers caring for a child with ID (Willingham-Storr, 2014), albeit limited in its scope, research highlights that some fathers experience intrusive thoughts relating to the burden they feel during this caregiving role (Catherall & Iphofen, 2006). However, there is no research as of yet that specifically focuses on the experiences of fathers during transition to adulthood for their child with ID, suggesting future research may warrant exploration within this sample group.

Some studies within this review included some interventions for the difficulties and challenges experienced by parents during the transition process. However, there is limited information regarding whether the strategies proposed by parents in the included studies would be representative of the current economical climate of the UK. Another limitation of this review is that it only included studies produced in the English language, potentially excluding studies that are written in other languages that report on the experiences of parents and possible interventions that may be helpful to facilitate smoother transitions to adulthood. This may potentially be a source of publication bias, accompanied by only including papers from peer-reviewed journals. Finally, this review highlighted that transitions to adulthood can be influenced by cultural differences, which questions whether the findings of this study are generalisable cross-culturally.

Implications and Future Research

The findings highlighted in this review point towards several recommendations toward facilitating and improving the transition process to adulthood for parents of children with ID. Firstly, transitions from the education service should begin early so that parents perceive the transition as a process and not a cumulative event. As the included studies mainly focused on the transition from school to adulthood, future research could perhaps study how parents perceive other transitions that occur during adulthood, such as moving out of the family home and getting married. Furthermore, as studies within this review mainly focused on the experiences of mothers, it is recommended that future studies include the perspectives of fathers as much as possible so that their experiences of the transition process for their child with ID is also understood.

Research continues to suggest that there is a clear need to better develop relationships with parents and professionals. Sharing accurate information between all services involved, including professionals and parents, may potentially alleviate parents' feelings of anxiety and frustration. Furthermore, service providers and education systems could broaden the ways they make information accessible and available to parents. For examples, using Internet websites, a telephone service, community guides and groups, to signpost parents to the services they may require and need. In terms of future research, studies could explore what services and strategies parents in the UK use to facilitate smoother transitions for PwID.

Conclusions

The present review conceptualises and frames the current literature available on parents' experiences of the transition process to adulthood for their offspring with ID. This review highlights that parents encounter a number of difficulties during the transition process and planning for their child with ID. Parents have an active role in these transitions, however this can have a psychologically and financially impact on them and the rest of the family. This review also highlighted that parents experienced a number of positive factors during their child’s transition to adulthood. Furthermore, the review offers possible solutions to the identified problems parents experience during the transition period. Future research is required to directly explore what strategies and services are helpful for parents during the transition to adulthood, therefore increasing knowledge within this field and informing how transitions can be facilitated more smoothly for PwID.

References

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

Bartlett, P. (2012). The United Nations Convention on the Rights of Persons with Disabilities and mental health law. *The Modern Law Review*, *75*(5), 752-778.

Bearman, M., & Dawson, P. (2013). Qualitative synthesis and systematic review in health professions education. *Medical education*, *47*(3), 252-260.

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

Berzin, S. C. (2010). Vulnerability in the transition to adulthood: Defining risk based on youth profiles. *Children and Youth Services Review*, *32*(4), 487-495.

Bhaumik, S., Watson, J., Barrett, M., Raju, B., Burton, T., & Forte, J. (2011). Transition for teenagers with intellectual disability: carers' perspectives. *Journal of Policy and Practice in Intellectual Disabilities*, *8*(1), 53-61

Bianco, M., Garrison-Wade, D. F., Tobin, R., & Lehmann, J. P. (2009). Parents' perceptions of postschool years for young adults with developmental disabilities. *Intellectual and Developmental Disabilities*, *47*(3), 186-196.

Biehal, N., & Wade, J. (1996). Looking back, looking forward: Care leavers, families and change. *Children and youth services review*, *18*(4-5), 425-445.

*Black, M. M., Molaison, V. A., & Smull, M. W. (1990). Families caring for a young adult with mental retardation: Service needs and urgency of community living requests. *American journal of mental retardation: AJMR*, *95*(1), 32-39.

British Psychological Society (BPS). (2015). *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood.* Retrieved from: https://www.rcpsych.ac.uk/pdf/ID%20assessment%20guidance.pdf

Carr, A. (1994). Involving children in family therapy and systemic consultation. *Journal of Family Psychotherapy*, *5*(1), 41-59.

Catherall, C., & Iphofen, R. (2006). Living with disability. *Learning Disability Practice*, *9*(5), 16-21.

Chambers, C. R., Hughes, C., & Carter, E. W. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities*, 79-94.

Clarke, S., Sloper, P., Moran, N., Cusworth, L., Franklin, A., & Beecham, J. (2011). Multi-agency transition services: greater collaboration needed to meet the priorities of young disabled people with complex needs as they move into adulthood. *Journal of Integrated Care*, *19*(5), 30-40.

Cope, C. (2003). *Fulfilling lives: inspection of social care services for people with learning disabilities*. Social Services Inspectorate, Department of Health.

Côté, J. E. (2006). Emerging Adulthood as an Institutionalized Moratorium: Risks and Benefits to Identity Formation. In J. J. Arnett & J. L. Tanner (Eds.), *Emerging adults in America: Coming of age in the 21st century* (pp. 85-116). Washington, DC, US: American Psychological Association.

Dean, J. (2003). *Unaddressed: the housing aspirations of young disabled people in Scotland*. York: Joseph Rowntree Foundation.

Department of Health. (2001). *Family Matters: Counting Families In*. London: Department of Health.

*Docherty, J., & Reid, K. (2009). 'What's the Next Stage?'Mothers of Young Adults with Down Syndrome Explore the Path to Independence: A Qualitative Investigation. *Journal of Applied Research in Intellectual Disabilities*, *22*(5), 458-467.

*Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. *Journal of Intellectual and developmental Disability*, *38*(2), 149-162.

Emerson, E., Shahtahmasebi, S., Lancaster, G., & Berridge, D. (2010). Poverty transitions among families supporting a child with intellectual disability. *Journal of Intellectual and Developmental Disability*, *35*(4), 224-234.

Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. *Journal of the Association for Persons with Severe Handicaps*, *13*(3), 177-187.

*Foley, K. R., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., ... & Leonard, H. (2013). Functioning and post-school transition outcomes for young people with Down syndrome. *Child: care, health and development*, *39*(6), 789-800.

Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *Journal of personality and social psychology*, *50*(5), 992.

Forte, M., Jahoda, A., & Dagnan, D. (2011). An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood. *British Journal of Clinical Psychology*, *50*(4), 398-411.

*Gauthier-Boudreault, C., Gallagher, F., & Couture, M. (2017a). Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing? *Research in developmental disabilities*, *66*, 16-26.

*Gauthier-Boudreault, C., Couture, M., & Gallagher, F. (2017b). How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*.

*Gillan, D., & Coughlan, B. (2010). Transition from special education into postschool services for young adults with intellectual disability: Irish parents' experience. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(3), 196-203.

Goodman, I., Henderson, J., Peterson-Badali, M., & Goldstein, A. (2016). Youth perspectives on the transition to adulthood: Exploring the impact of problematic substance use and treatment seeking. *Emerging adulthood*, *4*(2), 92-103.

Grant, G., & Ramcharan, P. (2001). Views and experiences of people with intellectual disabilities and their families (2) The family perspective. *Journal of Applied Research in Intellectual Disabilities*, *14*(4), 364-380.

Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*, *54*(s1), 48-57.

Hanley-Maxwell, C., Whitney-Thomas, J., & Pogoloff, S. M. (1995). The second shock: A qualitative study of parents' perspectives and needs during their child's transition from school to adult life. *Journal of the Association for Persons with Severe Handicaps*, *20*(1), 3-15.

Hassall, R., Rose, J., & 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.

*Heslop, P., & Abbott, D. (2007). School’s Out: pathways for young people with intellectual disabilities from out-of-area residential schools or colleges. *Journal of Intellectual Disability Research*, *51*(7), 489-496.

Hudson, B. (2006). Making and missing connections: learning disability services and the transition from adolescence to adulthood. *Disability & Society*, *21*(1), 47-60.

Keogh, B. K., Bernheimer, L. P., & Guthrie, D. (2004). Children with developmental delays twenty years later: Where are they? How are they? *American Journal on Mental Retardation*, *109*(3), 219-230.

Killaspy, H. (2006). From the asylum to community care: learning from experience. *British Medical Bulletin*, *79*(1), 245-258.

Kohler, P. D., & Field, S. (2003). Transition-focused education: Foundation for the future. *The Journal of Special Education*, *37*(3), 174-183.

Konstam, V. (2007). Emerging and Young Adulthood: Multiple Perspectives. *Diverse Narratives.*

Kraemer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation: School preparation, parent expectations, and family involvement. *Mental Retardation*, *39*(6), 423-435.

Laragy, C. (2004). Self-determination within Australian school transition programmes for students with a disability. *Disability & Society*, *19*(5), 519-530.

*Leonard, H., Foley, K. R., Pikora, T., Bourke, J., Wong, K., McPherson, L., ... & Downs, J. (2016). Transition to adulthood for young people with intellectual disability: the experiences of their families. *European child & adolescent psychiatry*, *25*(12), 1369-1381.

Liddle, H. A., & Schwartz, S. J. (2002). Attachment and family therapy: clinical utility of adolescent-family attachment research. *Family Process*, *41*(3), 455-476.

Lindstrom, L., Doren, B., & Miesch, J. (2011). Waging a living: Career development and long-term employment outcomes for young adults with disabilities. *Exceptional Children*, *77*(4), 423-43

*Martinez, D. C., Conroy, J. W., & Cerreto, M. C. (2012). Parent involvement in the transition process of children with intellectual disabilities: The influence of inclusion on parent desires and expectations for postsecondary education. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(4), 279-288

McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage & Family Review*, *6*(1-2), 7-37.

McIntyre, L. L., Blacher, J., & Baker, B. L. (2006). The transition to school: Adaptation in young children with and without intellectual disability. *Journal of Intellectual Disability Research*, *50*(5), 349-361.

McKenzie, K., Ouellette-Kuntz, H., Blinkhorn, A., & Démoré, A. (2017). Out of school and into distress: families of young adults with intellectual and developmental disabilities in transition. *Journal of Applied Research in Intellectual Disabilities*, *30*(4), 774-781.

*McNair, J., & Rusch, F. R. (1991). Parent involvement in transition programs. *Mental Retardation*, *29*(2), 93.

Mill, A., Mayes, R., & McConnell, D. (2010). Negotiating autonomy within the family: The experiences of young adults with intellectual disabilities. *British Journal of Learning Disabilities*, *38*(3), 194-200.

Moghaddam, N. (2014). Applying family life cycle concepts in psychological practice with children and young people. *Applied Psychological Research Journal*, *1*(2), 26-33.

Moher, D., Liberati, A., Tetzlaff, J. & Altman, D. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *British Medical Journal*, 339, b2535.

National Institute for Health and Care Excellence (NICE). (2012). *Methods for the development of NICE public health guidance (3rd ed.).* London: Author.

Neece, C. L., Kraemer, B. R., & Blacher, J. (2009). Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellectual and Developmental Disabilities*, *47*(1), 31-43.

Pluye, P., Gagnon, M. P., Griffiths, F., & Johnson-Lafleur, J. (2009). A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies*, *46*(4), 529-546.

Pollock, G. (2002). Contingent identities: updating the transitional discourse. *Young*, *10*(1), 59-72.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., … Duffy, S. (2006). *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews: A product from the ESRC methods programme.* Lancaster: Institute of Health Research.

*Raghavan, R., Pawson, N., & Small, N. (2013). Family carers' perspectives on post-school transition of young people with intellectual disabilities with special reference to ethnicity. *Journal of Intellectual Disability Research*, *57*(10), 936-946.

*Rapanaro, C., Bartu, A., & Lee, A. H. (2008). Perceived benefits and negative impact of challenges encountered in caring for young adults with intellectual disabilities in the transition to adulthood. *Journal of Applied Research in Intellectual Disabilities*, *21*(1), 34-47.

Rehm, R. S., Fuentes-Afflick, E., Fisher, L. T., & Chesla, C. A. (2012). Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability. *ANS. Advances in nursing science*, *35*(3), E57.

Schulze, P. A. (2004). Filipino Mothers' Beliefs about Parenting: a question of independence. *Contemporary Issues in Early Childhood*, *5*(3), 391-395.

Shanahan, M. J. (2000). Pathways to adulthood in changing societies: Variability and mechanisms in life course perspective. *Annual review of sociology*, *26*(1), 667-692.

Shelden, D. L., & K. Storey. (2014). “Social Life”. In K. Storey & D. Hunter (Eds.), *The Road Ahead* (pp. 233–254). Clifton: IOS Press.

*Strnadová, I., & Evans, D. (2013). Schooling transitions within the lifespan of people with an intellectual disability: Perceptions and recommendations of ageing mothers. *Australasian Journal of Special Education*, *37*(1), 64-78.

Stohler, R., Storo, J., Vincent, D., Wade, J., Schröer, W., Zeller, M., ... & Köngeter, S. (2008). *Young people's transitions from care to adulthood: international research and practice*. Jessica Kingsley Publishers.

Taylor, J. L., & Henninger, N. A. (2015). Frequency and correlates of service access among youth with autism transitioning to adulthood. *Journal of autism and developmental disorders*, *45*(1), 179-191.

*Thorin, E., Yovanoff, P., & Irvin, L. (1996). Dilemmas faced by families during their young adults' transitions to adulthood: A brief report. *Mental Retardation*, *34*(2), 117.

Tyrer, F., McGrother, C. W., Thorp, C. F., Donaldson, M., Bhaumik, S., Watson, J. M., & Hollin, C. (2006). Physical aggression towards others in adults with learning disabilities: prevalence and associated factors. *Journal of Intellectual Disability Research*, *50*(4), 295-304.

*Unwin, G., LeMesurier, N., Bathia, N., & Deb, S. (2008). Transition for adolescents and young adults with learning disabilities and mental health problems/challenging behaviours: the parent carers' views. *Advances in Mental Health and Learning Disabilities*, *2*(1), 22-28.

Ward, L., Heslop, P., Mallett, R., & Simons, K. (2003). Transition: The experiences of young people with learning disabilities and their families in England. *Tizard Learning Disability Review*, *8*(4), 19-28.

Wehmeyer, M. L. (1998). Self-determination and individuals with significant disabilities: Examining meanings and misinterpretations. *Journal of the Association for Persons with Severe Handicaps*, *23*(1), 5-16.

West, M. D., & Fuller, W. E. (2006). Housing and community living. *Life beyond the classroom (4th ed., pp. 369–385). Baltimore: Brookes*.

Wikler, L. (1986). Periodic stress in families of children with mental retardation. *American Journal of Mental Deficiency*, *90*(6), 703-706.

Willingham-Storr, G. L. (2014). Parental experiences of caring for a child with intellectual disabilities: A UK perspective. *Journal of Intellectual Disabilities*, *18*(2), 146-158.

Worth, N. (2009). Understanding youth transition as ‘becoming’: identity, time and futurity. *Geoforum*, *40*(6), 1050-1060.

Young-Southward, G., Rydzewska, E., Philo, C., & Cooper, S. A. (2017). Physical and mental health of young people with and without intellectual disabilities: cross-sectional analysis of a whole country population. *Journal of Intellectual Disability Research*, *61*(10), 984-993.

Part two: Empirical Paper

Young Adults with Intellectual Disabilities Transitioning from Children Services to Adult Services: Experiences of Residential Staff and Healthcare Professionals

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Abstract

Background: Leaving the looked after care system can often be a challenging and difficult time for young adults with intellectual disabilities (ID) as they begin to transition to adult life. There is an emphasis on services providing support during transition process for care leavers, although there is no literature that focuses on how services perceive this transition for young adults with ID. Therefore, this study aims to explore the experiences of residential staff and healthcare professionals that have worked with young adults with ID who have been in the care of the Local Authority and transitioned into adult services.

Method: Four focus groups with children residential staff, adult residential staff, healthcare professionals from children community learning disability teams, and healthcare professionals from adult community learning disability team were conducted. The data was analysed using thematic analysis.

Result: Three superordinate and nine subordinate themes were identified. Participants experiences consisted of what adulthood meant for PwID once they departed from the care system, how transitions to adulthood would begin, and the challenges of person-centred care in adult services.

Conclusions: This study emphasised the experiences of residential staff and healthcare professionals that have worked with young adults with ID during the transition from children's services to adult services, with broader implications for developing smoother transitions in the future.

Key words: Intellectual disabilities; looked after children; transition, adulthood.

Introduction

Disabled children and young people are consistently over-represented within the care of the Local Authority, often referred to as looked after children (LAC) in England (Winter, 2006). It has been estimated that between 10 and 25 per cent of LAC are disabled (Baker, 2007; Gordon, Parker & Loughrin, 2000). Despite these figures, research has continued to neglect this population, which has been attributed to the dearth of statistical information available (Morris, 1997). Young adults departing from the care of the Local Authority at the age of 18 have been identified as one of the most vulnerable groups in society (Hatfield, Harrington & Mohamad, 1996; Winter, 2006). Leaving the looked after care system can often be a challenging and difficult time for young adults with ID as they begin to transition to adult life (Priestley, Rabiee & Harris, 2003). The distinctive patterns of past experiences and current circumstances of LAC contribute to how the transition from the care system to adulthood is navigated (Cicchetti & Rogosch, 2002).

LAC leaving the care system often demonstrate poor outcomes across multiple domains of functioning and well-being (Stein, 2006). They are at an especially high risk of experiencing social exclusion, homelessness, unemployment and loneliness and involvement in the criminal justice system (Biehal & Wade, 1996; Stein, Pinkerton & Kelleher, 2000; Dixon & Stein, 2005). These findings do not specifically focus on the experiences of young adults with ID after leaving care; further suggesting this is a group that has been largely ignored within research (Stohler et al, 2008; Trout et al, 2009). Indeed, there has only been one study to date that has sought to specifically explore the experiences of young disabled people leaving looked after care and the transitioning into adulthood (Priestley et al, 2003). Priestley et al (2003) found young adults with ID experienced many unmet needs during the transition process to adulthood as they navigated the complexity of service systems. The transition process was often unplanned and abrupt, the services were unlikely to support the needs of each young disabled individual, and they were restricted by limited housing and employment (Priestley et al, 2003). Considering the disadvantaged personal histories of all LAC, it is unsurprising that these negative outcomes are experienced once young adults with ID leave the care of the Local Authority (Pecora et al, 2005).

Within the LAC research, a number of compelling reasons for these negative patterns have been suggested for young adults leaving care. The complex familial circumstances of LAC, as well as a history of long-term care, often leaves these young adults with impoverished networks to support them during the transition into adult life (Perry, 2006; Rosenfeld et al, 1997). They begin to lose critical supportive relationships with important teachers, child welfare staff and foster families, who were significant figures in their lives (Munson, Brown, Spencer, Edguer & Tracy, 2015; Priestley et al, 2013). Furthermore, discontinuing or fragmentation of the social services, mental health services, and accommodation services during the transition process can be a challenging period for LAC leaving care (Osgood, Foster & Courtney, 2010; Munson, Stanhope, Small & Atterbury, 2017). These services would often be their primary source of support during their developmental years, however departing from care can result in these relationships fading away as adjustments to adult service are made (Akister, Owens, & Goodyer, 2010). Although these relationships with healthcare professionals and residential staff cease once the young person transitions to adult services, it is suggested that these professionals provide valuable support in helping young adults make decisions during the transition to adulthood (Csikszentmihalyi & Schneider, 2008).

Studies have consistently found that LAC emphasise the central role of attachment and relationships with staff on their experiences of the care system. Often, LAC experience adversity over a prolonged period of time or intermittent patterns (Perry, Pollard, Blakley, Baker & Vigilante, 1995). The presence of psychological and emotional difficulties amongst this group is well documented within literature (Perry et al, 1995; Frederico, Jackson & Black, 2008). Research on attachment emphasises the importance of relational experiences in early childhood as these become foundations for the development of their personality (Bowlby, 1969; Fonagy, 2002). Furthermore, research delineates that LAC brought up in abusive home environments and subjected to rejection and aggression often produce insecure attachments (Cicchetti & Rogosch, 1997). Howe and Campling (1995) explain these experiences can potentially cause LAC to become distrustful towards other adults, have difficulties with empathy, forming and maintaining future relationships during adulthood. Although there are no studies that specifically explore attachment styles for young adults with ID in the care system, research suggests that individuals with ID are more likely display insecure attachments (Atkinson et al, 1999; Ganiban, Barnett & Cicchetti, 2000; Schuengel & Janssen, 2006). It is hypothesised that this could be due to increased stress appraisals and experiences of individuals with ID (Janssen, Schuengel & Stolk, 2002; Schuengel & Janssen, 2006), as well as the increased stress parents experience caring for a child with ID which may disrupt the caregiving system (Marvin & Pianta, 1996).

Research suggests the importance of consistent, reliable, and lasting relationships advocates security and well-being for LAC once they leave the care system (Cahill, Holt & Kirwan, 2016). Bowlby (1969) asserts that secure and sensitive relationships in childhood are often associated with development of healthy and happy relationships in adulthood. Although research is limited in highlighting the success of care-leavers (Martin & Jackson, 2002), some studies have found a key factor in facilitating successful transitions in adulthood is related to having positive and stable relationships with professionals (Dumaret, Donati & Crost, 2011; Martin & Jackson, 2002; McLeod, 2008). Despite research highlighting the importance of providing support during the transition to adulthood for LAC by professionals, it is often found that this support ends once the young person departs from care.

The study by Priestley et al. (2003) was the first to give a voice to young disabled individuals that had been in the care of the Local Authority and transitioned into adulthood. However, there continues to be a gap within literature regarding how healthcare professionals and residential staff experience the transition to adulthood for young adults with ID that have been in care of the Local Authority. As there has been an emphasis on providing support from services during transition process for care leavers, it is therefore fundamental to acknowledge the perspectives of staff working in this field. Providing staff with a voice to explain how they experience these transitions for young adults with ID can provide an insight into how professionals can navigate successful transitions in the future. This study therefore aims to explore the experiences of residential staff and healthcare professionals that have worked with young adults with ID who have been in the care of the Local Authority and transitioned into adult services.

Method

Design

A qualitative design was employed using semi-structured focus groups to explore how residential staff and healthcare professionals experience the transition process for PwID who have been in looked after care and transitioned into adult services. Focus groups were used to gather detailed information about how each particular group experiences the transition process for PwID. Furthermore, separate focus groups were conducted minimise social desirability bias between the participants. The focus groups were transcribed and analysed using thematic analysis (Braun & Clarke, 2006).

Sample

Purposive sampling was used to recruit a suitable homogenous sample of participants. The researcher consulted with professionals working within the field and it was decided that residential staff and healthcare professionals will have frequent contact with PwID during the transition process from children services to adult services. Participants were excluded if they did not meet the inclusion criteria.

The participants in this study were included if they:

- Had some involvement in the transition process from children services to adult services for PwID who were in care of the Local Authority.
- Were a residential staff member or healthcare professional.
- Were aged over 18.
- Had capacity to give informed consent to participation.

Participants were recruited through advertisement posters and information sheets (Appendix E-F) which were distributed by e-mail to potential participants by team leaders and managers of child and adult residential homes and child and adult community learning disability teams within the region of Yorkshire region. Prior to the focus groups, all participants provided written consent and demographic information (Appendix G-H).

The first focus group consisted of eight participants who all worked at the same child residential home, in line with guidelines that recommend 4-8 participants are required to conduct a focus group (Wilkinson, 2008). All the participants were care officers and the majority, apart from one, had over nine years of experience working within that specific children residential home. Participants were aged between 31 and 51 years (mean=44.4 years) and there were more females (n=5) than males (n=3). All participants identified themselves as White British. The demographics for the child residential staff (CRS) are presented in Table 1.

Table 1. CRS' demographic information.

Participants number	**Age**	**Gender**	**Ethnicity**	**Job title**	**Length of time working in service**
Focus group 1					
CRS1	38	Female	White British	Care officer	9+ years
CRS2	46	Female	White British	Care officer	9+ years
CRS3	31	Male	White British	Care officer	9+ years
CRS4	48	Female	White British	Care officer	9+ years
CRS5	50	Female	White British	Care officer	9+ years
CRS6	47	Male	White British	Care officer	9+ years
CRS7	51	Female	White British	Care officer	9+ years
CRS8	44	Male	White British	Care officer	1-3 years

The second focus group included four participants. All participants were recruited from the same adult residential home. There were more female (n=3) than male (n=1) participants. Participants were aged between 25 and 33 years (mean=28.7 years) and all identified as White British. The length of time working in the residential home ranged from one to six years. The participants job roles all differed, see Table 2 for further details of participant demographics for adult residential staff (ARS).

Table 2. ARS' demographic information.

Participants number	**Age**	**Gender**	**Ethnicity**	**Job title**	**Length of time working in service**
Focus group 2					
ARS1	28	Female	White British	Co-ordinator for clinical wellbeing, quality assurance, training and service user reviews	4-6 years
ARS2	33	Male	White British	Team leader	1-3 years
ARS3	29	Female	White British	Support worker	4-6 years
ARS4	25	Female	White British	Support worker	4-6 years

The third focus group also included four participants. The participants were recruited across two different children community learning disability teams within the Yorkshire region. Participants age ranged from 28 to 48 years (mean=41 years) and the majority were female (n=3). All participants identified as White British. The length of time working within the service ranged from 6 months to 9 years. Three participants were community nurses and one was a clinical team leader with a nursing background. The demographic information of the healthcare professionals from the children community learning disability team (CCTLD) are presented in Table 3.

Table 3. CCTLD' demographic information.

Participants number	Age	Gender	Ethnicity	Job title	Length of time working in service
Focus group 3					
CCTLD1	48	Female	White British	Clinical team leader	9+ years
CCTLD2	43	Female	White British	Community nurse	1-3 years
CCTLD3	28	Female	White British	Community nurse	6months-1 year
CCTLD4	45	Male	White British	Community nurse	9+ years

The final group consisted of three participants whom were all recruited from the same adult community learning disability team. Although 4-8 participants are recommended to conduct a focus group (Wilkinson, 2008), it is suggested for thematic analysis that 2-4 participants are required for a group to achieve data saturation for theme converge or diverge (Braun & Clarke, 2006), thus this focus group falls within the 2-8 range. The participants ages ranged from 36 to 53 (mean=43 years), all described themselves as White British. There were two males and one female. The length of time working within the service ranged from 6 months to more than 9 years. Two of the participants were clinical psychologists and one was a specialist learning disability nurse. Demographics for the healthcare professionals from the adult community learning disability team (ACTLD) are presented in Table 4.

Table 4. ACTLD' demographic information.

Participants number	Age	Gender	Ethnicity	Job title	Length of time working in service
Focus group 4					
ACTLD1	53	Male	White British	Specialist learning disability nurse	6 months-1 year
ACTLD2	40	Female	White British	Clinical psychologist	9+ years
ACTLD3	36	Male	White British	Clinical psychologist	6 months-1 year

Procedure

Ethical approval for this study was granted by a University Research Ethics Committee and the Research and Development Support Service from the local NHS Trust (see appendix I-J). Participants that agreed to participate in the study provided informed consent prior to the focus group, and a convenient date, time and location were agreed upon for the focus group.

Focus groups were guided by a semi-structured interview schedule, providing flexibility to allow participants to share own agendas (Smith, Flowers & Larkin, 2009). Participants were informed that the researcher was interested in hearing about their experiences of working with PwID in looked after care that had transitioned from children's services to adult services. The schedule was developed based upon discussions with healthcare professionals specialising in facilitating transitions from children services to adult services and reviewing the relevant literature (Appendix K). The same interview schedule was used with each focus group. At the end of each focus group, participants were provided with contact details of relevant support services following participation (Appendix L). The four focus groups were completed face-to-face and ranged from 1 hour and 28 minutes to 59 minutes. Focus groups were audio-recorded and then transcribed verbatim.

Data Analysis

A descriptive phenomenological epistemology underpinned this research, which focused on the experiences of participants as they shared them (Appendix N). The focus groups were analysed using thematic analysis, as research aimed to identify patterns and themes within data sets, and between groups (Braun & Clarke, 2006). Furthermore, thematic analysis allows for any similarities and differences to be identified between the services involved in the transition process from children services to adult services. Focus groups were initially analysed separately before themes were identified across the data sets, using Braun and Clarke's (2006) guide:

1. Each focus group was transcribed and read repeatedly by the researcher, noting any points of interest across the transcript.
2. Initial codes for each transcript were produced separately (see Appendix M for a worked example of analysis).

3. The codes for all the transcripts were combined and similarities amongst all data sets were searched for. The process involved considering how to organise and collate the codes into broader themes and subthemes. Themes and subthemes were considered when the data was represented in more than one focus group.
4. Within each theme, the coded extracts were re-read to identify whether they formed a pattern and the validity of each theme reflected the data set as a whole.
5. Themes were then defined, named and storied, and identified to fit with the broader narrative of the data and to other relative themes.

Quality

In designing this research, a number of meetings were arranged with health professionals to check the suitability of information sheets, consent forms and the research procedure. During the analysis process, various arrangements were taken to ensure rigour and transparency related to the qualitative research (Meyrick, 2006). The credibility and validity of the codes drawn upon during the analysis of this research were discussed in research supervision and a reflective journal was used by the researcher to monitor their own personal experiences and perceptions of the research process, potentially a source of bias (Appendix O). Furthermore, quotations are used throughout the results to demonstrate the connection between the original transcripts and the developed themes.

Results

Across the data sets, three superordinate and nine subordinate themes were identified (Table 5). The analysis illustrated that all participants had experiences of the transition process to adult services for PwID that had been in the care of the Local Authority. Participant's experiences consisted of what adulthood meant for PwID once they departed from the care system, how transitions to adult services would begin, and an absence of person-centred care in adult services. Two subordinate themes 'not listened to' and 'falling through the gaps' were experienced by only two focus groups, as indicated in Table 5.

Table 5. Overview of superordinate and subordinate themes. Brackets denote the participant group(s) the subtheme related to.

Adulthood	Becoming an adult
	Wanting a normal life
Starting transitions	Limited involvement
	Lack of communication
	Advocating
	Not listened to (CRS and ARS only)
Challenges of person-centred care	Lack of clarity between services
	Falling through the gaps (CCTLD and ACCTLD only)
	Unavailable services

1.1 Adulthood

All four focus groups discussed their experiences of what it meant to become 18 years for PwID that had been in care system and were beginning to transition to adult services.

1.1 Becoming an adult

Participants explained that many changes begin to occur for young people with ID in the care system once they *"become 18 that are very different from the day before when they were 17 years 11 months and 29 days old"* (ACTLD1). They discussed that before their 18th birthday, many decisions about these young people's lives are made by the Local Authority, however *"once they turn 18… they can make their own decisions"* (ACTLD1). Participants discussed that, although these young adults were 18 years old, they continued to have an ID: "*development wise they are only 10 or 11 or 12"* (CRS7). Furthermore, CRS had concerns regarding how services assume young adults have capacity to make decisions about their lives now that they were 18 years old:

"The other thing that bothers me is when they say that the young person has capacity when they turn 18, yet if that young man is 18 and says I want to live with my mum… they are saying because that person is 18, and if they have capacity to say it then they have capacity to go home" (CRS1).

Participants explained that when PwID leave the care of the Local Authority, some begin to reconnect with their birth families. ARS explained how they often have to "*ask permission and guidance from parents to allow certain things to happen"*, although they know it is "*the right thing"* (ARS2). However, ARS and birth families often found themselves "*disagreeing"* about what was in the best interest of the young adult which was *"frustrating"* (ARS4). Participants explained how "*there's a lot of interference at times"* from birth families, which prevents them from doing their *"jobs"* (ARS3). Similarly, CRS also experienced having disagreements with birth families of PwID. Furthermore, participants also had experiences of services aligning with what the birth family wants rather than thinking *"about what is best for the child" (CRS1),* therefore questioning *"who's needs were being met?"* (CRS2).

1.2 Wanting a normal life

When participants asked PwID what they want once they leave the care of the Local Authority, they often responded with *"well I want to be in a normal family, I want to be in a normal home"* (CRS2).

Participants explained that returning back to birth families was often not always the best decision for the young person, as they were initially *"placed in care for a reason" (ARS4).* Furthermore, participants discussed how some young people continue to be "*vulnerable"* (CCTLD1) and at risk when they return to birth families:

"but the frustrating bit is that these kids are here for a reason and obviously at some point they've done some risk management and brought them in because they weren't safe, and yet when they come to 18 they go back to their parents. What's the difference?" (CRS5).

CRS discussed how they have had experiences of PwID returning to their birth families but are "*dumped and left there" (CRS2).* Moreover, they explained these breakdowns often *"reinforce rejection"* and *"shows that they're not wanted*" (CCTLD2). Participants described feeling *"sad"* (CCTLD1) that some PwID experienced these outcomes once they leave the looked after care system.

Other participants described that, although these young people wanted a normal life, they were always going to be somehow different to their peers:

"it's easier to lose sight that they're just normal young people who don't want to be different to their peers, and everything we do, no matter how hard we try, tells them that they're different to their peers. You need to see a social worker, you need to do an assessment, you need additional support" (ACTLD1).

2. Starting transitions

Starting transitions across services was relevant to all participants, although the 'not listened to' subtheme only related to CRS and ARS. Participants discussed their role in the transition process for PwID in the looked after care system and the difficulties they've experienced during these transitions to adult services.

2.1 Limited involvement

Participants across all four groups discussed service involvement in the transition process for PwID. CRS discussed how some services will not "*take on the case until at least 6 months before"* (CRS5) the young adult transitions to adult services. In some cases, some "*adult social workers wouldn't get involved until they actually turn 18"* (CRS1). CCTLD also described having similar difficulties:

"they have to hit their 18th birthday before they'll even start the process" (CCTLD1).

In contrast, ARS explained the transitions they facilitate often depend on the needs of the individual. They also described the transitions they facilitate are orientated around a person-centred approach:

"everyone's different like here we work person centred so it's all about that individual… It could be a month, or it could be 6 months or a week, it all depends on the individual" (ARS2).

The lack of early involvement from services often leads to transitions being "*just rushed",* and therefore *"hinder the care that's being offered to that person"* (CRS2). Consequently, participants described how *"everyone panics"* (CCTLD2) about the lack of involvement in preparing PwID for the next stage of their lives, which can lead to *"a panic placement sometimes… it's like we haven't found somewhere"* (CCTLD3).

Moreover, participants discussed how there might not even be a transition for some young people if they *"are not actively involved with the team, and if they're coming up to that point of 18 nobody would flag that up so there's no transition across"* (ACTLD1).

Due to the lack of early involvement from services in the transition process, participants discussed that adult professionals often do not build relationships with PwID in the care system, although *"they're going to take over this young person's life… but they don't know them"* (CRS2). Finally, ACTLD reflected on the importance of building relationships with PwID in the care system:

"young people that have been in care struggle in relationships generally because of their past experiences… they might struggle building up trust with a new set of people" (ACTLD2).

2.2 Lack of communication

All focus groups discussed a lack of communication between services during the transition process for PwID:

"what you'll find with the different teams is that they don't communicate with each other" (CRS2).

Participants discussed that a lack of communication between services often meant that they had little or no information about the young adult in their service, resulting in *"scrambling around just looking for information"* (CCTLD1). In contrast to the other three focus groups, communication was not much of an issue for the ARS*: "it's communication, it isn't too bad"* (ARS2). When there was a lack of information about the young adult, ARS would contact services that were previously involved in the young adult's care to receive the necessary information. Participants emphasised that *"for services it's so important to have that knowledge of that individual"* (ACTLD1) to facilitate transitions to adult services for PwID once they children services.

2.3 Advocating

The role of residential staff and healthcare professionals extended beyond their job role title. All focus groups discussed the importance of advocating for PwID during the transition process. CRS described themselves as "*advocates"* and "*corporate parents*" (CRS7) for children and young adults in the care system. Furthermore, participants often "*wear lots of hats*" (CCTLD1) that were not specifically part of their job role. They discussed being more than just a member of staff with a job title:

"we're invested in them, their future and their lives. We try to do so much for them, to help, to give them the best outcome that they possibly could have, and the best opportunities" (CRS2).

Furthermore, participants discussed how PwID in the care of the Local Authority often *"don't have a voice"* or *"family involvement that will advocate for them during the transition process"* (CCTLD4). Participants emphasised that family involvement is often an essential part of the transition process to access services PwID require during adulthood, thus staff have a critical role in advocating for this client group:

"they don't always have family advocating for them, and often that is what it requires. You need a mum, a granny, an aunt, an uncle, somebody who shouts this isn't good enough" (ACTLD2).

Moreover, participants explained how sometimes they know the individual "*better than their own parents"* (ARS1) because of their daily involvement in their lives. Others described how they felt about advocating for these young people:

"*I think we're very passionate about advocating for our client group, I think cause if you don't nobody else will"* (CCTLD3).

2.4 Not listened to

Only participants in the child and adult residential homes discussed their experiences of not being listened to by other services involved in the care of the young adult, despite them knowing *"that service user, their capabilities, their interests and preferences the most"* (ARS2). CRS explained how they, as a collective, were not being listened to by services, although they were "*all saying the same thing"* (CRS3) about what a young adult may require once they transition from the children's residential home.

Participants discussed how some services differ in what they believe the young person may need once they've transitioned into adult services, and therefore they may *"not always be on the same page of what's best or right for that child"* (CRS1). Participants trying to get services to hear what they believe is best for the young adult was described similar to a battlefield, as participants often have *"to fight"* (ARS1) for services. Whilst the CRS felt their active involvement in trying to pursue services for these young adults was similar to "*losing battle in the class"* (CRS1).

CRS explained, although their active involvement in getting services to hear what they have to say, "*the final decision and the final plans will always rest with the social workers"* (CRS8). Staff felt "*frustrated"* (CRS1) about their opinions not being considered. One participant explained how they felt about these situations:

"we're powerless, everybody here" (CRS3).

Although participants in the residential homes were involved in the care of the young adults on a daily basis, they often felt that they were not appreciated as professionals:

"what they don't seem to do is appreciate us as professionals and what we bring to the table with regards to these children, but we're the ones that look after them every day. We know them more than anybody else… yet that is disregarded" (CRS2).

3. Challenges of person centred-care

The final theme included the challenges of person-centred care that were experienced by participants during the transition process from children services to adult services. Although participants across all focus groups discussed the challenges of person-centred care, one subtheme differed (falling through the gaps) which only related to the CCTLD and ACTLD focus groups.

3.1 Lack of clarity between services

All focus groups, apart from the ARS, discussed how some services have unclear pathways and eligibility criteria's, which can impact on the transition process for PwID: "*they're transitioning from different services at different points in time"* (ACTLD2). Furthermore, participants discussed how these service structures can also have an effect on the care PwID receive during their transition to adult services:

"you fall back into that thing where actually that person is 17 and a half so they're not eligible for adult services, we've got wait but then it's a bit too late to get them onto the children's services waiting list but actually they need help now" (ACTLD1).

Services being unclear of what they can provide was associated with how each service perceives adulthood on a "*complete different level"* (CCTLD1). One staff member discussed how the definition of ID differs across services:

"one of the problems with that in terms of those young people accessing adult services was that there was social care and education and health, and they have very different models of what a learning disability is" (ACTLD1).

Furthermore, participants discussed how the services they were employed by are *"constrained by budgets and there's no money*" (ACTLD1), which often meant participants were restricted to who they could work with:

"*we are funded to work with people with learning disabilities, so we need to stick to that group"* (ACTLD1).

Participants explained that these restrictions within services prevented them from being involved in the care of PwID once they left the care system:

"Whatever happens there we hope we've done our best… we know that as child care they're not going to let us help in adults because we're getting our wages paid from child care and not adult services, but we've got to move on to our next children, and I think that's the hard part" (CRS6).

3.2 Falling through the gaps

Only participants from the CCTLD and ACTLD had experiences of PwID falling through gaps, as *"there's just a lack of services"* (CCTLD3) available for this client group once they transition to adult services. Participants highlighted how these young adults are *"of the greatest risk of not getting services or falling into those grey areas"* (ACTLD1). Furthermore, participants discussed how these young adults are often not meeting the eligibility criteria for service involvement, further allowing them to fall through these gaps:

"there's a gap for people with learning disabilities that are struggling with life and are acting out in a strange way…. there are people who fall through the gaps like that" (ACTLD2).

The CCTLD focus group emphasised how this issue mainly occurs when PwID have been on an out of area placement, and then return back to area once they're 18 years old. They explained how these young adults have limited service involvement "*from a health perspective"*, and therefore they would "*literally work from scratch with that 18-year-old"* (CCTLD2). Furthermore, one participant explained how this issue is not even considered or explored by commissioners, as PwID are not entering these services in the first instance:

"If you look at it from a commissioning point of view… the kids are not hitting our radar for our figures, they're going straight into adults so in children it's not even been looked at" (CCTLD1).

ACTLD echoed this statement as they explained some PwID do not have any involvement from child healthcare services when they arrive at their service:

"more than often now people are arriving at our service at 18/19 having had a gap with nothing" (ACTLD1).

Furthermore, these gaps are preventing transitions from occurring between services, which results in *"nobody flagging that up so there's no transition across"* (ACTLD1). Participants described these young adults as *"unknown"* (CCTLD1) to services, which made them feel *"inadequate"* (CCTLD1) and *"sad"* (CCTLD2). Once participant summed this up as:

"It's like I should have known about this young person, even though I can't because of constraints with services… but I don't know. I think it's a real mix bag of feelings" (CCTLD1).

Other participants described having no control over this issue:

"It is out of our control whatever it makes us think… there's nothing we can do about it" (CCTLD2).

3.3 *Unavailable placements*

All four focus groups discussed a lack of available accommodation placements for PwID once they transitioned to adult services. Participants explained how young adults can often be placed in unsuitable accommodation, such as *"an elderly residential placement",* which meant that *"an 18-year-old would've been mixed with a 65-year-old" (CRS1).* Moreover, when there are no adult placements available, participants discussed that PwID can sometimes be admitted to inpatient units:

"We were just used to 18-year olds turning up and they didn't really fit the criteria to have an inpatient admission and be detained under the mental health act, but there was nowhere else for them" (CCTLD2).

Participants explained that the lack of unavailable placements meant that PwID would sometimes *"arrive in crises"* (ACTLD2) at inpatient units. ARS discussed having similar experiences, as half of their residents were *"placed as an emergency"* (ARS4) and some were *"just dropped"* (ARS1) at the adult residential home. Furthermore, ACTLD discussed how their service has a *"reactive"* approach when these young adults arrive in a crisis rather than a *"proactive"* one (ACTLD3).

CCTLD and CRS reflected on the differences between child and adult placements. They explained how young adults are provided with a *"home"* (CRS4) during their childhood, then Local Authority conveys *"this is what you can have but we aren't going to give it to you anymore after 10 years"* (CCTLD1). Some participants questioned whether they were to blame for not preparing young adults for these circumstances once they departed from the care system:

"But isn't that kind of our fault? it's like you can kind of think, we never would, but should we be preparing them for… for that kind of stuff?" (CRS6).

When placements were available for these young adults, participants explained that they were mainly provided by the "*private sector"* (CCTLD4). Participants discussed how private services "*start doing the sales pitch on these places"* (CRS5) and offer a service they are unable to provide for the young adult, consequently leading to a placement breakdown:

"They can look really good, can't they? Like they can do all this, and they've got all these services, but actually in reality it breaks down" (CCTLD4).

Participants discussed that placement breakdowns for PwID could also associated with a lack of transparency that occurs between services. ARS explained how services can sometimes not provide clear and accurate information about a young adult's presentation:

"it could be that they leave little bits out to make it sound like the perfect candidate to move to this home whereas in realistic terms it might not be the case at all, and then once they're here it can then become unsuccessful" (ARS2).

Participants described feeling "*quite awful*" (CRS5) for being involved in choosing these *"placements packages"* (CRS4) for PwID that eventually lead to a placement breakdown. Furthermore, participants described how placement breakdowns can have an "*impact on that young person"* (CCTLD2) and *"the damage it causes to the children when they come back is horrendous"* (CRS7). One participant reflected on how placement breakdowns may affect the young person during their adulthood:

"you see people move from place to place, some move out of area, some people are on that track of committing offences and go into the criminal justice systems" (ACTLD1).

Discussion

Overview of findings

This qualitative study explored how residential staff and healthcare professionals experience the transition from children services to adult services for PwID in the care of the Local Authority. This study emphasised how transitions from and between services can be a complex process for PwID, as well as the residential staff and healthcare professionals involved in their care. The first superordinate theme 'adulthood' related to how participants perceived what life was like for PwID once they left the care of the Local Authority. The second superordinate theme 'starting transitions' was associated with the difficulties residential staff and healthcare professionals experience when they begin transitions for PwID. Finally, the third superordinate theme 'challenges of person-centred care' related to how participants perceived what life can be like for PwID once they leave the care system and the challenges involved during the transition process to adult services. See appendix M for quotations from the data analysis supporting all the implications recommended in this study.

The first theme incorporated participants' experiences of the challenges PwID begin to experience once they become an adult. Participants explained that adulthood for PwID often meant they could begin to make choices and decisions about their own lives, increasing the control they have over what happens during their adulthood (Brown & Brown, 2009). From the perspective of self-determination, being able to make decisions about one's life can positively affect self-identity, psychological wellbeing, and quality of life for young adults leaving care (Nota, Ferrari, Soresi, & Wehmeyer, 2007). However, the current study highlighted this may not particularly be the case for PwID leaving the care system, as some decide to return to their birth families home. Healthcare professionals and residential staff in this study had concerns regarding whether these decisions are in the best interest of the young adult once they transition into adult services, as they continue to present as vulnerable at the age of 18 years. Despite these concerns, some young adults with ID were allowed to return to their families of origin, a finding that has also previously been highlighted in literature. McMillen and Tucker (1999) found half of the young adults in their sample returned to the birth family home once they left the care system, although this decision was against the wishes of the child welfare social workers. However, in the current study it was the residential staff of the children and adult's home that were against these decisions which were overruled by adult service professionals. McLeod (2007) found social workers were often more concentrated on the paperwork and performance outcomes rather than building a relationship with the young person in care. These findings, along with the ones highlighted in this study, suggest adult service professionals may perhaps be under too much pressure and have limited time to listen and build relationships with residential staff and healthcare professionals when making decisions about what PwID may require in adulthood.

This study further highlighted adult services can often be swayed by the birth family's decisions rather than the residential staff that have worked with these young adults for a number of years. The conflict of differing values and decisions between families and professionals is also highlighted in the research of ID (Bigby, Whiteside & Douglas, 2017). These findings suggest residential staff and healthcare professionals may aim to protect PwID from difficult experiences, however in parenting a child that is not in the care of the Local Authority, there has to be a balance between protecting a young adult and allowing them to make and take risky decisions in their adulthood lives. Similarly, the Government suggests individuals with ID receiving social care from the Local Authority should be supported in active risk taking (Department of Health 2007).

The second theme incorporated the experiences of residential staff and healthcare professionals during the transition process from children services to adult services for PwID. Residential staff and healthcare professionals experienced a lack of involvement and communication between services during the transition process. The unsatisfactory nature of transition planning experienced by participants within this study is similar to the findings of studies that have explored the experiences of families with a young adult with ID transitioning to adulthood (Gauthier-Boudreault, Gallagher & Couture, 2017; Young-Southward, Philo & Cooper, 2016). Furthermore, these families also found the transition to adulthood for their offspring was often planned late and there was a lack of communication between the services involved in the transition process (Gauthier-Boudreault et al, 2017). The current study found similar results amongst healthcare professionals and residential staff when they prepared the transitions for young adults leaving the care system, suggesting the transition to adulthood is generally a challenging period for PwID. A lack of communication between services could be a result of confidentiality issues which raises complex practice issues, as sharing information may breach the privacy of these young adults. The conflict between confidentiality and information sharing is acknowledged by the Department of Health (2000) which highlights that young people should understand why information is about them being shared, but that there may also be occasions whereby the Local Authority requests to make information available to other professionals.

Additionally, within the starting transitions theme, residential staff and healthcare professionals highlighted the importance of advocating for PwID, as they navigated services for them during the transition process. This assumes the role of a 'corporate parent' that substitutes or supplements the place of the parents for PwID in the care system. Furthermore, Munro (2001) found children without ID in care system emphasised the importance of having an advocate whom was a professional. Despite being advocates and having strong relationships with these young people, residential staff in this study felt that their opinions and perspectives were often disregarded by adult services. Furthermore, this study highlighted the importance of adult services building relationships with PwID in the care system prior to starting transitions. Across various studies, LAC value the importance of consistent and reliable relationships with trusted professionals that recognise the importance of these relationships (Augsberger & Swenson, 2015; Coady, 2014; Gallagher & Green, 2012). A study by Munro (2001) found young people criticised social workers for their reliability in day to day matters, such as keeping to appointments or holding reviews on time, despite viewing how powerful they were in making decisions about their lives. The value of on-going relationships and their importance is well recognised within research, whether to LAC or people in general (Bowlby, 1969; Polnay & Ward, 2000). However, research suggests professionals tend to perceive "children's development as a dichotomy rather than a continuum" (Munro, 2001)

The final theme, challenges of person-centred care, highlighted the difficulties residential staff and healthcare professionals experience when navigating services for PwID in adulthood. This current study emphasised service organisations tend to have unclear referral pathways and eligibility criteria's, which can influence the transition process from children services to adult services. Other research further highlights how these organisation barriers have an impact on the transition process between children and adult services for young adults (Mandarino, 2014; Sin, Francis & Cook, 2010). Mandarino (2014) found a lack of clear services predominantly occurred between mental health services, a finding that is consistent within this study. Healthcare professionals from children and adult community learning disability teams emphasised a gap within services for PwID leaving the care system and being unable to meet the eligibility criteria of adult services. Findings by Whittle, Fisher, Reppermund, Lenroot and Trollor (2018) suggest mental health services are often under financial pressure leading these organisations to focus on the ‘core business’ and neglecting the ‘non-core’ business issues, such as these gaps.

Moreover, the findings from this study suggest residential staff and healthcare professionals felt restricted to work with PwID during the transition across children and adult services, as the organisation and service they were employed by did not fund them to do so. The danger of this is that by institutionalising the split between children services and adults services, the gap continues to grow wider, and these young people continue to fall between opposing sides (Whittle et al, 2018). Responding to this dilemma involves a return to the ideas underpinning ‘person-centred planning’, which include the transition process not being about moving PwID from one service to another, but rather to support these young adults move towards a new life stage. Finally, this study found accommodation placements often failed to meet the needs of PwID transitioning to adult services. These issues can be a result of limited resources or budget cuts, which impact both the quality and quantity of the service delivery (Chorpita, Bernstein, & Daleiden, 2011). These problems may also result in services ineffectively and inefficiently providing care that is not within their realm of competency (Courtney & Heuring, 2005). The themes presented within this study may be interrelated and cyclical, therefore considering the earlier two themes together may illuminate the relationship to the final theme. For example, if children and adult services communicated effectively and started the transition process a year prior to the young person transitioning to adult services, then appropriate accommodation could be organised which would reduce the likelihood of PwID being admitted to inpatient units. Although participants felt they had limited control over these systemic complications, this study emphasised a lack of involvement, communication and preparation occurs across children and adult services during the transition process for PwID, consequently having an effect on their adulthood lives.

Limitations

All the participants within this study were 'White British', therefore it is unclear whether the findings from this study are found cross-culturally amongst residential staff and healthcare professionals. Furthermore, participants also volunteered to contribute to the study which may influence self-selection bias, and potentially favour the research towards negative experiences of participants as these may have been considered to be the most important. Apart from the children community learning disability team focus group, all the others were conducted with participants that worked within the service. Thus, the focus groups may not have represented the views of other organisations and services that work with PwID during the transition to adult services.

The use of focus groups can also be a limitation within this study. Some participants within the focus groups contributed more than others because they had more experience of working with PwID during the transition to adulthood, therefore their experiences may more represented in the findings (Stewart & Shamdasani, 2014). Moreover, social desirability can also affect the validity of focus groups (Stewart & Shamdasani, 2014), although the effect of this appears to be minimal as the focus groups involved open discussions and participants seemed willing to share negative and positives of experiences of working with PwID during the transition process. Finally, one focus group (adult community learning disability team) only included three participants as a result of healthcare professionals having restricted diaries. Although it is recommended that 4-8 participants should be included to conduct a focus group (Wilkinson, 2008), the focus group analysis provided rich enough qualitative data saturation for theme coverage and divergence (Braun & Clarke, 2006).

Finally, the use of qualitative analysis allowed the research to explore the experiences of participants involved in the study, however it does not indicate generalisability to others (Willig, 2013). Other professionals, such as social workers, that may be involved in the transition to adulthood for PwID once they leave the looked after care system may have different, but equally valid experiences that were not captured within this study. However, this research utilised the perspectives of residential staff and healthcare professionals from four services. The use of triangulating data that compared different perspectives on the same issue facilitated an in-depth understanding of complex transitions for PwID in the looked after care system.

Implications and Future Research

Although there continues to be limited research on PwID leaving the care of the Local Authority, the findings from this study begin to reveal important implications for future research and practice. Firstly, healthcare professionals and residential staff working across different organisations presents with some difficulties for integrated joint working for PwID in looked after care system. Furthermore, participants emphasised the importance of following PwID through the transition process across children's services to adult services. Participants recommended having a key worker that works across all services would implement a person-centred care approach as young adults would have access to appropriate services, preventing them from falling through the gaps and placement breakdowns. Furthermore, the key worker would be able to have time to build a relationship and possibly become an advocate for a young adult, which participants highlighted as crucial component for successful transitions for PwID. The participants in this study emphasised a solution to a more person-centred care approach involves systematic integration of all four services to allow for a multiagency approach, which Whittle et al (2018) also recommend for service improvement. Clearly such an approach has to be considered at a strategic level between health and social service commissioning providers, and policies and procedures have to be re-evaluated. Future research could perhaps study the perspectives of a multi-agency service that works with PwID during the transition to adulthood, which would provide an understanding of how all services involved perceive these transitions.

Secondly, this study highlights that services often use the age of 18 as a date for discharge, which often leads to transitions being rushed and unplanned. For smoother transitions to adulthood, children and adult services need to have enough time to prepare for the transitions. A resolution to this problem, as proposed by participants in this study, is to have a year before the young adults 18th birthday to plan and prepare for the transition, facilitating a person-centred care approach. Furthermore, having this length of time would allow for information to be shared coherently and consistently between all four services. In terms of future research, it would be important to have an understanding of how birth families experience their offspring with ID transitioning back into the family home. Such research would give an indication of how services could prepare young adults with ID to return to their birth families.

The importance of sharing information during the transition to adulthood for PwID has been highlighted by a number of studies (Gauthier-Boudreault et al, 2017; Raghavan, Pawson & Small, 2013; Martinez, Conroy & Cerreto, 2012). This study further highlighted the issue of communication and information sharing between children and adult's services, and when this was achieved a lack of transparency occurred between these facilities. To prevent such issues in the future, it is recommended that a shared document used between all services involved in the transition process would allow for consistent and transparent information to be shared. Furthermore, participants in this study recommend for all services involved with the young adult to be honest and transparent regarding information about the young person's presentation and needs.

Finally, research has found that PwID can be placed in the care of the Local Authority as a result of birth families struggling to cope with the demands of the child (Llewellyn, Dunn, Fante, Turnbull & Grace, 1999). Healthcare professionals from the children's community learning disability highlighted this as an issue for the birth families they have worked with. Participants discussed how services should prevent these children from becoming LAC in the first place. Solutions proposed by participants include having enough funding and resources, including an intensive support time and an out if hours service to support families during difficult times, and prevent them from becoming LAC.

Conclusion

This is the first study that provides residential staff and healthcare professionals from residential homes and community learning disability teams a voice to share their experiences of working with PwID whom have been in the care of the Local Authority and transitioned from children's services to adult's services. This study highlighted three main findings that influence the transition from children's services to adult services for PwID. Firstly, a number of challenges persist when a young adult becomes 18 years old. Secondly, starting transitions was often associated with limited involvement and communication, a need for advocating for this client group, and some participants feeling not listened to during the transition process. Finally, this study emphasises that there is a reduction in person-centred care for PwID when they transition to adult services due to the lack of clarity and gaps within services, as well as the unavailability of adult services These findings have implications for solutions articulated by the participants in this study; that systematic integration of all four services would allow for a multiagency approach to enable smoother transitions to adult services for PwID.

References

Akister, J., Owens, M., & Goodyer, I. M. (2010). Leaving care and mental health: outcomes for children in out-of-home care during the transition to adulthood. *Health Research Policy and Systems*, *8*(1), 10.

Atkinson, L., Chisholm, V.C., Scott, B., Goldberg, S., Vaughn, B.E., Blackwell, J., Dickens, S. & Tam, F. (1999). Maternal Sensitivity, child functional level, and attachment in Down syndrome. Monographs of the Society for Research in Child Development, 64, 45-66. Cited In: De Schipper, J.C. & Schuengel, C. (2010). Attachment behaviour towards support staff in young people with intellectual disabilities: Associations with challenging behaviour. Journal of Intellectual Disability Research, 45, 584-596.

Augsberger, A., & Swenson, E. (2015). “My Worker Was There When It Really Mattered”: Foster Care Youths' Perceptions and Experiences of Their Relationships With Child Welfare Workers. *Families in Society: The Journal of Contemporary Social Services*, *96*(4), 234-240.

Baker, C. (2007). Disabled children’s experience of permanency in the looked after system. *British Journal of Social Work*, *37*(7), 1173-1188.

Biehal, N., & Wade, J. (1996). Looking back, looking forward: Care leavers, families and change. *Children and youth services review*, *18*(4), 425-445.

Bigby, C., Whiteside, M., & Douglas, J. (2017). Providing support for decision making to adults with intellectual disability: perspectives of family members and workers in disability support services. *Journal of Intellectual & Developmental Disability*, 1-14.

Bowlby, J. (1969). Attachment. Attachment and Loss: Vol. 1 Loss. New York: Basic Books. Cited In: Gallagher, B., & Green, A. (2012). In, out and after care: Young adults' views on their lives, as children, in a therapeutic residential establishment. *Children and Youth Services Review*, *34*(2), 437-450.

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

Brown, I., & Brown, R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1), 11-18.

Cahill, O., Holt, S., & Kirwan, G. (2016). Keyworking in residential child care: Lessons from research. *Children and Youth Services Review*, *65*, 216-223.

Chorpita, B. F., Bernstein, A., & Daleiden, E. L. (2011). Empirically guided coordination of multiple evidence-based treatments: An illustration of relevance mapping in children's mental health services. *Journal of Consulting and Clinical Psychology*, *79*(4), 470.

Cicchetti, D., & Rogosch, F. A. (1997). The role of self-organization in the promotion of resilience in maltreated children. *Development and psychopathology*, *9*(4), 797-815.

Cicchetti, D., & Rogosch, F. A. (2002). A developmental psychopathology perspective on adolescence. *Journal of consulting and clinical psychology*, *70*(1), 6.

Coady, P., & Council, E. L. (2014). Relationship boundaries in residential child care: connection and safety in group care relationships. *Research, Policy and Planning*, *31*(2), 79-91.

Courtney, M. E., & Heuring, D. H. (2005). The transition to adulthood for youth “aging out” of the foster care system. *On your own without a net: The transition to adulthood for vulnerable populations*, 27-67.

Csikszentmihalyi, M., & Schneider, B. (2008). *Becoming adult: How teenagers prepare for the world of work*. New York: Basic Books. Cited In: Keller, T. E., Cusick, G. R., & Courtney, M. E. (2007). Approaching the transition to adulthood: Distinctive profiles of adolescents aging out of the child welfare system. *Social Service Review*, *81*(3), 453-484.

Department of Health (2000). *Looked After Children: Assessing Outcomes in Child Care. Revisions to Planning and Review Forms*. HMSO: London.

Department of Health (2007) *Independence, Choice and Risk: A Guide to Best Practice in Supported Decision Making*. Department of Health, London.

Dixon, J. and Stein, M. (2005). *Leaving Care, Throughcare and Aftercare in Scotland.* London: Jessica Kingsley

Dumaret, A. C., Donati, P., & Crost, M. (2011). After a Long‐Term Placement: Investigating Educational Achievement, Behaviour, and Transition to Independent Living. *Children & Society*, *25*(3), 215-227.

Fonagy, P. (2002). Psychosocial therapies for young people: Individual approaches. *Psychiatry*, *1*(8), 137-140.

Frederico, M. M., Jackson, A. L., & Black, C. M. (2008). Understanding the impact of abuse and neglect on children and young people referred to a therapeutic program. *Journal of Family Studies*, *14*(2-3), 342-362.

Gallagher, B., & Green, A. (2012). In, out and after care: Young adults' views on their lives, as children, in a therapeutic residential establishment. *Children and Youth Services Review*, *34*(2), 437-450.

Ganiban, J., Barnett, D. & Cicchetti, D. (2000). Negative reactivity and attachment: Down Syndrome's contribution to the attachment-temperament debate. *Development and Psychopathology*, 12, 1-21.

Gauthier-Boudreault, C., Gallagher, F., & Couture, M. (2017). Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing?. *Research in developmental disabilities*, *66*, 16-26.

Gordon, D,. Parker, R. & Loughrin, F. (2000). *Disabled Children in Britain: A Re-analysis of the OPCS Disability Survey*. London; Stationery Office.

Hatfield, B., Harrington, R., & Mohamad, H. (1996). Staff looking after children in local authority residential units: The interface with child mental health professionals. *Journal of Adolescence*, *19*(2), 127-139.

Howe, D., & Campling, J. (1995). *Attachment theory for social work practice*. London: Macmillan.

Janssen, C.G.C., Schuengel, C. & Stolk, J. (2002). Understanding challenging behaviour in people with severe and profound intellectual disability: A stress attachment model. *Journal of Intellectual Disability Research*, 46, 445-453.

Llewellyn, G., Dunn, P., Fante, M., Turnbull, L., & Grace, R. (1999). Family factors influencing out-of-home placement decisions. *Journal of Intellectual Disability Research*, *43*(3), 219-233.

Mandarino, K. (2014). Transitional-age youths: barriers to accessing adult mental health services and the changing definition of adolescence. *Journal of Human Behavior in the Social Environment*, *24*(4), 462-474.

Martin, P. Y., & Jackson, S. (2002). Educational success for children in public care: advice from a group of high achievers. *Child & family social work*, *7*(2), 121-130.

Martinez, D. C., Conroy, J. W., & Cerreto, M. C. (2012). Parent involvement in the transition process of children with intellectual disabilities: The influence of inclusion on parent desires and expectations for postsecondary education. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(4), 279-288

Marvin, R.S. & Pianta, R.C. (1996). Mothers' reactions to their child's diagnosis: Relations with security of attachment. *Journal of Clinical Child Psychology*, 25, 436-445.

McLeod, A. (2008). 'A friend and an equal': do young people in care seek the impossible from their social workers?. *British Journal of Social Work*, *40*(3), 772-788.

McLeod, A. (2007). Whose agenda? Issues of power and relationship when listening to looked-after young people. *Child & Family Social Work*, *12*(3), 278-286.

McMillen, J. C., & Tucker, J. (1999). The status of older adolescents at exit from out-of-home care. *Child Welfare*, *78*(3), 339.

Meyrick, J. (2006). What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality. *Journal of health psychology*, *11*(5), 799-808.

Morris, J. (1997). Gone missing? Disabled children living away from their families. *Disability & Society*, *12*(2), 241-258.

Munro, E. (2001). Empowering looked-after children. *Child and Family Social Work*, *6*(2), 129-138.

Munson, M. R., Brown, S., Spencer, R., Edguer, M., & Tracy, E. (2015). Supportive relationships among former system youth with mental health challenges. *Journal of Adolescent Research*, *30*(4), 501-529.

Munson, M. R., Stanhope, V., Small, L., & Atterbury, K. (2017). "At times I kinda felt I was in an institution": Supportive housing for transition age youth and young adults. *Children and Youth Services Review*, *73*, 430-436.

Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research*, *51*(11), 850-865.

Osgood, D. W., Foster, E. M., & Courtney, M. E. (2010). Vulnerable populations and the transition to adulthood. *The future of children*, *20*(1), 209-229.

Pecora, P. J., Kessler, R. C., Williams, J., O'Brien, K., Downs, A. C., English, D., ... Holmes, K. E. (2005). *Improving family foster care: Findings from the northwest foster care alumni study*. Seattle, WA: Casey Family Programs.

Perry, B. D., Pollard, R. A., Blakley, T. L., Baker, W. L., & Vigilante, D. (1995). Childhood trauma, the neurobiology of adaptation, and? use? dependent? development of the brain: How? states? become? traits?. *Infant mental health journal*, *16*(4), 271-291.

Perry, B. L. (2006). Understanding social network disruption: The case of youth in foster care. *Social Problems*, *53*(3), 371-391.

Polnay, L., & Ward, H. (2000). Promoting the health of looked after children: Government proposals demand leadership and a culture change. *British Medical Journal, 320*(7236), 661-662.

Priestley, M., Rabiee, P., & Harris, J. (2003). Young disabled people and the 'new arrangements' for leaving care in England and Wales. *Children and youth services review*, *25*(11), 863-890.

Raghavan, R., Pawson, N., & Small, N. (2013). Family carers' perspectives on post-school transition of young people with intellectual disabilities with special reference to ethnicity. *Journal of Intellectual Disability Research*, *57*(10), 936-946.

Rosenfeld, A. A., Pilowsky, D. J., Fine, P., Thorpe, M., Fein, E., Simms, M. D., ... & Nickman, S. (1997). Foster care: An update. *Journal of the American Academy of Child & Adolescent Psychiatry*, *36*(4), 448-457.

Schuengel, C. & Janssen, C.G.C. (2006). People with mental retardation and psychopathology: Stress, affect regulation and attachment. A review. *International Review of Research in Mental Retardation*, 32, 229-260.

Sin, C., Francis, R., & Cook, C. (2010). Access to and experience of child and adolescent mental health services: barriers to children and young people with learning disabilities and their families. *Mental Health Review Journal*, *15*(1), 20-28.

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, Method & Research*. London: SAGE Publications

Stein, M. (2006). Research review: Young people leaving care. *Child & family social work*, *11*(3), 273-279.

Stein, M., Pinkerton, J., & Kelleher, J. (2000). 'Young people leaving care in England, Northern Ireland and Ireland', *European Journal of Social Work*, 3(3), 235–246.

Stewart, D.W. & Shamdasani, P.N. (2014*). Focus Groups: Theory and Practice* (3rd ed.). London: SAGE Publications.

Stohler, R., Storo, J., Vincent, D., Wade, J., Schröer, W., Zeller, M., ... & Köngeter, S. (2008). *Young people's transitions from care to adulthood: international research and practice*. Jessica Kingsley Publishers.

Trout, A. L., Casey, K., Chmelka, M. B., DeSalvo, C., Reid, R., & Epstein, M. H. (2009). Overlooked: Children with disabilities in residential care. *Child Welfare*, *88*(2), 111.

Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2018). Barriers and enablers to accessing mental health services for people with intellectual disability: A scoping review. *Journal of Mental Health Research in Intellectual Disabilities*, *11*(1), 69-102.

Wilkinson, S. (2008). Focus groups. In J.A. Smith (Ed) Q*ualitative Psychology A Practical Guide to Research Methods: Second Edition* (pp. 186-206) London: Sage Publications.

Willig, C. (2013). *Introducing Qualitative Research in Psychology* (3rd ed.). Berkshire, England: Open University Press.

Winter, K. (2006). Widening our knowledge concerning young looked after children: the case for research using sociological models of childhood. *Child & Family Social Work*, *11*(1), 55-64.

Young-Southward, G., Philo, C., & Cooper, S.A. (2016). What is the effect of transition to adulthood on health and wellbeing in young people with intellectual disabilities? A systematic review. *Journal of Applied Research in Intellectual Disabilities, 30*(5), 805-823.

Part three: Appendices

<u>Appendix A</u>**:** Author guidelines for Journal of Applied Research in Intellectual Disabilities

1. GENERAL

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

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

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

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

2. ETHICAL GUIDELINES

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

2.1 Authorship and Acknowledgements

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

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

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

2.2 Ethical Approvals

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

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

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

2.3 Clinical Trials

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

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

2.4 Conflict of Interest and Source of Funding

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

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

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

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4.1 Manuscript Files Accepted

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

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

Please upload:
1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

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

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

4.2 Blinded Review

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

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and ***Letters to the Editor***are accepted. ***Theoretical Papers*** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

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

6.2 Structure

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

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.
Running Title: A short title of not more than fifty characters, including spaces, should be provided.
Keywords: Up to six key words to aid indexing should also be provided.
Main Text: All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.
Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:
-Include all figure legends, and tables with their legends if available.
-Do not use the carriage return (enter) at the end of lines within a paragraph.
-Turn the hyphenation option off.
-In the cover email, specify any special characters used to represent non-keyboard characters.
-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
-Use a tab, not spaces, to separate data points in tables.
-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

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

6.3 References

APA - American Psychological Association

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

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

Journal article

Example of reference with 2 to 7 authors

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

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

Example of reference with more than 7 authors

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

Book Edition

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

6.4 Tables, Figures and Figure Legends

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

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

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

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Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following website:
www.adobe.com/products/acrobat/readstep2.html
This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

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Appendix B: Bespoke Quality Assessment Checklist

Study Identification: Include full citation details		
Assessed by:		
Section 1: Theoretical Approach		
1.1 Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question(s)? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear (1) Unclear (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
Section 2: Study Design		
2.1 How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?	Defensible (1) Not defensible (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
2.2 How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriate (1) Inappropriate (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
Mixed methods only 2.3 Is the mixed methods research design relevant to address the qualitative and quantitative	Appropriate (1) Inappropriate (0)	Comments:

research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)? For example: • The rationale for integrating qualitative and quantitative methods to answer the research question is explained.	Not sure/Inadequately reported (0) Not applicable (N/A)	
Section 3: Population		
3.1 Is the source population or source area well described? For example: • Was the country (e.g. developed or nondeveloped, type of health care system), setting (primary schools, community centres etc), location (urban, rural), population demographics etc adequately described?	Clear (1) Unclear (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
3.2 Is the eligible population or area representative of the source population or area? For example: • Was the recruitment of individuals, clusters or areas well defined (e.g. advertisement, birth register)? • Was the eligible population representative of the source? Were important groups underrepresented?	Clear (1) Unclear (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
3.3. Do the selected participants or areas represent the eligible population or area? For example: • Was the method of selection of participants from the eligible population well described? • What % of selected individuals or clusters agreed to participate? Were there any sources of bias? • Were the inclusion or exclusion criteria explicit and appropriate?	Clear (1) Unclear (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:

Section 4: Validity		
4.1 Is the role of the researcher clearly described? For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Clear (1) Unclear (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
4.2 Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances? • Was context bias considered?	Clear (1) Unclear (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
4.3 Were the methods reliable? For example: • Do the methods investigate what they claim to?	Reliable (1) Unreliable (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
Section 5: Analyses		
5.1 Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – is it clear how the data were analysed to arrive at the results? • How systematic is the analysis – is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data?	Rigorous (1) Not rigorous (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
5.2 Are the data 'rich'? For example:	Rich (1) Poor (0)	Comments:

• How well are the contexts of the data described? • Has the diversity of perspective and content been explored?	Not sure/Inadequately reported (0) Not applicable (N/A)	
5.3 Was the precision of association given or calculable? Is association meaningful? • Were confidence intervals or p values for effect estimates given or possible to calculate? • Were CIs wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered?	Clear (1) Unclear (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
5.4 Were the outcome measures and procedures reliable? For example: • Were outcome measures subjective or objective (e.g. biochemically validated nicotine levels ++ vs self-reported smoking −)? • How reliable were outcome measures (e.g. interor intra-rater reliability scores)? • Was there any indication that measures had been validated (e.g. validated against a gold standard measure or assessed for content validity)?	Reliable (1) Unreliable (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
5.5 Is the analysis reliable? For example: • Did more than one researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feedback on the transcripts/data? (if possible and relevant) • Were negative/discrepant results addressed or ignored?	Reliable (1) Unreliable (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
5.6 Are the findings convincing? For example:	Convincing (1) Not convincing (0)	Comments:

• Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Not sure/Inadequately reported (0) Not applicable (N/A)	
5.7 Are the findings relevant to the aims of the study?	Relevant (1) Irrelevant (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
5.8 Are the conclusions adequate? For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this study enhance understanding of the research subject? • Are the implications of the research clearly defined? • Is there adequate discussion of any limitations encountered?	Adequate (1) Inadequate (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
Mixed methods only 5.9 Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)? For example: •There is evidence that data gathered by both research methods was brought together to form a complete picture, and answer the research question; authors explain when integration occurred (during	Relevant (1) Irrelevant (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:

the data collection-analysis or/and during the interpretation of qualitative and quantitative results); they explain how integration occurred and who participated in this integration.		
Mixed methods only 5.9.1 Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results)?	Appropriate (1) Inappropriate (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
Section 6: Ethics		
6.1 How clear and coherent is the reporting of ethical considerations? For example: • Have ethical issues been taken into consideration? • Are ethical issues discussed adequately – do they address consent and anonymity? • Have the consequences of the research been considered; for example, raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Clear (1) Unclear (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:
Section 7: Summary		
7.1 Are the findings generalisable to the source population (i.e. externally valid)? For example: • Are there sufficient details given about the study to determine if the findings are generalisable to the source population? • Consider: participants, interventions and comparisons, outcomes, resource and policy implications.	Clear (1) Unclear (0) Not sure/Inadequately reported (0) Not applicable (N/A)	Comments:

Adapted from:

Quantitative checklist - National Institute for Health and Care Excellence (NICE) (2012). Methods for the development of NICE public health guidance (third edition). Retrieved from https://www.nice.org.uk/process/pmg4/chapter/appendix-g-qualityappraisal-checklist-quantitative-studies-reporting-correlations-and#checklist.

Qualitative checklist - National Institute for Health and Care Excellence (NICE) (2012). Methods for the development of NICE public health guidance (third edition). Retrieved from https://www.nice.org.uk/process/pmg4/chapter/appendix-h-quality-appraisalchecklist-qualitative-studies

Mixed Methods checklists - Pace, R., Pluye, P., Bartlett, G., Macaulay, A. C., Salsberg, J., Jagosh, J., & Seller, R. (2012). Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International journal of nursing studies*, *49*(1), 47-53.

Appendix C: Quality checklist rating for the included studies.

Table 1. Breakdown of quality assessment ratings

Study	**Theoretical Approach**	**Study Design**	**Population**	**Validity**	**Analyses**	**Ethics**	**Summary**	**Total score**	**Total score**	**Percentage**
Black, Molaison & Smull (1990)	1.1 Clear (1)	2.1 NR (0) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Unclear (0) 3.2 Unclear (0)	4.1 Unclear (0) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Poor (0) 5.3 NS/IR (0) 5.4 NS/IR (0) 5.5 NA 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 NA 5.9.1 NA	6.1 Unclear (0)	7.1 Clear (1)	10	18	56%
Docherty & Reid (2009)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Clear (1) 3.3 Clear (1)	4.1 Clear (1) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3. NA 5.4 NA 5.5 NS/IR (0) 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 NA 5.9.1 NA	6.1 Clear (1)	7.1 NA (0)	15	17	88%

Dyke, Bourke, Llewellyn, Leonard (2013)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Clear (1) 3.3 Clear (1)	4.1 Unclear (0) 4.2 Unclear (0) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3. NA 5.4 NA 5.5 NS/IR (0) 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 NA 5.9.1 NA	6.1 NS/IR (0)	7.1 Clear (0)	12	17	71%
Foley et al. (2013)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Clear (1) 3.3 Clear (1)	4.1 NS/IR (0) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3 Clear (1) 5.4 Reliable (1) 5.5 NA 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 NA 5.9.1 NA	6.1 Clear (1)	7.1 Clear (1)	17	18	94%

Gauthier-Boudreault & Couture Gallagher (2017)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Clear (1) 3.3 Clear (1)	4.1 Unclear (0) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3. NA 5.4 NA 5.5 NS/IR (0) 6.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 NA 5.9.1 NA	6.1 Clear (1)	7.1 Clear (1)	15	17	82%
Gauthier-Boudreault, Gallagher, & Couture (2017)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Clear (1) 3.3 Clear (1)	4.1 Unclear (0) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3. NA 5.4 NA 5.5 NS/IR (0) 6.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 NA 5.9.1 NA	6.1 Clear (1)	7.1 Clear (1)	15	17	82%

Gillam & Coughlan (2012)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Clear (1) 3.3 Clear (1)	4.1 Unclear (0) 4.2 NS/IR (0) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3. NA 5.4 NA 5.5 Reliable (1) 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 NA 5.9.1 NA	6.1 Unclear (0)	7.1 Clear (0)	13	17	76%
Heslop & Abbott (2007)	1.1 Clear (1)	2.1 NS/IR (0) 2.2 Appropriate (1) 2.3 NA	3.1 Unclear (0) 3.2 Clear (1) 3.3 NS/IR (0)	4.1 Unclear (0) 4.2 Unclear (0) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3 NA 5.4 NA 5.5 NS/IR (0) 5.6 Convincing (1) 5.7 Relevant (1) 5.8 NS/IR (0) 5.9 NA 5.9.1 NA	6.1 Unclear (0)	7.1 Clear (0)	8	17	47%

Leonard et al. (2016)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 Appropriate (1)	3.1 Clear (1) 3.2 Clear (1) 3.3 NS/IR (0)	4.1 Unclear (0) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3 Clear (1) 5.4 NS/IR (0) 5.5 Reliable (1) 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 Relevant (1) 5.9.1 Appropriate (1)	6.1 NS/IR (0)	7.1 Clear (1)	18	22	82%
Martinez, Conroy & Cerreto (2012)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 Appropriate (1)	3.1 Clear (1) 3.2 Clear (1) 3.3 Clear (1)	4.1 NS/IR (0) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3 Clear (1) 5.4 Reliable (1) 5.5 Reliable (1) 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 Relevant (1) 5.9.1 NS/IR (0)	6.1 NS/IR (0)	7.1 Clear (1)	19	22	86%

McNair & Rusch, (1991)	1.1 Clear (1)	2.1 Defensible (1) 2.3 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Unclear (0) 3.3 Clear (1)	4.1 NS/IR (0) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3 Unclear (0) 5.4 NS/IR (0) 5.5 NA 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Inadequate (0) 5.9 NA 5.9.1 NA	6.1 NS/IR (0)	7.1 Unclear (0)	11	18	61%
Raghavan, Pawson, & Small (2013)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Clear (1) 3.3 NS/IR (0)	4.1 Unclear (0) 4.2 NS/IR (0) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3 NA 5.4 NA 5.5 Reliable (1) 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 NA 5.9.1 NA	6.1 Clear (1)	7.1 Clear (1)	14	17	82%

Rapanaro, Bartu, & Lee (2008)	1.1 Clear (1)	2.1 NS/IR (0) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 NS/IR (0) 3.3 Clear (1)	4.1 Unclear (0) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3 NA 5.4 NA 5.5 Reliable (1) 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Adequate (1) 5.9 NA 5.9.1 NA	6.1 Clear (1)	7.1 Clear (1)	14	17	82%
Strnadová & Evans (2013)	1.1 Clear (1)	2.1 Defensible (1) 2.2 Appropriate (1) 2.3 NA	3.1 Clear (1) 3.2 Clear (1) 3.3 NS/IR (0)	4.1 Unclear (0) 4.2 Clear (1) 4.3 Reliable (1)	5.1 Rigorous (1) 5.2 Rich (1) 5.3 NA 5.4 NA 5.5 Reliable (1) 5.6 Convincing (1) 5.7 Relevant (1) 5.8 Inadequate (0) 5.9 NA 5.9.1 NA	6.1 Unclear (0)	7.1 Unclear (0)	12	17	71%

Thorin, Yovanoff, Irvin (1996)	1.1 Unclear (0)	2.1 Defensible (1) 2.1 NS/IR (0) 2.3 NA	3.1 Unclear (0) 3.2 Unclear (0) 3.3 Unclear (0)	4.1 Unclear (0) 4.2 Unclear (0) 4.3 NS/IR (0)	5.1 Not rigorous (0) 5.2 Poor (0) 5.3 NA 5.4 NA 5.5 NS/IR (0) 5.6 Not convincing (0) 5.7 Relevant (1) 5.8 Inadequate (0) 5.9 NA 5.9.1 NA	6.1 Unclear (0)	7.1 Unclear (0)	2	17	12%
Unwin, LeMesurier, Bathia, & Deb (2008)	1.1 Clear (1)	2.1 Not defensible (0) 2.2 Inappropriate (0) 2.3 NA	3.1 Unclear (0) 3.2 Unclear (0) 3.3 Unclear (0)	4.1 Unclear (0) 4.2 Unclear (0) 4.3 NS/IR (0)	5.1 NS/IR (0) 5.2 Poor (0) 5.3 NA 5.4 NA 5.5 Unreliable (0) 5.6 NS/IR (0) 5.7 NS/IR (0) 5.8 Inadequate (0) 5.9 NA 5.9.1 NA	6.1 Unclear (0)	7.1 NS/IR (0)	1	17	6%

Appendix D: Data extraction form

Author, Year, & Location	
Research aims	
Participants - Participants – age Participants – gender	
Child's intellectual disabilities Age of child	
Design	
Measure	
Main findings	
Conclusions	

Appendix E: Advertisement poster for recruitment.

Participants Needed!

Are you a residential staff member or a healthcare professional working in child services or adult services?
Have you worked with individuals with intellectual disabilities who have been in looked after care and transitioned into adult services or adult residential homes?

- If these questions apply to you then you may be interested in taking part in a focus group to share your experiences!
- I'm interested in finding out about the experiences of residential staff and health care professional who have worked with or supported individuals with intellectual disabilities during the transition process from children's services to adult services.

If you want to find out more contact:

Ava on the phone – 07835333515
Or email: a.doski@2015.hull.ac.uk

Appendix F: Information sheet for recruitment.

Research Study Information Sheet

Title of study: The experiences of residential staff and healthcare professionals working with individuals with intellectual disabilities during the transition process from children services to adult services.

We would like to invite you to take part in our research study. This sheet will explain why the research is being done and what would happen if you took part. You can talk to others if you would like before you decide if you want to take part. The researcher will answer any questions you may have before you decide if you want to take part.

What is the study about?
This study is exploring the experiences and the perspectives of residential staff and healthcare professionals who have worked with individuals with intellectual disabilities during the transition process from children services to adult services. We are aware that the transition process for young people with intellectual disabilities leaving care can be challenging and complicated, which can lead to unsatisfactory transitions for these individuals. We understand that support from different services for individuals with intellectual disabilities can have a number of benefits. We are interested in finding out what is helpful during the transition process and what can be accomplished to achieve successful transitions for individuals with intellectual disabilities.

Why are we inviting you to take part?
We are asking people who work in children's accommodation, adult's accommodation, children community learning disability teams, and adult community learning disability teams to share their experiences of their work.

What will I have to do?
If you want to take part, you will be involved in a "focus group". This will involve having a discussion around some questions that the researcher will ask. The focus groups will include 3 to 7 other people who are also a part of an Adult CTLD team and have been involved in working or supporting young individuals with intellectual disabilities during the transition process. Other participants may include those from your service, other services you may work with, or those you may have not previously met. You can choose to be involved in the discussions around as many or as few questions as you feel comfortable with. The focus groups could take part at your service or around Hull and East Riding. Information will be provided about the date, time and location in advance to the focus groups. The focus group will last between an hour and an hour and a half, with a break at around half way. The focus group will be recorded so it can be listened to and typed up later. All of the recordings and typed up interviews will be kept locked away and have no personal details on them.

What are the possible disadvantages of taking part?
The study will require you to give up 60-90 minutes of your time. You will not be paid to take part in the study however a reimbursement for the travel expenses to attend the focus group will be made. Talking about your experiences of working with individuals with intellectual disabilities in looked after care can be a sensitive subject, so it might

bring up some difficult feelings for you. However, if this happens to you, the researcher will offer support and will help you to gain access to further support from your GP, if needed.

What are the possible benefits of taking part?
Although there will be no direct benefit or payment as a result of your involvement in this study, some people find it useful to talk about their experiences. It is hoped that the information you give us will contribute to understanding how successful transitions can be achieved for individuals with intellectual disabilities when they leave care. This may help to improve support and training for residential staff and healthcare professionals, and how services operate.

Do I have to take part and what if I change my mind?
You are under no obligation to participate in this study. Participation is completely voluntary. If you decide to take part you will be asked to sign a consent form to indicate that you agree to take part. Even if you give consent to participate, you can still ask to withdraw at any time however the information you share during the focus group will not be removed due to difficulties with extrapolating data from the audio recording.

Will my details be kept confidential?
All typed interviews and information about you will be stored securely in a locked cabinet, in keeping with University guidelines, for up to ten years, after which time it will be destroyed.

As this research is being used for a university course, it will be sent for assessment to the University of Hull. The research will also be sent to a journal, which means that anybody else who is interested in the research will be able to read it. It will not be possible for anyone to know who you are from the research as all of your details are taken out, and different names are used.

The only time we may need to breach this confidentiality is in the unlikely event that we become concerned about the safety of you or somebody else. We will discuss this with you, and consider what to do next.

Who is organising and funding the study?
The researcher is a doctoral student in Clinical Psychology at the University who is also employed by the Humber NHS Foundation Trust. This study is part of her doctoral research project. Research expenses are being provided by the University of Hull.

Who has reviewed the study?
Independent Research Ethics Committees protect the interests of people who participate in research. This study has been reviewed by the Faculty of Health and Social Care Research Ethics Committee at the University of Hull and has received a favourable opinion.

What if there is a problem?
If you have any concerns about the study, it might be helpful to discuss these with the researcher, who will do their best to answer your questions. You may also contact either of the researcher's supervisors at the University of Hull.

I am interested in participating and would like further information

If you are interested in participating you can contact the researcher via the details on the bottom of this page.

Contact Details

Researcher: Ava Doski
School of Health and Social Work
Clinical Psychology Programme
Aire Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Telephone: **07835333515** (please leave a message if the call is not answered and the researcher will get back to you).

Email: **A.Doski@2015.hull.ac.uk**

Research supervisor: Dr Nick Hutchinson

School of Health and Social Work
Aire Building, University of Hull
Cottingham Road
Hull
HU6 7RX
Telephone: 01482 464804
E-mail: N.Hutchinson@hull.ac.uk

Appendix G: Consent form.

Consent Form

Title of Project:
The experiences of residential staff and healthcare professionals working with individuals with intellectual disabilities during the transition process from children services to adult services.

Name of Researcher: Ava Doski

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 26/06/2017 for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily. ☐

2. I understand that taking part is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data transcription, without my legal rights being affected. ☐

3. I understand that other people will be involved in the focus group, and I confirm that I will not divulge sensitive details or information about other participants from the discussions outside of the group. ☐

4. I confirm that I will keep client, patient, and resident confidentiality during the focus group by not stating names, places or other information that could identify them. ☐

5. I confirm that direct quotes I have contributed in the focus group may be used for the researcher's doctoral thesis and future publications. I understand that this information will be anonymised. ☐

6. I understand that some of the data collected during the research may be looked at by individuals from the University of Hull, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐

7. I agree to take part in the interview part of the study and understand that my interview will be audio taped. ☐

☐

8. I would like to find out about the results of the study once it has been completed.

Name of Participant:	Date:	Signature:
____________________________	_______________	_________________________
Name of Researcher:	Date:	Signature:
____________________________	_______________	_________________________

Appendix H: Demographic information sheet.

Participant number:

Information about you

Please tick ☑

1. What is your age in years?

....

2. What is your gender?

Male ☐
Female ☐
Non-binary/third gender ☐
Prefer to self-describe ………………
Prefer not to say ☐

3. Which ethnic group describes you best?

☐ White British
☐ Other White background
☐ Black British
☐ Black African
☐ Black Caribbean
☐ Other Black background
☐ Indian
☐ Pakistani
☐ Other Ethnic Group
☐ Other Asian background
☐ Black Caribbean and White
☐ Black African and White
☐ Asian and White
☐ Other Dual Heritage
☐ Chinese
☐ Traveller
☐ Bangladeshi
☐ Prefer not to say

4. What is your job title?

…………………………………………………………………..

5. Where do you work?

……………………………………………………………………

6. How long have you worked in this service?

☐ Less than 6 months
☐ 6 months-1 year
☐ 1-3 years
☐ 4-6 years
☐ 7-9 years
☐ More than 9 years

Thank you for completing this questionnaire

Appendix I: Documentation of ethical approval from University of Hull Research Ethics Committee.

Removed for hard binding

Appendix J: Documentation of ethical approval from Research and Development Support Service from the local NHS Trust

Removed for hard binding

Appendix K: Focus group schedule.

Focus Group Schedule

The focus group schedule will not be strictly followed, but rather, used to guide questions and the general direction of the discussion.

Research Question:

What are the experiences of healthcare professionals and residential staff working with individuals with intellectual disabilities transitioning from looked after care to adult services?

Focus group aims:

1. To investigate the experiences of residential staff and healthcare professionals working/supporting individuals with intellectual disabilities leaving looked after care and transitioning into adult services.

2. To discover what makes a successful or unsuccessful transition for individuals with intellectual disabilities leaving looked after care.

Questions:

1. What does the transition process involve for young people with intellectual disabilities?
2. When do adult services become involved?
3. How do you decide what services may be most helpful for a young person with intellectual disabilities?
4. What are your experiences of working with individuals with intellectual disabilities during the transition process?
5. What makes a successful/unsuccessful transition?
6. What changes may be needed to make successful transition for individuals with intellectual disabilities?

Appendix L: Sources of support information sheet.

Thank you feel you need further support, then below is a list that might help.

If you have any specific problems or questions that taking part in the research has raised, you can contact the research team:

Ava Doski 07835333515

You can also speak to **your team leader or manager.**

If you are worried about your own health or well-being: You could speak to a family member or friend, a member of staff or your doctor.

Online support and general information available:

Samaritans

Website: https://www.samaritans.org

Telephone: 0845 790 9090

Foundation for People with Learning Disabilities

Website: http://www.learningdisabilities.org.uk/

Appendix M: Worked example of analysis.

Descriptive Codes	Analysis	Exploratory Comments
Joint system	P4: Yeah, a joint system with social care that'd be even more amazing	Healthcare and social care both on the same system?
	Participants: Laughter	
	P4: But I know it's just a dream	It seems like it would be really helpful ↓
	Participants: Laughter	
	P4: I dream about this	
	Participants: Laughter	
Lack of information Systemic working Unknown	P2: That young person whose placement had broken down three weeks before his 18th birthday and it looked like he was gonna end up at [inpatient unit name] whether that was appropriate or not, we were asked will you provide that support whilst he's in there cause he probably would be detained and to produce care plans and risk assessments, which we would've done but we would've done that blind cause we didn't know him at all so we would have had to create all those important documents so we would have done it but the validity of them and how accurate they were because obviously we didn't know him that well	There's a need for involvement from child services. Not sure why he was being detained?
Systemic working	P3: And even at that time we had that discussion of who was available as of when	
Unknown	P2: Yeah so, we could go in to the inpatient unit every day to support the staff even though we don't know him	Child services are willing to help
Preparation	P3: Yeah so, we were even making space because it felt like it had got to that point where it was about to happen, so we were having to prepare	The difficulties with the transition were expected?
Inappropriate provision Forced? Inadequate Unknown	P2: Yeah, the inpatient was even providing a bed which was an inappropriate bed but because they were being forced into it, so we felt we should support even though we felt inadequate cause we didn't know him. We had phone calls asking do you know this person, I was copied into some emails and it	Being admitted to an inpatient unit because appropriate provision was unavailable.

Limited information available Staff struggling with transitions?	was like we don't, they've historically been in the team but that nurse has left so we can't even pull on them for their experience but that was everybody sort of… nobody knew him so everyone's grappling, the adults are grappling, we're grappling.. trying to make the best out of a bad situation erm…	Even within teams, information can be an issue. Staff seem to be struggling with these transitions?
	P3: Yeah, yeah	
	P1: On a plus side	Need for a positive?
Access to groups	Participants: Laughter	
Reflective group Joint working Complexities of having an ID	P1: We have err, we're a part of quite a lot of erm disability sort of groups where you know.. like a panel sort of thing so if kids need any sort of PA or any respite or anything like that. And from there we set up like a reflective group with one of the looked after children's homes erm for LD in [location name] and the disability social work team. As part of that reflective group there were three young people, two of them were coming up to transition and one of them I think was 15 erm… all three of them are nonverbal, two of them are coming up to that age, one the girls is a year older than the other girl but they've been brought up as siblings basically for like the past 7 years or 9 years, about 9 years	Services being connected to helpful groups Services working together Personal experience of working with a transition process
	P3: Awww	
Joint working Available provision	P1: Erm.. they have a really good nonverbal sort of communication going on between 'em. One of them is moving on in the summer time, I think they've extended her placement as much as they can, but it was looking at that wishes and feelings and there was nobody else that actually could do that cause she was nonverbal and people were saying we can't do anything with her. So I got our art therapist to actually go out and he's going into the children's home to work with all of the kids in there to look at the nonverbal stuff but to look at what her wishes and feelings are cause I think what my concern was is that they might have this really good communication system and you	Even children's home struggle with the complex needs of some children. Different services are working together to provide the care the children need

Joint working Positive	might think yeah they do need to live together cause they've been brought up as siblings but they could hate each other [laughter] you just don't know	It seems that children's services were able to provide the provision that was unavailable
	Participants: Yeah	
	P1: Or they might want that natural break so we're currently just doing a piece of work around that erm to just find out where they want to live, whether they want to live together, whether it'll be successful or not I don't know but that's part of LD and social care, and children's working together. So hopefully we'll get it neat	An experience of child healthcare and social care There's a hope for a smooth transition
Proximity	P2: That's really good	
Familiarity	P3: Yeah	
Joint working	R: So, from what you're saying there, when different teams come together	
Reflective groups Services communicating with one another	P1: It depends on what it is. I think because they're in [location name] we know each other cause LD is so close nit and I think social care from an LD perspective, I don't know what it's like in [location name], but in [location name] we work really closely together. We all used to be located in the children's centre before it flooded but never really lost those contacts and we have quite a lot of reflective discussions group stuff going on erm.. and it's working really well for that young person because we're all involved, we all know each other, we speak. There's a common goal, outcome that we want but that's quite a straight forward case and you very rarely get those through. We very rarely get someone who's in area and who will transition in area who's looked after, usually they're out of area	Being in the same area and being familiar with one another seems to be positive

Appendix N: Epistemological statement.

Ontology refers to the study of being and the meaning of reality, whereas epistemology refers to the study of that reality (Guba, 1990). Within research, it is important to acknowledge the authors assumptions and adopted stance in regard to the nature of reality and knowledge, as this can impact the way in which research is approached, developed and conducted. This epistemological statement seeks to outline the underlying epistemological assumptions that have contributed to the development of the empirical paper of this portfolio thesis.

This aim of the current study was to develop an understanding of the experiences of residential staff and healthcare professionals that have worked with young adults with intellectual disabilities (ID), in care of the Local Authority, transition to adulthood. The research was developed in the absence of literature that considers how residential staff and healthcare professionals experience working with young adults with ID in the care system and how they perceive the transitions to adulthood for these young people. To understand this subjective experience, a qualitative approach was deemed necessary. A positivist and realist stance was rejected as this position did not fit with the current study.

A positive stance, typically adopted by quantitative methodologies, proposes that knowledge is objective and exists in the world, and the 'truth' of something can be discovered and measured through research (Braun & Clarke, 2006; Willig, 2008). Furthermore, a positivist stance highlights that participants can be studied without the influence of researcher bias (Ponterotto, 2005). A positivist position was not considered suitable for exploring the experiences of residential staff and healthcare professionals that had worked with young adults with ID during their transition to adulthood, which may have made the analysis too reductionist. In contrast, constructionist epistemologies assume that within the world, there is no objective truth, however language is used as a strategy to construct social realities. Therefore, a constructivist stance emphasises that realities are entirely subjective and different for every individual, based upon their experiences, social environment and views of the world (Guba & Lincoln, 1994; Willig, 2013). Similarly, a constructionist stance did not fit with the current study as the focus of this study was not about how residential staff and healthcare professionals had come to construct their reality in that way.

Between positivist and constructivist stances, there are phenomenological epistemologies that focus on the participant's experiences and understanding a concept from their perspective (Willig, 2008). Thus, what is important for the participants is discussing what a reality is for them, rather than the external validity or objective truth of their experiences. This appeared to fit with the current study, as the researcher wanted to understand the participants experiences of the transition to adulthood for young adults with ID. The current study was conducted as part of a Doctorate in Clinical Psychology and a part of the training programme involves listening to people's experiences and perspectives, therefore a phenomenological epistemology also fits similar to the researcher's values. Within phenomenological epistemologies, an interpretative phenomenology goes beyond what an individual articulates to understand such meaning in relation to broader social, cultural and theoretical concepts (Willig, 2008). However, a descriptive phenomenology focuses thoroughly on the data and wanting to know about participants' experiences as they are shared instead of using meaning from external sources to relate to their experiences (Willig, 2008). The researcher was interested in how participants experiences were incorporated within the broader context, but this was only in relation to the implications of the results rather than a guide for analysis. As the researcher was interested in the participants experiences and how these possibly related to the aims of this research, the researcher positioned themselves within descriptive phenomenological epistemology.

Once this approach was established to understand the knowledge of participant's experiences of the transition to adulthood for young adults with ID, a number of qualitative methodologies were considered to conduct such research. After careful consideration, it was decided that Thematic Analysis was the most suitable methodology to address the research aims of this study. Interpretative Phenomenological Analysis (IPA) and Grounded Theory were considered as alternative methods, which are discussed below.

Grounded theory aims to build upon existing theory or developing new theory that are grounded within the analysis (Strauss & Corbin, 1994). Using a grounded methodology to build upon existing theoretical theory would have been challenging to do within this study due to the limited research available. As there is very limited research that focuses on the experiences of children and young adult's experiences of being in the care of the Local Authority, and no research that focuses on the experiences of how residential staff and healthcare professionals that work with these individuals during their transition to adulthood, a grounded theory method would have been difficult to conduct. Furthermore, this study did not aim to develop theory of how a concept worked or how residential staff and healthcare professionals storied their experiences of the transition process to adulthood, therefore this method was discounted. On the other hand, IPA focuses on the subjective meanings of participants experiences, but also involves developing meaning from these experiences based upon their context (Smith, Flowers & Larkin, 2009). Although IPA fits with a phenomenological position, it appeared inconsistent with the research aims of this study, as there was little focus on making meaning of the experiences of residential staff and healthcare professionals.

Thematic Analysis is another qualitative method that was considered by the researcher for this study. Thematic analysis does not align with any particular epistemological stance (Braun & Clarke, 2006). This method appeared the most suitable for this research as the study aimed to hear about participants' experiences of the transition to adulthood for young adults with ID and believing that this was a 'true' representation of their reality. Furthermore, thematic analysis allowed to researcher to stay with participants' accounts and experiences, rather than using external information to construct meaning of their experiences, a position that is consistent a descriptive phenomenology. Thematic analysis also allows to conceptualise a phenomenon in a group, but also whether there any variations occur across the groups (Joffe, 2012). This study used multiple participant groups, which also fitted with current research design.

Within thematic analysis, an inductive or 'bottom-up' approach was implemented which focuses on what derives from the data rather than coding the data based upon what previous research has suggested to be importance, as when adopting a deductive approach (Braun & Clarke, 2006). As this was the first study to focus on the experiences of residential staff and healthcare professionals of the transition to adulthood for young adults with ID in the looked after care system, an inductive appeared more appropriate. The researcher did have some understanding of how young adults with ID that had been in the care of the Local Authority experienced the transition to adulthood (Priestley, Rabiee & Harris, 2003), however this was not used to guide the analysis of this study. Relating to this topic, the thematic analysis within this study was more semantic than latent, as it particularly considered explicit meanings rather than what structures the semantic content respectively (Braun & Clarke, 2006).

However, semantic content was not the only analysis presented, as the themes within this research are contextualised more broadly and patterns across the data sets were considered. Thematic analysis has moved beyond counting the number of times experiences are mentioned to develop themes (Willig, 2008), therefore the themes developed in this analysis were classified based upon how meaningful the experiences of the participants were.

References

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

Guba, E.G. (1990). *The Paradigm Dialog*. California: SAGE Publications Ltd.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research*, *2*(163-194), 105.

Joffe, H. (2012). Thematic Analysis. In D. Harper & A.R. Thompson (Eds*) Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 209-224) West Sussex, UK: John Wiley & Sons, Ltd

Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of counseling psychology*, *52*(2), 126.

Priestley, M., Rabiee, P., & Harris, J. (2003). Young disabled people and the 'new arrangements' for leaving care in England and Wales. *Children and youth services review*, *25*(11), 863-890.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, method, research*. London: Sage Publications

Strauss, A., & Corbin, J. (1994). Grounded Theory Methodology: An Overview. In N. K. Denzin & Y. S. Lincoln (Eds.). *Handbook of qualitative research*. (pp. 273-285). California: SAGE Publications Ltd.

Willig, C. (2008). I*ntroducing qualitative research in psychology: Adventures in theory and method* (2nd ed.). Buckingham: Open University Press.

Willig, C. (2013). *Introducing Qualitative Research in Psychology* (3rd ed.). Berkshire, England: Open University Press

Appendix O: Reflective statement.

The past three years in developing this thesis were both challenging and enjoyable, however there were many lessons to be learnt from this. I hope this reflective statement will give you an idea into the journey I've had over the past three years in conducting this thesis project.

Choosing a topic

Choosing a research topic was very important to me when I first started this course, as I knew I had to be committed to the project for the duration of the three years of the course. During my undergraduate degree, my final year dissertation was about obesity and numerical estimation – a new and exciting area that was thriving in the field of research. When I started this course, I wanted to continue researching about this area as I really enjoyed my dissertation project. However, as the course progressed, and the research topic conversations began to float, I began to really think about what was it that interested me the most. After a lot of thinking, I finally knew what I wanted to do…

I arrived into the U.K. from Kurdistan, Iraq at the age of 6 years with my parents and my two younger brothers. Initially, I found the move very difficult when I was child, as I only knew my family. I remember always asking my mother to adopt a little girl, so I had a younger sister, somebody I could talk to and play with. As I got older, I never stopped nagging my mother about adopting a young girl, but then during my adolescent years I began to understand some of her reasons for this. After I'd completed my first year of my undergraduate degree, I visited Kurdistan and volunteered at an inpatient unit and a mental health centre for young children and adolescents. I quickly began to realise that, although children and adolescents were being neglected and abused by their families, the government did not interfere in such these circumstances. I remember questioning the psychiatrist I was shadowing at the time about the lack of interference from the government regarding these situations. She explained that these young people have a family, although it may not be the 'best' family for them, they had somewhere to live and they had food. She further explained that there was nowhere for these young people to go even if they were removed, in fact, they'd end up homeless in the streets without a family. I went home with this new information and discussed with my mother about this not being right, that these young children and adolescents needed protecting. I remember my mother's response very vividly: *"this isn't England, there is no one else to care for them, that's why we don't have children here to adopt".*

When I returned back home to England, I began to research about why children and adolescents within this country were being placed into the care of the Local Authority. I remembered the cases of Victoria Climbié and Baby P and how the government had apparently failed to protect these children from abuse and neglect from their families. But, I quickly began to realise that a government cared about these young people and there were laws, policies and procedures in place to protect these young children from abuse and neglect, unlike the government of my birth country. As my interests within this area become stronger, I always knew that one day I wanted to work with children and young people in the looked after care system.

Fast forward to the first year of the doctorate, we had a workshop about thesis research project, which included the research team discussing their areas of interest. When Dr Nick Hutchinson began to discuss his area of research (people with ID), I had a light bulb moment *"what about children with ID in the looked after care system, what happens to them?".* As I returned home from that workshop, I did some research around my idea… I found nothing. I remember thinking *"how could this be possible, I must not be researching things properly".* I eventually found out that it wasn't my research skills that were poor, but actually there was very very limited research into this area. Although I knew it was difficult to complete a thesis project that did not have much of a literature base, it motivated me more to do something about this. As I debated about this topic for a thesis project, I began to wonder whether I should just stick with something I already knew that would make things much easier – my undergraduate dissertation topic. However, I eventually realised that was something I had already completed, and I was excited about the opportunity of conducting a research project that I was very passionate about.

Designing the project

Designing this research project was challenging as I had many ideas about what I wanted to do. Initially, I met with Dr Nick Hutchinson and Dr Annette Schlosser to discuss my ideas. My first idea for this thesis project was to explore how children and young adolescents with ID experienced the looked after care system. After the meeting, I began to realise that this may too much of challenge to do as a Doctorate thesis due to time constraints and ethical issues around this. As I began to research this area, I came across the paper by Priestley, Rabiee & Harris (2003) which explored the experiences of young adults with disabilities that had been in the care system and transitioned into adulthood. The findings of this paper were striking, as I began to have an understanding of how difficult adulthood can be for these young adults. I then contacted the author of the paper, Mark Priestley, and explained my research project and whether he had any other papers or information that would be of help for me. He explained that it would be difficult to recruit this client group but that he wished me the best with this. Nonetheless, I took his advice on board and continued to go ahead with this idea. I then contacted a nurse that worked specifically with transitions from children's services to adult services for young adults with ID. The nurse also echoed Mick Priestley's advice, however this did not change my mind. I then attended a meeting with the headteacher of a specialist school for young people with ID, and he also stated that this would be a difficult area to research. At this point, I had completed my final research proposal on this area as I was adamant in pursing this research topic, however I then began to question whether it would be feasible to complete this research project given the time constraints of the course.

Although it would have been interesting to hear the subjective experiences of young adults with ID transitioning from the looked after care system to adulthood, I began to realise that many of the decisions that would be made on behalf of these young people would be by the staff involved in their care. After many conversations with Dr Nick Hutchinson, we decided that it would be interesting to understand the perspectives and experiences of the adults involved in these young people's care, as they were ultimately the ones that knew these young people the best. We then began to think about who would be involved in the care of young adults with ID that were in the looked after care system, and after a meeting with a nurse, we decided upon residential staff and healthcare professionals that work in community learning disability teams. We also agreed that having the four perspectives of children and adult residential staff, and healthcare professionals from children and adult community learning disability team would provide an in-depth understanding of how decisions are made for these young people across all four services.

Methodology

During my undergraduate degree, I had only ever gained experience of using quantitative methodology. I knew for this project that I wanted to understand the subjective experiences of the participants and felt this would only be achievable through the use of qualitative research. Initially, I didn't know much about how qualitative research was conducted and the processes involved within this methodology, however I quickly had to learn that there were no right or wrong answers.

I initially considered completing interviews with participants, but later realised that I might not get enough participants that capture a broad sense of how residential staff and healthcare professionals experience the transition to adulthood for young adults with ID leaving the looked after care system. I then realised that completing focus groups with all four groups of participants would provide rich in-depth qualitative data, which would hopefully capture many of the participants experiences. It was also around this time that Dr Nick Hutchinson and I began to discuss what type of analysis I would use for this research project. As outlined in my epistemological statement (Appendix M), I chose thematic analysis as this methodology provided me with the opportunity to hear participants experiences, but also how these experiences may differ between the different services involved in the transition process for young adults with ID. As I began to research on the number of participants recommended to conduct a focus group (4-8 participants, Braun & Clarke, 2006), I prepared myself for the challenges I may experience when I begin to recruit participants. Upon reflection, using a thematic analysis provided me with a foundation of how to conduct future research. I realised the importance of listening to the recordings of the focus groups over and over again, as well as coding the data and how this process would provide me with the skills to conduct future qualitative data.

Recruitment and data collection

To begin the process of recruitment, I contacted the residential homes and community learning disability teams that I had been informed of by Dr Nick Hutchinson and my supervisors on my child placement. When I reached to the managers and team leaders of these services, the majority seemed enthusiastic about the research. However, some were also very busy and unable to speak with. I became aware that many healthcare professionals were very busy due to their high caseloads. Despite this, I remained determined and with the advice of Dr Nick Hutchinson, I began to attend team meetings and multi-disciplinary meetings to discuss my research project. I had many healthcare professionals tell me how interesting the research topic was, but also how difficult it would be recruit participants. I felt disheartened at times, as I felt I wasn't progressing much with my data collection for the adult community learning disability team focus group in particular.

Despite these challenges, I continued with data collection and conducting the focus groups. My first experience of conducting a focus group was with the children's residential home. Initially, I felt quite daunted by the prospect of having so many participants in one focus group. I wondered whether I had the right questions to ask and how I was going to manage such an atmosphere. Conducting this focus group was an amazing experience that I will always remember. Every participant made me feel very welcome and comfortable. All the participants in the focus group had an experience of the transition to adulthood for young adults with ID. Upon reflection, I realised how little I actually contributed, as a researcher, to the focus group. The flow of the conversations between the participants continued throughout the focus group. I began to realise how passionate every single staff member was about the young people they cared for in the residential home. The conversations were very emotive, and participants spoke so passionately about what they believed in. However, I could also sense feelings of hopelessness amongst the staff members as some of the issues they talked about were out of their control. Upon reflection, this focus group provided me with an understanding about what may come up in the other focus groups. However, I was also aware of my own biases and discussed these in supervision to eliminate any source of bias that may arise in other focus groups.

Following on from the children residential focus group, I conducted a focus group with the adult residential staff and healthcare professionals from the children's community learning disability team in March 2018. Both focus groups provided me with further insight into what transitions for young adults with ID were like. Again, these focus groups were emotive and eye-opening, as I continued to learn how difficult transitions were for young adults with ID in the looked after care system. At this point I'd conducted three out of the four focus groups but was not progressing any further with the adult community learning disability one. I contacted a number of professionals but failed to get through to them. I eventually organised a focus group in April 2018 for the adult community learning disability team, however no one turned up. It was at this point that I felt very hopeless about finishing this research project on time. However, with the help of my supervisor, family and friends, I was determined to continue with the recruitment process. Eventually, I had three participants for my final focus group, which was arranged for beginning of May 2018. This was a very stressful period as I began to realise that I did not have much time until the deadline, but also very overwhelmed to have completed all my data collection! After a few supervision meetings, I was adamant that I'd be able to get this thesis project completed before the deadline.

The whole process

Overall, this project has provided me with an insight into how important it is to be passionate about the research you conduct, as the process can involve many challenges and hurdles along the way. I believe my interest and passion for working with looked after children thoroughly motivated me to continue with this research project, despite all the difficulties I've encountered along the way. Although, there were times where I did want to give up, I knew how important this research could be for young adults with ID in the looked after care system. Interestingly, I never lost interest in my research project, despite the write up period being a difficult due to the limited time I had to get everything done. Nonetheless, as I began to merge all my research together, I hoped that this project would have a small impact on how transitions to adulthood were facilitated young adults with ID. To conclude, this journey has been an unforgettable one and the lessons I've learnt about qualitative research will inform any further research I purse in the future.

References

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

Priestley, M., Rabiee, P., & Harris, J. (2003). Young disabled people and the 'new arrangements' for leaving care in England and Wales. *Children and youth services review*, *25*(11), 863-890.

Appendix P: Quotations from data analysis supporting the implications recommended in the empirical study.

A multi-agency approach and young adults being followed through the process to adulthood:

"If you had that multidisciplinary team with a good resource we wouldn't be having these and then they wouldn't be transition issues because the kids would be in the right service, in area" (CCTLD2).

"Yeah, a joint system with social care that'd be even more amazing" (CCTLD4).

"I think it needs to be that sort of four-way thing. I think [location name] and [location name] I think should come together but children's and then sort of like adult's but then social care. I think there needs to be a wider sort of discussion meeting because it's kept so separate isn't it" (CCTLD1).

"Health and social need to be commissioned together" (CCTLD1).

"Like you used merging sort of services so we've got similar procedures so we don't have this confidentiality and consent issue" (CCTLD2).

"If there was a multidisciplinary multi-agency team with some authority to act on their decisions then you might have something that would work but you'd still need that linkage into children's and adult services rather than it being separate" (ACTLD1).

"It does help with that joint understanding and multi facility understanding" (ACTLD2).

"Maybe get a multidisciplinary team involved as well so you're getting it from all sides cause not everybody comes with it" (ARS1).

"That transition was better, the transition from children's services to adult services worked better because one of our social workers was attached and built up a really good relationship with his family and that helped smooth things" (CRS2).

"It's not always easy, it's not always quick but there's an overwhelming sense that these people need be followed through the process" (ACTLD1).

*"For me that's when it's always worked better when you've got an allocated key worker who steps over that age boundary into children's services, gets a grip of what needs to be done and walks alongside the young person into adult services, and makes sure everything is in place before they say goodbye" (*ACTLD2).

"They are better off having somebody from 16-21 year old and then when they turn 21 they move on to a different social worker" (CRS1)

"There is a very structural problem that unless you give somebody permission to cross those boundaries then it's always going to be a difficulty" (ACTLD1).

Having enough time to prepare the transitions:

"It would be really good like a year before they turn 18 for a worker to put them sort of on our radar cause they're on their radar and then maybe that'll be fair for us to then to go to the services, start gathering the information to help them with the transition" (CCTLD2).

"A year in advance and it's not about holding the case, it's literally about gathering information and doing that referral to the adult team and getting an assessment up to date to handover. That's, that is what would make it smoother" (CCTLD2).

"Time, having the right length of time to do it in" (ARS2).

"Cause we all know we can support all those young people if we were given the time and resources to do it" (CCTLD2).

"The more communication and information that's passed on between homes as such then it's going to make transition ten times easier. It has to be relevant, it has to be accurate cause then if it isn't then you've failed straight away" (ARS2).

"She used to come into the home, she was more involved, so the transition was better cause information was shared" (CRS4).

Importance of sharing information and being transparent:

"Transparency, information, communication" (ARS1).

"You see if there was a regulation for the paperwork between the care homes cause everyone has a different way of presenting it so by passing it on you have to alter it and put it into different areas cause every care home has different files and care plans. If everyone knew the same sort of system and layout then that would make things a lot easier but there isn't any" (ARS2).

"Well when everybody works as a team, nobody sugar-coats anything erm… no one tries to sweep anything under the carpet kind of thing" (ARS1).

"Just being totally transparent about the kid, do you know what I mean? Like being told honest about what the kid does, the good things, the not so good things they do" (CRS3)

"Wording it differently the things, try not to use the words that'll stop people looking cause like you say going into a place and he only plays with fire well he doesn't really, he's just trying to put the" (CRS46).

"The information being shared there was an honesty, there was an openness with regards to the issues" (CRS2).

Preventing young adults from becoming looked after children:

"You made a point really cause erm in terms of preventing that.. LAC in the first place, you kind of need that intensive support team to go in and support families" (CCTLD4).

"Cause it's preventable" (CCTLD2).

"Those kids with increased support in the first place if we could've provided that and erm… an out of hours support they wouldn't be LAC" (CCTLD2)

"It would have been easy to manage with a home environment with that extra support so it's about prevention" (CCTLD4).

"Cause we all know we can support all those young people if we were given the time and resources to do it" (CCTLD2).

"And that early intervention that you mentioned earlier on that actually let's prevent them from becoming LAC in the first place and actually put in that service" (CCTLD2).