

Transition from school to adult services for young people with severe or profound Intellectual Disability: a systematic review utilizing framework synthesis

Running title: Transitions for young people with severe ID

Keywords:

Transition; severe intellectual disability; profound intellectual disability; framework analysis

Abstract

Background: The transition to adulthood has been described as a difficult time in the lives of young people with intellectual disability. There has been little emphasis on young people with severe or profound intellectual disability specifically, even though their pathways may differ, due to greater support needs across the life course.

Methods: A systematic review was conducted utilising Bronfenbrenner's ecological model to inform framework analysis to synthesise qualitative findings.

Results: Taking an ecological perspective proved valuable. The transition process was described as stressful and barriers were identified across the ecological levels. Parents accounted for

the majority of participants in studies, and the needs of young people and their parents emerged as highly interdependent.

Conclusion: Themes reflect the complex nature of the question what adulthood should look like for individuals with severe or profound intellectual disability.

There is a lack of involvement of multiple stakeholders and young people themselves within studies.

Introduction

The transition to adulthood for young people with intellectual disabilities has been highlighted as an area of significant importance (Foley et al, 2012; Hardy et al, 2005; Doran, 2011). In relation to those with severe or profound intellectual disability, the transition process poses questions about decision-making capacity and how others can choose on behalf of the individual themselves (Ware, 2004; Nind 2013). Studies that examine transitions and involve the person with intellectual disability mostly include participants with mild to moderate intellectual disability (Daviso et al, 2011; Foley et al, 2012; Mitchell, 2015), or do not differentiate in their findings between degrees of disability (Ward et al, 2003; Pilnick et al, 2011). However, lives and pathways of those with severe or profound intellectual disability may differ due to higher support needs, dependency on others across the life course and difficulties in accessing further education or achieving

employment (Hogg, 1999; Foley et al, 2012; Gauthier-Boudreault et al, 2017b).

Aim and scope of the review

The aim of this systematic synthesis was to critically review what is known about the transition to adult services for young people with severe or profound intellectual disabilities. In the case of young adults with severe or profound intellectual disability, decisions regarding future support happen, typically, within the context of multiagency involvement that includes family members, statutory services, such as Education, Health and Social Work, third-sector care providers and others such as advocates (Hardy et al, 2005; Murphy et al, 2011; Kaehne & Beyer, 2013). Thus, this review attempted to address the research question from an ecological perspective, in order to capture not only the perspectives of family members but also to incorporate findings in relation to the decision-making process of different stakeholders and organisational and cultural influences. To capture the complexity of the transition process and its impact on those involved, the review focused on qualitative studies. Qualitative research is based on a subjective epistemology and attempts to understand meaning and subjective views of phenomena as they occur in a specific context (Saini & Shlonsky, 2012) and provides a means to enhance our understanding of the how and why (Snilstveit et al, 2012).

Methods

Inclusion criteria

This review defines transition as the move from school to adult services. When and how transitions take place differs between and within countries. Furthermore, studies within this review were conducted at different points in time, spanning three decades of changing transition policies and service commissioning. Thus, the definition used was broad, including transitions to further education, respite, day and care provision. Although health care transitions are considered within some of the included studies, this was not the focus of this review. Essentially, the focus of this review is on young people ending school and being at the threshold to adulthood.

Inclusion criteria were (1) studies published in English, (2) examining the transition process from school to adult services, (3) relating to severe or profound intellectual disability and presenting (4) qualitative data. Severe or profound intellectual disability was defined in accordance to ICD-10, the AAIDD framework and DSM-5, referring to young people who are nonverbal or use very rudimentary forms of communication, who are in need of substantial supervision and support and reliance upon others to make life changing decision. To ensure that studies were meeting inclusion criteria 3, studies were not solely included on the basis of the diagnostic terms used but

based on the description of participants and their needs and abilities. To be included, studies that included a range of young people with differing levels of disabilities were required to differentiate their findings specifically in relation to severe or profound intellectual disability. Many studies reported samples of young people with both autism and severe or profound intellectual disabilities and these were included in the review. Throughout this article the term parents will be used to refer to all main carers that participated in the studies.

[Table 1 here]

Search strategy

The systematic search comprised of electronic database searching, review of retrieved articles' reference lists, hand searching, contacting experts within the field, and the search of grey literature sources. Databases included were: Ovid, Social Work Abstracts, CINAHL, MEDLINE, PsychInfo, Sociological Abstracts, ERIC, ASSIA, Social Care Institute for Excellence SCIE. The following search terms were applied to each database and combined using AND. Truncations were used to ensure the retrieval of variations of the chosen terms. Full details of the search strategy can be obtained from the first author.

Search Retrieval Protocols were used to document all searches and authors were contacted in cases where important information in relation to inclusion criteria was missing. The search identified two publications based on the same data by the same research team (Gauthier-Boudreault et al, 2017; 2017c). It was found that both publications had significant overlap in the reporting of their results. Thus, the second article was excluded as a duplicate (Gauthier-Boudreault et al, 2017c), although its content was closely examined to complement findings of the included article (Gauthier-Boudreault et al, 2017).

[Figure 1 here]

Critical appraisal of included studies

Included studies consisted of eight peer-reviewed journal articles, four academic theses, one book and one government report. Three studies^{2,4,5} used mixed methods; the current review only synthesizing their qualitative data. There were differences in the studies' methodological quality, with some providing little information about their analysis of qualitative data^{2,3,11,12,13}, with one study providing no information (Dee & Byers, 2003). Additionally, two studies provided little to no examples of their data^{2,4} to support their interpretations. Both of these studies did not use interviews but described the

evaluation and implementation of projects to improve practice. As those two studies focused on collaborative practice, organisational barriers and facilitators they were still included in order to enrich an ecological understanding of the subject, albeit with the caveat that they offered very little data that was possible to use within the review. All studies were critically appraised using the guidelines for appraisal of qualitative research developed by the Critical Appraisal Skills Programme (CASP, 2017). The first author reviewed all studies. Eight of the studies were peer reviewed by a second, independent researcher and the appraisal of all studies was discussed within the research team. An overview of studies and the quality assessment can be seen in the Tables 2 and 3. Surprisingly, there was no mention of ethical considerations for five of the included studies ^{2,4,5,11,13}.

[Table 2 and 3 here]

Data analysis

Framework analysis was the chosen analytic approach to synthesize findings of the 14 included studies. Framework analysis involves the use of an a-priori framework that is suitable for answering the review question, and using it as the basis of coding evidence (Richie & Spencer, 1994). By combining inductive and deductive approaches it is able to explore predefined themes of concerns that have been

developed within the focus of the review, in this case the decision-making process involving different stakeholders, while remaining receptive to unforeseen and unexpected findings (Carrol et al, 2011; Snilstveit et al, 2012; Parkinson et al, 2016). In the analytic process the framework might be modified in response to the evidence reported, so that the final product is a revised framework that may include both modified themes and new themes that were not captured in the initial framework (Stuart et al, 2017; Richie & Spencer, 1994).

Identifying an ecological framework for data analysis

Initially, the existing literature base was visited in depth and the selected studies were read carefully. In this case there was no clear existing framework. In relation to young people with profound and severe intellectual disability, multiple stakeholders and levels are involved within the decision-making process and therefore a nuanced framework, able to capture the surrounding systems in detail, seemed an optimal solution. An ecological framework was deemed appropriate as it allows researchers to capture the complexity of processes (Yin, 2002; Onwuegbuzie et al, 2013). Bronfenbrenner's (1979) theory of the ecology of human development requires the researcher to maintain a double vision: (1) identifying the dynamic relationship between the individual and his/her immediate environment and (2) how this relationship is shaped by peripheral systems and forces.

Data synthesis

Qualitative data was extracted from all 14 identified studies. This included not only original data but themes and meanings that were highlighted by authors. Abstracts, introductions, results and the discussion sections were included, as authors made references to their results throughout the included journal articles. Due to issues of feasibility only results sections of the included government report, PhD theses and the one book were extracted. The ecological framework was systematically applied to the findings, and themes proposed by the authors were set aside. The framework codes and sub-codes were applied to the findings using NVIVO qualitative analysis software (Version 11). Thus, the existing model acted as the base that was built upon, changed, reduced and combined within the process. Throughout the process the development of the framework was documented and changes were applied to all studies continually. Towards the end of the analytic process, a second researcher used the framework and applied it to a selected sample of the data. The final application of the framework was discussed within the research team.

Results

Overall, studies reflected the variety of needs and heterogeneity of abilities in young people with severe or profound intellectual disability. The samples ranged from individuals with complex

health care needs and limited mobility, to young people who were physically very able but who required constant support and supervision within daily life. The latter group was often described as being on the autistic spectrum. Sample sizes ranged from 4 to 26 participants. The majority of studies utilised interviews to explore the transition process through the perspective of parents. A minority of studies explored the perspectives of different stakeholders and therefore were able to address the ecological framework. These included a focus on transition meetings (Carnaby et al, 2003), further education and inter-agency work (Dee & Byers, 2003); three studies^{3,5,9} related the perspectives of parents to views of professionals and organisational practices and policies. Additionally, one study explored the views of parents within Black and minority ethnic (BME) communities (Doyle, 2012): a gap within the literature of intellectual disabilities and across the included studies.

Studies that included participants with mild to profound intellectual disability^{2,13,14} provided less relevant data than those with an exclusive emphasis on severe or profound intellectual disability.

In most studies, young people themselves were not involved in the research process and choices made about the involvement or exclusion of young people as participants were not discussed by the majority of studies. Interestingly, the lack of involvement of young people in the transition process appears

to be mirrored in their lack of involvement in the research process. Yet, three studies were able to give presence to young people's lives and identity within the narratives of their studies. This was achieved by in depth case studies and descriptions of the likes and dislikes of young people. One study described the use of art, pictures or Talking MatsTM (Murphy & Cameron, 2006) to involve young people directly in the research process (Cox, 2017), while Hubert (1991) and Haddow (2004) described spending time with young people and family members during the research process. Young-Southward et al (2017) reported that some young adults with severe intellectual disability were present during interviews alongside their parents, but visual aids were not provided due to experiences resulting from a pilot study. Young people that were present during interviews appeared to be able to express their views verbally about the transition, and hence not meeting inclusion criteria for this study. Young people with profound intellectual disability were not present during interviews.

Themes across ecological levels

Bronfenbrenner's ecological framework was considered suitable to synthesise findings. Notably, two changes required to be made to the framework during the analytic process. Firstly, it appeared more appropriate to have the family, as opposed to the young person, at the centre of the framework. This might be explained partly by the designs of the included

studies, as all relied predominantly on descriptions of the young people as seen by parents. With regard to planning for adulthood, the needs, wishes, concerns and views of parents were discussed concurrently with the perceived needs and possible wishes of young people. Often, when reviewing, it was challenging to understand if addressed wishes and needs related to young people or to their parents. Therefore, the decision was made to take the whole family as the first system

Secondly, at the beginning of the review, the chronosystem had been thought to be useful to capture the transition as a process over time. However, within the analysis it became apparent that time was a more important theme, spanning the whole life course of young people and their families from the time of birth and diagnosis to the far future when parents might cease to be able to care for their adult children. An incorporation of the theme of time facilitated an understanding of the transition within the whole life course of the young person and his/her family. Thus, it was decided that the immediate decision-making process of ending school and starting adult services was better captured within immediate family systems (Micro and Meso). An overview of the a-priori and a-posteriori framework can be seen below (Tables 4 and 5). Subthemes comprised environments and processes that were identified as influences within different ecological levels.

[Table 4 and 5 here]

Some themes were discussed in more detail than others. As can be seen in Table 6, themes relating to the first three systems were discussed by more studies than, for example, cultural or political influences. Themes relating to the family system showed the greatest complexity and content provided. Other themes such as the organisational context were widely mentioned but the degree of elaboration was less. Participants appeared to acknowledge the role and importance of 'wider' ecological systems, while not being deeply involved in them and having little information about how they worked.

The Family

The subthemes within this master theme mirror the interdependence of the young person's needs and needs of the family as a whole. These two sub-themes describe young adults and parents separately, while the third theme 'Quality of life', explores issues discussed in both.

The Young Adult

Difficulties with communication, and the question of how to involve young people and access their views, were highlighted as problematic by participants across all studies. However, the need to understand and engage with individuals was emphasised in seven studies^{2,3,4,5,8,10,11}. These studies highlighted the importance of attuned and consistent

relationships, valuing the unique and subtle communication of individuals.

Adolescence and the move into adulthood had the potential to result in an increase of support needs, in relation to health needs, mental health or behaviour that challenges. For example, while young people physically matured they became larger and stronger and care tasks as well as behaviour that challenges were more difficult to handle for carers. The gap between young people's intellectual development and their emerging sexuality was described as a concern within three studies ^{1,3,10}.

There was some fluctuation in both parents' and professionals' accounts that described small developmental steps towards adulthood and more independence, while also acknowledging the consistency of needs of young people and seeing them as 'eternal children' (DeZonia, 2008).

"There's something that's still inside saying he's my little boy. It's a bit peculiar and you don't have the normal signals to tell you this child has grown up." (Hollinrake, 2005)

In relation to developmental processes that were observed by participants, this related to greater abilities in choice making and life skills, comprising small steps for example learning to carry a laundry basket ¹.

Parents

In the majority of studies, parents were acting as main carers. Parents' responsibilities involved daily care tasks such as personal care, medical care, facilitating meaningful activities and advocating on behalf of the young people. Parents also managed collaborative practice with involved professionals such as social workers, teachers, health professionals and third sector agencies or respite services. Mothers accounted for the clear majority of participants in the study sample.

Consistent, or increasing care demands, within young adulthood, were at once described in the context of parents becoming older and being less able to meet all the needs of young people. In five studies, parents described how the birth of their children had taught participants a new perspective on life and the deep love inherited within the relationship^{3, 5, 9, 10, 11}.

"I love her very much and she's taught me a lot of lessons in life. I think about how everything is a struggle for her, you know? (...) It has taught me how not to give up in life and my own challenges in life. I look at her and think everything is a struggle, and when I have a rough day I think about Linda and it helps me move on." (DeZonia, 2008)

Quality of Life

Quality of Life (QoL) of the young people was framed around meeting basic health care needs, providing activities and space for social interaction and stimulation. The responsibility to

provide adequate QoL appeared to heavily rest on the family, especially mothers. Concerns about the QoL of parents dominated the analysis and was discussed by all studies except the two studies whose focus was not on parents ^{2,4}. Offering a high QoL for their children seemed to negatively affect parents' own QoL. Parents were struggling with a lack of sleep and little time for themselves. Siblings were only mentioned in four of the studies ^{3, 4, 9, 10}, and parents seemed to try to discourage siblings to feel responsible to take on caring roles.

Moving out of the family home was discussed in nine ^{3,5,6,7,9,11,12,14} of the studies and in six studies ^{1,3,7,11,13,14} some young people lived in supported accommodation or residential placements, but this was the minority of cases with most young people living in the family home. There were variations in families who wished their adult children to move out of the family home, advocating for their children's right to independence, while, at times simultaneously, parents had little trust in services to be able to adequately care for their children. Two studies described that some parents felt their own QoL had increased once their children were looked after outwith the family^{7,11}, while other participants reflected on their perceptions of poor quality of care within residential or supported living services^{5,6,11}.

A wish for more support outwith the family lived alongside parental worries of risk and safety. Those fears seemed to stem

from media coverage, but also direct experience of adult services.

“There are horror stories about care homes and things, with abuse, and the worry was if she goes away and she’s abused, how would she be able to tell us? Because if she went very quiet, that wouldn’t be her, but then the carers don’t know her. So they wouldn’t pick up on it either.” (Biswas et al, 2016)

The thought that parents would have to continue to provide substantial care until the end of their lives was described as a very difficult process by some participants.

“It’s a daunting feeling because ... the older they get the more reality hits that you’re like ‘I’m going to be a carer for the rest of my life’.” (Young-Southward et al, 2017)

There was too little data to make any judgment on types of accommodation in relation to quality of services but the need for trusting relationships with qualified staff was emphasized by parents in eight studies ^{1,3,5,8,9,10,11,12}.

Changing networks

The subthemes included ‘Ending school’ and ‘Perceptions of adult services’ and captured the process of moving from school to adult services. ‘Additional networks’ described systems that had an influence on participants’ experiences of transitions. There was a significant overlap with the previous theme ‘Quality of life’, which discussed the impact of leaving

education and starting adult services on the quality of life of both parents and young people.

Ending school

Ending school related to a feeling of loss. This was described in relation to the loss of a focus on learning and therapy services, and the loss of a well-known environment. As previously stated, uncertainties about young people's future lives increased anxiety, worries and stress for families.

“I was really scared ... it was a really emotional time and because you are leaving this environment that you’ve been a part of for 15 years.” (Dyke et al, 2013)

Perceptions of adult services

Participants described a change in approach in adult services, and there appeared to be a conflict between adult norms, which may be encouraged within adult services, and their children's developmental age.

Studies described that within adult services young people either accessed home-based services, outreach services, day centres or a mix of the above. Parents expressed worries about adult provision compared to the school environment in relation to programs, peer-networks, equipment and hours offered.

“We didn't want someone to take Geri out in the car to take her round the shops and sit in coffee malls all day.” (Haddow, 2004)

For young people with challenging behaviour^{3,5,6,10,11,13,14} or complex medical needs^{3,9,11} there appeared to be fewer services able to meet their needs.

Parents described an ideal adult placement as centre-based with small, same-aged groups, that facilitated learning and skills, and that was available 4 – 5 days per week, staffed with caring and qualified staff. Transport stood out as a topic^{3,7,9,10,12} and there seemed to be issues to secure transport funding, while parents described transport as highly important for them to be able to continue to work and offer them respite.

Additional networks

The move to adult day or supported living services was accompanied by other transitions, such as the move from child to adult respite services^{3,9,10,11,12}. This was reported to be a significant difficulty, as the amount of hours decreased in adult respite services compared to child respite, resulting in young people being at home more. Parents struggled with the reduction in respite, as the needs of young people remained stable and at times increased. Two UK studies described respite transitions happening at the age of 16 and before the end of school^{3,11}.

“How will families barely coping in school years cope with reduced services in adult years?” (Cox, 2017)

Additionally, the transition to adult health care services was emphasized as an additional and worrying change. The transition to adult health care was discussed in detail by three studies^{3,9,12} and related dominantly to young people with complex health care needs such as epilepsy.

Other parents were seen as a welcome support system for families, especially in relation to sharing information on processes, existing services and the offer of emotional support. Yet, a few families spoke about feeling socially isolated and feeling that the behaviours of their children were not understood or accepted within their communities^{1,5,6,7,9}.

“It's not well understood out in my community you know- when they see him behave bad they don't always accept he's disabled.” (Doyle, 2012)

Decision-making and Collaborative Practice

The Mesosystem comprised three themes in relation to decision-making and collaborative practice.

Choice and information

Across all studies, a lack of options and choices was described; this was one of the strongest themes in relation to the amount of content that was provided by all studies. Parents and, in a few

instances, also professionals, such as education⁵ and social work professionals^{3,12} felt that there was a lack of guidance and information about the transition process. Many parents suggested that a list of available local services would be instrumental in supporting them to understand options and choices.

“Give us a directory of resources and processes. We have no time to run around doing research” (Cox, 2017)

Lack of choice was linked to parents accepting “inadequate” offers as they felt they needed to work with what was available.

“I have got to make a compromise if you like that it is not what I would really want but until I can get what I really want we have just got to accept that this is the only thing that is there for her.” (Murray, 2007)

Roles and Relationships

There was variability across studies describing the quality of collaborative practice. Tension between parents and professionals was identified as a barrier to successful transitions, while some parents spoke of individual professionals as their main support system. Tensions seemed to be related to the discrepancy between parents’ perception of the extensiveness of needs of the young person, in contrast to services and resources available to them. A difference in

perspective between parents and teachers was highlighted by DeZonia (2008) in relation to priorities in future planning.

Meetings appeared to be arranged through schools, while budget and funding decisions lay with Social Work. Funding decisions appeared to be especially powerful in shaping the transition process. For example, even when parents started the planning process early, uncertainties remained if budget decisions were not made and last minute budget decisions could result in periods without support for families. In most cases, parents were strong advocates for their children, visiting available services and acting on behalf of their children. However, three studies^{2,6,10} were able to show a different perspectives from some families where parents felt uncomfortable acting in an advocacy role and taking the lead in working with professionals.

“I still don't know Mark's behaviour, what Mark needs and don't need you know ... It's so hard to know - his behaviour is different in different places depends on who he's with. I'd rather school take over - sort it for me. I don't know answers really (...)” (Doyle, 2012)

Involvement of the Young Person

Another strong theme was the lack of involvement of the young person within the transition process. Due to communication difficulties, young people were largely excluded and parents

acted on the behalf of young people. Parents based their decisions on the known preferences of their children. Only in Doyle's (2012) study did parents voice concern about their role.

The difficulty of facilitating participation of the young person was discussed across all studies, with four studies discussing possible means to facilitate participation; for example through the use of videos and photographs^{2,4} or professionals spending time with young people^{2,8,9}.

"I think it helped the [intellectual disability rehabilitation centre] that did not know her apart from a picture, but then they really saw her interaction, they really saw her strengths and limitations." (Gauthier-Boudreault et al, 2017)

Organisational context

Subthemes related to coordination of services and budget and funding processes.

Coordination of services

As many different professionals were involved in the decision-making process, participants asked for more transparency and clearer pathways to responsibility and accountability^{3,7,8,9,10}.

Parents spoke about the need for continuous support throughout their children's lives and there seemed to be a need for services that were able to accompany them and plan for future changes.

“We don ’ t know what would happen or where she would go ... we ’ ve got an aged care facility and I look at that and think that could be our option which is a scary option.” (Dyke, 2013)

Budget and funding processes

Families struggled to understand how budget decisions were made and this seemed to increase tensions between families and local authorities.

An increase in individualised and self-directed support appeared to have potential to allow parents to create a care package they found most suitable, able to facilitate support that was more flexible and person-centred. At the same time the management of organising individualised packages was described by some parents as demanding and stressful and some current packages appeared to not be able to cover what families would ideally like.

“Complexity of managing personal care team under SDS – ‘needs the skills of running a small business.’”(Cox, 2017)

Society

This theme encompassed data that related to cultural norms and values and the current political climate. Both themes were only tentatively sketched and especially within the realm of politics and economy there were only a few excerpts of data across studies that described participants’ views on this theme.

Culture

Societal norms of adulthood were seen in conflict with abilities and opportunities in the lives of individuals with profound and severe intellectual disabilities. References to a 'meaningful' adult life were made but it often remained unclear what such a life could look like. Especially parents, and to a lesser extent professionals^{3,5,9}, seemed to feel a tension between recognising that young people had different needs and were following different life paths, while at the same time hoping for or working towards the attainment of some 'normality'. This 'normality' for young people was viewed as having peer groups of a similar age or living out with the family at some point in the future.

"Oh, I wish....and you're breaking down crying because you think what the hell do you buy him... if he'd been alright you'd be buying him his car now, you know, and all you can think of is a rattle or something." (Hollinrake, 2005)

Thus, this theme expressed a discrepancy between 'typical' development and the continuing dependency on the family of young people with severe or profound intellectual disability.

"The social worker kept saying to us all the time, 'of course you're not responsible for him anymore', I sort of joked with her when she said 'you're not responsible' and I said 'oh good, does that mean I can, I can nip off to the cinema then and just

leave him here?’ and she says ‘oh no of course not’. “ (Biswas et al, 2016)

Two studies^{5,6} described how religion and faith offered support to parents and this was highlighted particularly within Doyle’s study that focused on BME communities.

Politics and economy

There appeared to be ambiguity between policies and practice. Policies were described as promoting values such as autonomy and self-determination while young people were going to need high levels of support for the rest of their lives. Those who supported young people seemed to find it difficult to relate to these values or to apply them to their situation. Families felt that they were not seen as a priority by governments and left alone with the responsibility of care. Within a difficult economic climate available support and services seemed to decrease.

“Do they think about kids who can't do anything - are they just left?” (Doyle, 2012)

A Life course perspective: From past to future

Participants spoke of transition as an ongoing process and anticipated further transitions due to the changing needs of the individual and family, on-going reviews of care provision or services ending their support for young people by their mid-twenties. There was a clear need to understand the continuing

dependency of individuals into the far future. At the same time development was also present within some studies and young people were described as learning and changing.

Concerns about the long-term future dominated the narratives of parents and was discussed within nine of the included studies. The experience of diagnosis and early childhood on one side^{5,6,9,10,11}, and thinking about the long term future and their own aging at the other side^{1,3,5,6,7,9,10,11,12,14} framed the stories of parents. The biggest worry of parents related to what would happen to their children once they were unable to continue to be strong advocates.

[Table 6 here]

Relationships between themes

During the analytic process the researcher became interested in the relationship between themes across the ecological levels. Thus, the data were also explored with a focus on influences of one level to another. As a starting point, the first researcher looked at the overlap of themes, examining extracts of data that were coded to more than one ecological level using NVivo (Version 11). Then she went back and looked at the data line by line to look for descriptions of relationships.

An overarching theme of discrepancy emerged in relation to the experience of the family and the needs of the young person and wider ecological levels. Policies and societal values

emphasizing independence and self-determination seemed to stand in contrast to lifelong high dependency. Additionally, a discrepancy seemed to exist between an organisational context that conceptualises the transition as an event, while parents asked for an understanding that acknowledges their lifelong and continuing needs. However, relationships between systems were only tentatively sketched and studies did not provide detailed information on how different systems interrelate. Nonetheless, this does highlight an important issue of the extent to which high-levels policies in this area influence the outcomes for young people with severe or profound intellectual disabilities.

Discussion

This review has highlighted the needs and life paths of young people with severe or profound intellectual disabilities and their families. The transition from childhood to adulthood is often an exciting time in the lives of typically developing young adults. It is characterized by growing independence, leaving school and entering the world of employment or further education. It is a time when young people explore their identities, and relationships with others, outside the family, become more important (Arnett, 2015; Wehmeyer & Webb, 2012). This is a stark contrast to the experience of the transition to adulthood for young people and their families in the studies included in this review. The experience of ‘difference’ has been

highlighted by others (Simmons & Watson, 2014; Nind, 2013; Ward et al, 2003) and can lead to ambiguity for those supporting adults with severe or profound intellectual disability (Bigby et al, 2009; Dunn et al, 2007; Hubert, 2011). Jacobs and MacMahon (2015) found that the views of siblings illustrated this tension between difference and normality, of being both a different family, and being just like any other. It seems as if the experience of 'difference' is more prominent in this context compared to the literature on those with mild or moderate intellectual disability, pointing to the need for research to differentiate within the spectrum of intellectual disability (Foley et al, 2012; Gauthier et al, 2017b).

During the analytic process the decision was made to have the family in the centre of the framework, as opposed to the young person. It might be argued that this is problematic and stands in contrast to 'person-centeredness' and individualised approaches. However, within the field of severe and profound intellectual disability it seems more meaningful to take a relational perspective (Simmons & Watson, 2014; Grove, 2012). Research shows that individuals with profound intellectual disability have little influence over their environments, with the family and school often remaining individuals' main social networks (Kamstra et al, 2015; Wilder, 2008), coupled with a decrease in networks outwith the family towards adulthood (Gauthier-Boudreault et al, 2017b).

Organisational and societal influences were described by the majority of included studies, but remained on the periphery of parental experiences or views. Those studies that incorporated different perspectives were able to illustrate organisational barriers and facilitators in more detail. For example, Cox's (2017) report described organisational barriers that correspond to a similar study by Hardy et al (2005). In their comparative study on transitions for young people with intellectual disability and older people who suffered stroke, Hardy et al (2005) found that inter-organisational complexity, overlapping responsibilities and historic underfunding of adult social care acted as barriers to successful transitions. Hardy et al (2005) found that the availability of resources and available options seemed to be particularly influential in relation to those with profound intellectual disabilities and that transitions were viewed as points in time rather than a continuous process. Although not specifically referring to young people with severe or profound intellectual disabilities, guidelines around healthcare transitions make a differentiation between transfer and transition. The transition is defined as the whole process involving early planning and later support while transfer refers to the actual move (NICE, 2016; Care Quality Commission, 2014). Understanding that transition is not a single process might be a good starting point. Parents seem to ask for an understanding of their children's lifelong need for support,

defining transitions as complex processes that are inevitably interlinked with past and future.

How to involve young people in meaningful ways emerged as a problem across studies in relation to the transition process and the research process. Spending a great deal of time with young people and the use of pictures and video seemed to be possible solutions. Similarly, a recent transition project (Art in Transition, 2008) made film portraits of young people accompanying them in their different environments and speaking with professionals and family members. The project describes how the use of multiple perspectives helped family members and professionals to see new facets of the young person. Thus, the incorporation of many perspectives might be able to aid a better understanding of young people with severe or profound intellectual disability in future research.

Limitations

Although the review was able to identify themes across ecological levels, this was mainly from the perspectives of parents. Different stakeholders might highlight different themes and could add more clarity, or give more evidence of the complexity inherent in this area. Additionally, most studies stated that recruited parents were very proactive and engaged and thus views of parents might not be representative.

Transitions are processes that can span many months and years, but in most studies researchers only collected data at one point in time. An experimental design able to capture changes and developments across time appears to be more suitable to describe the transition process as participants at the beginning of the process might have different views at the end of it.

All studies were published in English and conducted in countries of the western world. Comparisons to other cultural contexts could be considered in future studies.

Conclusion

This review found that pathways and needs for young people with severe or profound intellectual disability differ. Thus, it can be argued that there is value in differentiating between degrees of intellectual disability and there seems to be a need to have more studies that focus on those with severe or profound intellectual disability.

Participation and user involvement is placed at the center of present UK, EU and UN policies (Scottish Government, 2013; DoH, 2001; EU, 2010; UN, 2006). However, research suggests that when it comes to decision-making, participatory practices are often limited to the individual level (Omeni et al, 2014; Urek, 2017). Families and service users seem to have very little involvement in ‘wider’ decision-making such as service commissioning. Similarly, this review identified a lack of

understanding of organisational and political decision-making by families. Urek (2017) argues that to achieve true participation all ecological levels need to be given equal importance to avoid a widening of the gap between practice and the ideology of policies. In this review, relationships between the different ecological systems were only tentatively sketched. Yet this seems to be an important avenue for future research. The influence of wider systems does seem to have an impact on the transition experience, while the question of how these influences operate in practice seems to be less well understood.

Implications for practice and future research

The family appears to be the main support system for young people, highlighting the need for more substantial support for families in advocating and caring for their children.

Furthermore, the ecological synthesis highlighted the need for families to be involved across levels of decision-making and to have more access to information and involvement in service delivery.

While reviewing full text records of identified studies it became apparent that authors gave different meanings to the terms severe or profound intellectual disability. Often, studies described participants with the ability to express their views, to live independently or be employed while using the terms severe or profound. Future research should show a greater awareness

in using terminology and labels such as ‘sever’, ‘complex’ or ‘profound’ and report levels of intellectual disability more clearly. Moreover, in cases of mixed samples a discussion of differences within results sections is highly recommended in light of the above finding.

The exclusion of young people with severe or profound intellectual disability from the research process requires attention. The reasons for this may include ethical concerns in regards to consent and vulnerability, alongside the sheer complexity of involving individuals with profound communication difficulties in meaningful ways (Nind, 2013; Ware, 2004). However, a new body of research and literature is exploring the possibilities of including individuals with profound intellectual disability within research (Simmons & Watson, 2014; McVilly & Dalton, 2006; Nind, 2013) and this should be considered by future studies. Additionally, in decision-making processes a variety of stakeholders are involved. Yet, research on transition for young people with intellectual disability seems to be largely limited to the views and perspectives of parents. An inclusion of multiple perspectives could aid a better understanding of how decisions are made between members who have the complex task of identifying what is in the best interest of another person.

Interestingly, studies highlighted similar concerns and barriers although the points in time of data collection spanned from the

end of the 1980s to early 2017. Moreover, included studies encompassed five different countries and hence it is likely that the economic and political context varied between studies. Yet, similarities were more striking than differences within participants' accounts. Atkinson et al (2005) argue for the need of a better understanding of the influence of social change on the lives of individuals with intellectual disability, stating that there appears to be a 'continuing centrality' of the family in the history of intellectual disability (Atkinson et al, 2005; Johnson & Traustadottir, 2005). This might be an interesting starting point for future research.

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Table 1: Search terms

Search terms Population	Search terms Context	Search terms Context
Intellectual, learning, developmental, cognitive, neurodevelopmental, mental handicap, disability, difficulty, impairment, deficiency, incapacity, delay, disorder, retardation	Transition Adult services Adulthood Adult life Post-school Leaving school	Profound, Complex, Multiple, Severe, Dual, Serious

Table 2: Overview of included studies

Authors (year) and country	Study aims	Setting	Participants	Qualitative methods	Qualitative findings (relating to severe and profound ID)
1. Biswas et al (2016) UK	To explore parents' views of the transition of their child into adulthood	Recruitment was supported by various charitable organisations utilising non-probabilistic purposive sampling.	12 parents of children with severe intellectual disabilities (age 44-78) 8 mothers, 4 fathers 11 young people (age 19-29, one child 57*)	Interviews with parents using open-ended structured questions and non-directed probing. Grounded theory used to analyse data.	Identified an overarching theme of parents making comparisons with perceived norms of adulthood and the following themes: <i>Defining adulthood:</i> Using broad definitions of adulthood as starting point to understand transition. Differences in taking a chronological or developmental view.

			<p>*Data relating to this case was excluded due to age of child and indication that child did not meet criteria for severe or profound ID.</p>		<p><i>Noticing adult development:</i> Identifying biopsychosocial changes within own children. At times difficulty to identify signs of adulthood or to support gap between emotional, intellectual and physical development.</p> <p><i>Perceiving barriers to adulthood:</i> Necessity to rely on professionals. Continuing dependency of adult children.</p> <p><i>Worrying:</i> Transition as a 'black hole'. Concerns about safety, risks and long term future.</p> <p><i>Making psychological adjustments:</i> Some parents encourage age-appropriateness while others continue to be accepting of children's 'child-like' interests. Other parents are a source of support, while some participants find it difficult to share their experience.</p>
<p>2. Carnaby et al (2003)</p> <p>UK</p>	To evaluate the involvement of students with learning disabilities within transitions meetings and to facilitate and evaluate subsequent practice	Case study of one special school. Evaluation of practice (phase 1) and 4 year follow up of implementation of recommendations (phase 2)	<p>Phase 1: 15 students and their families (age 16 – 18; mild to profound ID)</p> <p>Phase 2: 12 students and their families (age 16 – 18; mild to profound ID)</p>	Qualitative data includes observations of meetings, field notes and reflection of themes present within decision-making process. No information on method used for qualitative data except stating that it included a review of main themes.	<p>The following themes were identified in relation to severe or profound ID:</p> <p>Little to no participation within transition meetings.</p> <p>Lack of concrete future planning.</p> <p>Last year of school “waiting” for transition to day centre.</p>

	improvements				<p>Transport important for parents.</p> <p>Use of creative methods such as video and photographs suitable to facilitate involvement of students unable to speak for themselves.</p>
3. Cox (2017) UK	<p>To inform improvements by outlining themes and suggestions arising from experiences of transitions. The lived experience of young people and their families form the basis of the study.</p>	<p>Participants from five different local authorities within Scotland. Recruitment through local organisations and services.</p>	<p>29 families and additional consultation with professionals and service managers.</p> <p>Young people (age 15-24)</p> <p>Disability: Ranging from 'high functioning' to profound and multiple disabilities.</p> <p>10 cases were identified as meeting review definition of severe or profound in correspondence with author of study. Only data in relation to those 10 cases was included.</p>	<p>Meetings and interviews with families and professionals. Semi-structured conversations. Use of questionnaires, charts, pictures and talking mats.</p> <p>Gives summaries of all 29 case studies, followed by discussion of themes.</p> <p>No mention of method employed to analyse data but uses 'bridges' (strengths) and 'cliffs' (weaknesses) to frame the narratives of cases and makes reference to 'lived experience' as underlying approach.</p>	<p>The following themes were identified in relation to severe or profound ID:</p> <p>Need for an understanding of the whole family system and a life course perspective.</p> <p>Need for continuity within the co-ordination of transition.</p> <p>Need for professional guidance and detailed information.</p> <p>Need for partnership work across professional and family systems.</p> <p>Need for support and respect for parents and carers.</p>
4. Dee and Byers (2003) UK	<p>To improve quality of life for people with profound and complex learning difficulties during periods of transitions.</p>	<p>3 year project working across four case study sites and involving a variety of stakeholders in the dissemination of produced project</p>	<p>4 case study sites</p> <p>One specialist college, one sector college, one community-based adult education and</p>	<p><i>Action research phase:</i> Working with 4 case study sites to identify areas of improvement.</p> <p>Interviews, field notes, observations and focus</p>	<p>The following themes were identified in relation to severe or profound ID:</p> <p>Often no transition procedures in place to support young people moving on.</p> <p>Further adult education can make a</p>

	To explore inclusive environments and to foster inter-agency collaboration and staff development	material.	one social and employment services Dissemination phase: colleges, universities, schools, day centres, therapy services, students and families.	groups. Using data to produce project material <i>Dissemination phase:</i> Working with organisations and individuals to explore how to improve service provision. No mention of method used for data analysis.	contribution to the lives of adults with profound and complex learning difficulties. There is a paucity of provision post-school, as well as wide regional variations. Provision is fragile, relying on short-term funding and/or committed individuals. An understanding of individual's unique communication behaviours is important.
5. DeZonia (2008) USA	To examine parent, teacher and institutional formulations of adulthood for students with profound developmental disabilities.	Recruitment through special educational schools with the researcher being the director and founder of one of the schools. Utilisation of stratified non random sampling.	8 trio's of students, parents and teachers. 8 teachers within public (2) and private (6) schools 8 parents (age 36-62) 7 mothers, 1 father, 6 white, 2 latino) 8 students (age 16-21) Disability: Autism (5), Cerebral Palsy (2), Down syndrome (1)	Multiple case study and triangulation of multiple methods. Interviews, educational documents (IEP, ITP) and governmental documents, field notes and online newspaper blog* Cross-case, constant comparison, inductive analysis. *not referring to transition and therefore excluded from review. Referring to case study of public opinion in relation to individuals with profound ID	The following themes were identified in relation to severe or profound ID: Parents, teachers and institutional settings have differing perspectives on adulthood and future adult lives for people with profound developmental disabilities. IEP and ITP goals are more consistent with teacher's views compared to parents and institutions. There is a need for information on future options for teachers and parents.
6. Doyle (2012)	To gain insight into the	Study conducted within an ethnically	5 mothers of children with	Interpretative Phenomenological	The author identified the following themes:

UK	experiences of parents whose children are transitioning to adult services and to identify key themes relating to parents' experiences during the transition	diverse outer London borough with participants from BME communities. Parents recruited through one special school utilising purposive sampling.	<p>profound intellectual disabilities</p> <p>Ethnicity: Bangladeshi, Sri Lankan, African, Filipino, Caribbean/British</p> <p>5 young people (age 17-18)</p> <p>Disability: Cerebral Palsy (3), Autism (1), Leigh's Syndrome Mitochondrial Disorder (1)</p>	Analysis (IPA) utilising semi-structured interviews.	<p><i>Young Person's diagnosis:</i> Moment of diagnosis still very present in mothers' narratives. Young peoples' needs become more complex towards adulthood.</p> <p><i>Experience of Transitions:</i> Anxiety about transition process and confusion about expected roles.</p> <p><i>Planning for the Future:</i> Concerns about recent cuts and impact on transition. Worries about quality and suitability of adult provision. Difficulty to know what young people want themselves.</p> <p><i>Experience of Working with Professionals:</i> Positive and negative experiences of working with professionals. Parents would like smaller transition meetings and be guided more by professionals.</p>
<p>7. Dyke et al (2013)</p> <p>Australia</p>	To explore the perspective of mothers on the transition to adult life for their children with Down-syndrome* compared to mothers of daughters with Rett- syndrome.	<p>Purposive sampling. Sample selected through two national databases.</p> <p>Participants from both rural and urban areas.</p>	<p>7 parents of 7 young adults with Down syndrome.</p> <p>11 mothers of young women with Rett-syndrome (age 19-33)</p> <p>Living arrangements of young women with Rett-syndrome:</p>	<p>Qualitative semi-structured phone interviews.</p> <p>Transcripts were manually coded using content analysis.</p>	<p>Authors identified the following themes:</p> <p><i>Adult roles assumed during the day:</i> Transition Process characterized by uncertainty with limited information. Need for strong parental advocacy. No involvement of the young person in decision-making process.</p> <p><i>Accommodation:</i> Worries in relation to future living arrangements and wanting to outlive</p>

	*Data relating to young people with Down-syndrome was excluded due to indication that young people did not meet inclusion criteria of severe or profound ID.		6 with family, 4 supported accommodation and 1 partly home and partly in supported accommodation		<p>children. Difficulty to secure supported accommodation.</p> <p><i>Quality of life:</i> Most mothers describe own QoL as poor. Concerns about own aging.</p> <p><i>Living a 'good' life:</i> Most mothers believe daughters live a good life.</p> <p><i>Family impact:</i> Loss of safe environment of school and loss of other informal support networks and impact on maternal employment. Importance of transport.</p>
8. Gauthier-Boudreault et al (2017) Canada	To propose realistic solutions to meet the needs of adults with profound intellectual disability and their families during and after the transition to adulthood.	Recruitment through intellectual disability rehabilitation centres utilising both convenience and snowball sampling.	14 parents of young adults with profound ID* (age 18-26) *based on APA definition	Descriptive, interpretative approach employing two semi-structured interviews. First interview to document different solutions and second interview used to validate and deepen the researcher's understanding of themes.	<p>Authors identified the following themes:</p> <p><i>Need for informal support:</i> Lack of information on procedures and responsibilities and lack of information sharing between stakeholders resulting in increased demands placed on parents. Need to develop a step-by-step transition plan starting 3 years before end of school. Responsibility of coordination should be placed with a professional.</p> <p><i>Need for material support:</i> Lack of full-time day care services. Need to increase available places and to continue to support learning and development of skills.</p> <p><i>Need for cognitive support:</i></p>

					<p>Lack of understanding of profound ID within services resulting in unsuitable approaches and lack of stimulation. Need for training for staff.</p> <p><i>Need for emotional support:</i> Lack of emotional support for parents during the transition process. Need to create parent support groups with professional input.</p>
<p>9. Haddow (2004)</p> <p>UK</p>	<p>To investigate the experiences of family carers in relation to Future-Needs-Assessments, transition process and provision of post-school placements.</p> <p>To explore practice improvements and to develop criteria for good quality provision and services.</p>	<p>Four cases from one local authority in Scotland utilising purposive sampling.</p>	<p>4 Families with children with profound and multiple learning disabilities (young people age 19-27)</p> <p>5 Professionals: Education, Social Work, Health, Third sector.</p>	<p>Multiple case studies.</p> <p>Interviews with data presented as 4 case stories. Interviews analysed using 'interpretative-descriptive' method informed by grounded theory.</p> <p>Uses interview data and analysis of documents to develop focus groups focusing on practice improvements.</p> <p>Policy discourse analysis used to analyse documents.</p> <p>Uses nominal group technique to develop quality criteria for adult provision.</p>	<p>The author identified the following themes:</p> <p><i>Information:</i> Lack of information about assessments and the transition process</p> <p><i>The FNA process:</i> At times not all stakeholders present at meetings. At times there is a lack of knowledge about the young person's needs or available services. Little progress is made between meetings</p> <p><i>The transition period:</i> Difficulty of arranging transition with post school places being identified late or not at all.</p> <p><i>Post-school provision:</i> Lack of available provision. Provisions often not able to meet complex healthcare needs. Provision is short term and there is unclarity about long term future provision.</p>

<p>10. Hollinrake (2005)</p> <p>UK</p>	<p>To gain an understanding of how parents make sense of the transition time and to explore if there are differences within coping.</p>	<p>Recruitment supported by one local authority social care services department utilising purposive sampling. Study area rural and predominantly 'white'.</p>	<p>20 parents with children with severe intellectual disabilities. 15 mothers, 1 father, 4 parent pairs</p> <p>18 Young people (age 18-29) Disability: cases with challenging behaviour (11), epilepsy (9), autism (5), health difficulties (4), physical disability (3), non-verbal (4), very limited communication (5), limited verbal abilities (9)</p>	<p>Phenomenological approach.</p> <p>Semi-structured interviews and field notes.</p> <p>Grounded theory used to analyse data.</p>	<p>The following themes were identified in relation to severe or profound ID:</p> <p><i>Overarching theme:</i> Being a main carer is demanding, enduring, time-consuming and intense.</p> <p>Three different groups identified across participants in relation to their views, adaptation and coping styles. Groups are named (1) Balanced and resilient, (2) Self-reliant and rational and (3) Preoccupied and overwhelmed.</p>
<p>11. Hubert (1991)</p> <p>UK</p>	<p>To understand the worlds of families caring for young people with severe learning difficulties.</p> <p>To describe the lives of families with a focus on respite</p>	<p>Participants from one county in southern England. Participants recruited through special schools, residential care services and social and health care professionals</p>	<p>20 families.</p> <p>Young people (age 15-22) Disability: Some described as immobile, some mobile with additional behaviour problems.</p> <p>Study heavily based</p>	<p>Ethnographic research study. Researcher spend two years with families.</p> <p>Several in-depth interviews, observations, participating in daily life activities and interviews with others such as professionals.</p>	<p>The following themes were identified in relation to severe or profound ID:</p> <p>Transition from children respite service to adult services is traumatic and distressing for parents and young people. Too abrupt.</p> <p>Young people's needs increase in adulthood while there is less respite provision. Provision is often</p>

	services and families who choose to keep their children at home.		on involvement with mothers.	<p>5 families selected as in depth case studies.</p> <p>Study discusses a variety of themes. Data only included in relation to transition.</p>	<p>uncoordinated, less reliable and haphazard.</p> <p>Age-appropriateness seems more important within adult services than individual needs.</p> <p>Parents would like smaller units with groups of young people with similar ages.</p> <p>Parents worry about the future and being aging carers.</p>
<p>12. Murray (2007)</p> <p>Australia</p>	To explore the experience of parents and their care work during transition to adult services	Study advertised in newsletter of a support and advocacy organisation. Other participants recruited through subsequent snowball sampling. Participants from two different regions: Melbourne and regional Tasmania.	<p>8 mothers with daughters with severe or profound intellectual disabilities.</p> <p>Young women: (age 16 to 24) Disability: majority neuro-developmental disorder. All with intellectual and physical disabilities.</p>	<p>Qualitative semi-structured in-depth interviews.</p> <p>Transcripts coded by key themes.</p>	<p>The author identified the following themes:</p> <p><i>Leaving school: Transition or continuation?:</i> Leaving school connected to moving setting and not to an increase in independence or attainment of adult status. Transition from paediatric to adult health care additional big change and less respite services available. Future worries in relation to dependency across lifespan.</p> <p><i>Finding a suitable program:</i> Demanding and stressful time for parent. Difficulties in accessing right information.</p> <p><i>Families' involvement in developing new programs:</i> Several mothers developed</p>

					individualised programs to meet their daughters' needs and challenge expectations to fit into existing services.
13. McIntyre and Kraemer (2004) USA	<p>To describe and evaluate the quality of life (QoL) for adult children with severe intellectual disabilities from their mothers' perspectives in relation to their current life stage of transitioning into adulthood</p> <p>Focus of the study is more on quality of life rather than the transition process.</p>	Participants recruited through Southern California Regional Centres.	<p>Mothers (mean age 49.4) of 30 young adults with severe ID.</p> <p>Young adults* (age 18-24) Disability: Cerebral Palsy (11), Down syndrome (1), Autism (4), ID only (14)</p> <p>Not all young people in the study fit the definition of profound or severe ID with some described as having a paid job or being able to express their views to some extent.</p>	<p>Dominantly qualitative methodology utilising two interviews and open questions alongside a standardised Quality of life questionnaire.</p> <p>Interviews recorded verbatim and coded.</p>	<p>The following themes were identified in relation to severe or profound ID:</p> <p>A qualitative analysis using interviews was more meaningful to form an understanding of QoL for this population as reported by mothers in contrast to using the standardised QoL questionnaire during the first interview.</p> <p>Mothers highlight the need to meet their children's basic needs, to offer activities that keep their children busy and to provide social interactions in providing a good quality of life.</p> <p>Family is important for young people.</p> <p>Communication difficulties, challenging behaviour and health concerns impact on young people's QoL.</p> <p>Independent living skills are valued by mothers whose children have exited school. There is a tension between the hope for independence and young people's needs and abilities.</p> <p>The QoL of the young adult is interdependent with parent's QoL.</p>
14. Young-Southward et al	To explore transition	Recruitment through special	26 young people (age 16 -27)	Hermeneutic qualitative design employing	The following themes were identified in relation to severe or profound ID:

(2017). UK	experiences of young adults with intellectual disabilities and their parents. To identify health and wellbeing implications.	education schools and organisations providing support to individuals with ID across the West of Scotland.	Disability: mild ID (7), moderate ID (4), severe (7), profound (8)*	interviews alongside behavioural screening and general health questionnaire (SDQ and EQ-5D)	<p>Increase in challenging behaviours for some young people on leaving structured school environment leading to exclusion from services and thus alleviating lack of routine and activities.</p> <p>Parents struggle with the widening gap between their children's abilities and adult norms such as independence. Thus the transition is perceived to be primarily organisational instead of developmentally.</p> <p>Parents envision caring for their children into old age but hope for the attainment of some independence such as a move to supported accommodation for their adult children in the future.</p>
			23 carers, 20 mothers, 2 fathers, 1 grandfather and 1 grandmother	Semi-structured interviews with young people, their carers or both.	
			6 young people with severe ID present during interviews in the other cases of young people with severe or profound ID interviews only with carers.	Thematic analysis deploying emic and etic coding categories.	
			*based on Vineland adaptive behaviour scale-II		

Table 3: CASP assessment

Study	Aims and purpose	Suitability of qualitative design	Link between aim and study design	Participant selection	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Strengths and Weaknesses
Biswas et al (2016)	++	++	+	++	++	++	++	++	++	++	Detailed account of analytic process and ethical considerations. Coherence within all aspects of study.

											No discussion on why grounded theory was chosen. One adult child a lot older than others recruited. No discussion of impact of choosing an age range from 19 to 57.
Carnaby et al (2003)	+	++	+	+	++	0	0	+	+	++	<p>Involvement of different stakeholders.</p> <p>No mention of ethics and little information on the research process and the process of qualitative data analysis.</p> <p>No information on overall number of participants meeting severe/profound definition. From eight meetings recorded only one meeting with student meeting inclusion criteria.</p>
Cox (2017)	++	++	+	++	+	+	++	+	++	++	<p>Inclusion of young people with severe or profound ID within study through visual methods and spending time.</p> <p>Little information on data collection and analysis.</p>
Dee and Byers (2003)	++	+	+	+	+	0	0	0	+	++	<p>Involvement of different stakeholders.</p> <p>Lack of detail in relation to data collection and analysis. No mention of ethical considerations and no example data presented.</p>

											Article limited to do justice to scope of project. Other articles connected to project have quantitative focus and were consequently excluded.
Dezonia (2008)	++	+	++	++	++	++	0	++	++	++	Involvement of different stakeholders. Reflective of researchers' own role. No mention of ethics. Poor discussion on using quantitative analysis alongside dominantly qualitative design while comparing parent/teacher thinking and IEP and ITP goals
Doyle (2012)	++	++	++	+	++	++	++	++	++	++	Focus on BME communities. Strong coherence within all aspects of study. Four participants had English as an additional language. Interviews were conducted without a translator present. Difficulties in conducting and transcribing the interviews were noted by the researcher
Dyke et al (2013)	+	++	+	++	++	+	+	++	++	++	Aims not clearly stated and no discussion on link between research aim and method chosen.
Haddow (2004)	++	++	++	+	++	++	+	++	+	++	Involvement of different stakeholders. Researcher reflexive of own role as a mother of a young woman with profound ID.

											Little information on the recruitment process and no mention of ethical approval.
Hollinrake (2005)	++	++	++	++	++	++	++	++	++	++	<p>Reflexive account of the research process given with an in depth discussion of ethics.</p> <p>Coherent study throughout.</p>
Hubert (1991)	+	++	++	+	+	++	0	+	++	+	<p>In depth reflection of author's own involvement as researcher. Research involvement over two years.</p> <p>There is a lack of information on recruitment, data collection and analysis and little use of existing literature. No mention of ethical considerations.</p>
Murray (2007)	+	++	++	+	++	+	+	+	+	++	No clear statement of research objectives. Little information on analysis.
McIntyre and Kraemar (2004)	++	+	+	++	++	0	0	+	++	++	<p>Discusses the issue of proxy reporting.</p> <p>No mention of ethics. Little information on data analysis.</p> <p>As not all participants and themes met the inclusion criteria only a small amount of data was included for the review.</p>
Young-Southward et al (2017)	++	++	+	++	++	0	+	++	++	++	<p>High credibility of findings with high degree of consistency found in identified themes.</p> <p>Use of quantitative</p>

											<p>questionnaires alongside qualitative interview not discussed.</p> <p>Only small amount of data relevant for review.</p>
Gauthier-Boudreault et al (2017)	++	++	++	++	+	+	++	++	++	++	<p>Very comprehensible and coherent study throughout</p> <p>One participant was unreachable for second interview.</p>

Table 6: Framework applied to studies

	The Family			Changing network			Decision-making and collaborative practice			Organisational context		Society		Life course perspective
	Young Person	Parents	QoL	Ending school	Adult services	Additional networks	Choice and information	Roles and Relationships	Involvement of young person	Coordination of services	Funding processes	Culture	Politics and economy	From past to future
1. Biswas	X	X	X		X	X	X	X	X	X		X		X
2. Carnaby	X			X			X	X	X	X				
3. Health and Social Care Alliance Scotland	X	X	X	X	X	X	X	X	X	X	X			X
4. Dee & Byers	X				X		X		X	X		X		X
5. DeZonia	X	X	X	X	X	X	X	X	X		X	X	X	X
6. Doyle	X	X	X	X	X	X	X	X	X	X	X	X	X	X
7. Dyke	X	X	X	X	X	X	X	X	X	X	X			X
8. Gauthier-Boudreault	X	X	X	X	X	X	X	X	X	X	X			X
9. Haddow	X	X	X	X	X	X	X	X	X	X	X	X	X	X
10. Hollinrake	X	X	X	X	X	X	X	X		X	X	X		X
11. Hubert	X	X	X		X	X	X	X		X		X	X	X
12 .Murray	X	X	X	X	X	X	X	X		X	X	X		X
13 .McIntyre	X	X	X		X		X						X	
14. Young-Southward	X	X	X		X	X								X

Table 4: A-priori framework

Master Theme
The Individual
Microsystems
Mesosystem
Exosystem
Macrosystem
Chronosystem

Table 5: A-posteriori framework

Master Theme	Subthemes
The Family	The young adult Parents Quality of life
Microsystems (Changing Networks)	Ending school Perceptions of adult services Additional networks
Mesosystem (Decision-making and Collaborative Practice)	Choice and information Roles and Relationships Involvement of the Young Person
Exosystem (Organisational context)	Coordination of services Budget and funding processes
Macrosystem (Society)	Culture Politics and economy
Chronosystem (A Life course Perspective)	From past to future