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

Method: Twelve parents of 11 children with a severe intellectual disability were recruited for interview from charitable organisations accessed by parents (e.g., Mencap). Data collection used a combination of open-ended structured questions and non-directed probing. NVivo 10 software was used to assist the grounded theory coding and analysis process.

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

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

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

Introduction

Transitions from one life stage to another are challenging and complex for most people. Existing transition theories offer explanations for how an individual may experience significant life events (e.g., Family Life Cycle; Carter and McGoldrick, 1980). However, such general theories may give a misleading impression of homogeneity across families, which could undermine recognition and acceptance of variability in type, sequence and timing of life cycle transitions according to family context and characteristics (e.g., Moghaddam, 2014).

Moving from adolescence into adulthood can be difficult, with some individuals and their families viewing it as a crisis period (Pittman, 1987). However, the challenges associated with the transition into adulthood may be compounded for people with intellectual disabilities[1], especially those with more severe levels of disability (Task Force, 2009). Consequently, the transition process may occur more slowly compared to individuals without a disability. This, together with the general care for an individual with an intellectual disability, may induce further stress and ruptures in relationships between parents, parents and child, or other family members. Disruptions within the transition process may be stressful for parents. Research suggests that parental stress heightens when they perceive themselves (or their child) to deviate from cultural norms – e.g. having *more* involvement in their child's adult life as opposed to the standard 'norm' of less involvement as their child transitions into adulthood (Ferguson, Ferguson and Jones, 1988). Additionally, the types of meaning that parents make when confronted by transitional stress (e.g., global versus situational) are suggested

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

to have implications for parental adjustments, and for the wellbeing of their child and wider family system (Park, 2010).

Parents' views

Existing intellectual disabilities literature focusing upon parents' views of their child's transition into adulthood have explored perceptions of their child's vulnerability to risk (e.g., Almack, Clegg and Murphy, 2008; Heslop, Mallet, Simons and Ward, 2002) and the parent-professional relationship (e.g., Clegg, Sheard, Cahill and Osbeck, 2001; Knox, 2000). Additionally, a recent systematic review of 17 empirical studies identified that factors such as child behavioural difficulties (e.g., challenging behaviour), unhelpful parental coping strategies (including avoidance and self-blame) and poor family cohesion were associated with parental stress when caring for a child with an intellectual disability (Biswas *et al.,* 2014).

Conversely, parenting a child with an intellectual disability may also be experienced positively (Grant, Ramcharan, McGrath, Nolan and Keady, 1998; Scorgie and Sobsey, 2000). Possible explanations for these contrasting experiences could include some parents having more effective coping strategies than others (Cummins, 2001). Such differences between parents may be understood in terms of the Transactional Stress Coping Model, which emphasizes that an individual's appraisal of a situation may mediate stress levels (Lazarus, 1966). Specifically, parents who appraise the transition into adulthood as stressful may have more negative experiences than parents who appraise the situation as rewarding. In light of these contrasting experiences, further

research was needed to explore how parents perceived and made sense of their child's transition. .

Rationale and research questions

There are currently no published studies within the intellectual disabilities field that explore parents' retrospective views of their child's developmental transition into adulthood, or how parents adjust and adapt to this transition. It was considered imperative to address this gap by asking the following research questions:

(1) How do parents view the transition into adulthood for their child with a severe intellectual disability?

(2) What processes (if any) do parents engage in to make psychological adjustments for this transition (e.g., in terms of coping or emotional regulation)?

Method

Design and participant recruitment

This study used a retrospective cross-sectional exploratory design. Grounded theory (Corbin and Strauss, 2008) was deemed to be the most appropriate methodology for addressing the research questions. A non-probabilistic purposive sample was adopted to encourage variation with regards to parents' views. The study received recruitment support from charitable organisations including Mencap, IRIS project, MIND and the Foundation for People with Learning Disabilities. The study was advertized through charity newsletters, social media websites and online forums. Individuals who volunteered to participate were considered if they (i) were a parent (biological, step-parent,

adopted parent or foster parent) of an adult[2] with a severe intellectual disability; (ii) could read, write and speak English; and (iii) had witnessed their child's transition into adulthood – this was necessary as little experience would limit the data and subsequent theory of the phenomenon being studied (Cutcliffe, 2000).

The total sample included 12 White British parents (aged 44 to 78 years) of 11 children. There were seven mothers, three fathers, one step-mother and one step-father. None of the participants had other children with any form of disability. All but one participant stated that their child had additional physical or sensory disabilities. These included "double incontinence", "dyslexia", "epilepsy", "poor minor motor movement" and being diagnosed with additional syndromes (e.g., Wooster-Drought syndrome and Hornes syndrome). Additionally, some parents reported that their child had additional physical care needs. Two participants explained that their child needed mobility support but the remaining participants did not elaborate upon this variable. None of the participants' children were employed. Further key participant demographics are presented in Table 1.

[2] Participants defined the term "adult" in the interviews.

Table 1. Parent and child demographics

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

Participant pseudonym	Age	Relationship to child	Sole carer?	Child pseudonym (Age)	Physical or sensory disability?	Physical care needs?	Number of siblings	Accessed support system(s)?
Samantha	62	Mother	No	Jane (28)	Yes	No	1	Adult care
Roger	77	Father	No	Luke (24)	Yes	Yes	1	Adult care
Louise	50	Step-mother	Yes	Joseph (19)	Yes	Yes	5	College and Adult care

N.B. * denotes parents of same child

Ethical approval and considerations

Ethical approval was obtained from the University of Nottingham. Prior to the interviews, the first author (SB) provided all participants with an information sheet about the study. They were also given a consent form outlining that they would be able to withdraw from the research without reason at any time. All participants were given pseudonyms to ensure anonymity. All were offered the chance to ask any questions before and after the interview, and all were debriefed about the study after interview.

Data collection

The first author (SB) conducted twelve individual[3] semi-structured interviews between December 2013 and December 2014, face to face (n=3), via Skype (n=2) and via telephone (n=7). Participants were interviewed individually to enable an in-depth exploration of their experiences. Each interview lasted between 60-90 minutes. Consistent with grounded theory, data collection and analysis was an iterative process. Thus, a piloting procedure was not required as the interview schedule was revised three times to add new topics/questions if they appeared salient within previous interviews (see Table 2).

[3] Parents of the same child were also interviewed separately.

Table 2. Examples of semi-structured interview questions (and topics).

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

Data analysis

The interviews were transcribed and imported into NVivo 10 qualitative data analysis software (QSR, 2014). All transcripts were analysed according to the grounded theory guidelines outlined by Corbin and Strauss (2008). The first author (SB) read each transcript line by line. Words or phrases were highlighted to facilitate the process of "open-coding". Coding checks were provided by the second author (AT) who is an experienced grounded theory analyst and practitioner psychologist working within intellectual disability services. Some quotes used "in vivo" codes whereby vertabim quotes from participants were used to label the codes (Birks and Mills, 2011). The open codes were grouped together to form "concepts". Constant comparisons between the concepts were made whilst clustering them together to form "themes". "Axial coding" was used to identify contrasting data within the concepts or themes.

Salient themes throughout the transcripts were then grouped together to form "categories", which were labelled accordingly. The final stages of analysis involved re-visiting the data for evidence to further develop the depth and breadth of the categories. The "core category" that tied all the categories together was also identified. Theoretical sufficiency had been established after nine interviews. The model was then shared with the final three participants in interview to seek their opinions and identify further relationships between the concepts or categories. Supervision was sought from the second (AT), third (NM) and fourth authors (KA) throughout the analytic process. This encouraged new insights and

minimized the risk of the first author (SB) influencing the data with her own assumptions/biases.

Evaluating quality

Evaluation criteria set out by Corbin and Strauss (2008; 1990) were used to evaluate the "credibility" of the research. This involved asking specific questions throughout the research process that focused upon "fit", "applicability", "concepts", "contextualisation of concepts", "logic", "depth", "variation", "creativity", "sensitivity" and the "use of memos" (see Appendix).

Results

Parents frequently made comparisons to perceived "norms"[4] when making sense of their child's transition into adulthood and the subsequent adjustments made. This process was salient throughout all participant interviews and evolved throughout development of categories. "Making comparisons" was thereby deemed to be the core process that parents engaged in. Parents made comparisons with their own personal experiences of the transition and/or the experiences of children without intellectual disabilities in general. The five categories/processes encapsulated within this core category are elaborated upon below.

Defining adulthood

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

This was an implicit process that all parents engaged in to understand adulthood generally. Relating to broad definitions of adulthood offered a relative point from which to understand their child's transition into adulthood. Ten parents reflected upon physical/bodily changes common to adult development. Some parents defined adulthood as "turning 18" (Carla), thereby highlighting legal markers of transition. However, whilst most parents found age to be important for defining adulthood, three believed it to be meaningless. These parents viewed themselves as becoming adults before the age of 18 years. They emphasized the importance of social markers as signs of adulthood rather than age:

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

Thus, there were contrasting views when defining the term 'adulthood'; some held a chronological view whereas others placed importance upon the developmental/social aspects of becoming an adult. Parents' definition of adulthood seemed to influence how they noticed adult development in their child with a severe intellectual disability. These definitions were likely to influence whether and/or how parents made adjustments for their child's transition.

Noticing adult development and sexuality

All parents noticed adult development in their child through identifying

biopsychosocial changes[5], which were largely related to notions of independence. Some parents explained that they had noticed their child become an adult through an increase in independent behaviours:

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

- Carla

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

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

This highlights how the nature of transition may vary in time-length. Indeed, for an "average" non-disabled 18 year old, adulthood does not happen overnight but is a gradual process that is signposted in different ways (e.g., subtle or more overt developments).

However, sometimes it was difficult for parents to notice signs of adulthood due to the severity of their child's intellectual disability. Such barriers to noticing adult development may have consequences for

[5] Biopsychosocial changes were defined as being biological (e.g. physical), psychological (e.g., thoughts, feelings, behaviours) and social (e.g., socio-environmental and cultural) factors.

whether or how parents adjust for their child's transition into adulthood. For example, if a parent struggles to notice signs of adult development in their child, they may be less inclined to make any changes to encourage their child's transition into adulthood.

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

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

This lack of synchrony between the child's physical and cognitive-emotional development left parents unsure of how to best support their child's sexuality development. Subsequently, they often sought professional support. One parent agreed with healthcare professionals to use medication as a way to suppress their child's sexual needs. Whilst such strategies may help to contain an individual's sexual frustrations (and parent/staff anxieties), it could also be seen as inhibiting the child's adult development.

Perceiving barriers to adulthood

Most parents perceived barriers to adulthood when viewing their child's development as deviating from perceived "norms". This included being

unable to plan for activities related to adulthood (e.g., a career); needing to rely upon professional support to facilitate adult development; and their child's limited cognitive or social skills and personal responsibility. For most parents, these barriers were not necessarily expected/planned for.

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

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

Sarah's quote demonstrates how professionals also draw upon "normative" ideas of adulthood i.e. that parental responsibility and accountability generally reduce as young people reach the legal age of adulthood. This, coupled with the current policy agenda promoting autonomy and self-determination for young people with an intellectual disability – e.g. Valuing People (Department of Health [DoH], 2001) and Valuing People Now (DoH, 2010) – may be frustrating for parents. Such contradictory messages from healthcare staff do not take into account the

parallel need to protect vulnerable young people with severe intellectual disabilities and/or the on-going parental responsibilities should anything "go wrong".

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

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

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

Worrying – The "black hole" of transition

Parental worry was viewed by all parents as an on-going process that

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

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

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

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

Thus, most parents faced dilemmas of wanting their child to become more

independent but worrying about the risk of abuse. These worries, along with further concerns about their child's future, made it difficult for parents to know how to adjust, especially if services offered little support/information.

Making psychological adjustments

All parents made adjustments to overcome perceived barriers to the transition and to manage their feelings of worry. Some explained that encouraging "age appropriateness" was important for reducing their child's vulnerability within society:

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

Parents encouraged their child to engage in social activities that they viewed as being "age appropriate". This included taking them to nightclubs and bars. However, accompanying their child to access "age appropriate" community settings suggests that developing independence is not a spontaneous process for individuals with a severe intellectual disability. As a result, parents may find themselves in a dilemma of wanting their child to have a "normal" adult life whilst knowing that they may need extra support to achieve it.

By contrast, two parents were more accepting of their son/daughter's "child-like" interests. It seems that sometimes parents do not encourage

their children to make changes to their lifestyle just because they perceive them to be an adult.

Establishing a supportive network helped parents to gain knowledge about the transition process and encouraged them to feel supported:

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

However, two fathers felt reluctant to share their difficulties with others. This could have been due to avoiding being a burden on other people and/or avoiding issues that were burdensome for them. This finding may also be indicative of gender differences between the types of adjustments made. Parents also made adjustments for their child's transition by doing their own research to inform their understanding of the transition process.

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

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

From Samantha's quote, it could be argued that some parents avoid

making adjustments to reduce the threat of losing responsibility or being over-ruled/excluded by healthcare professionals.

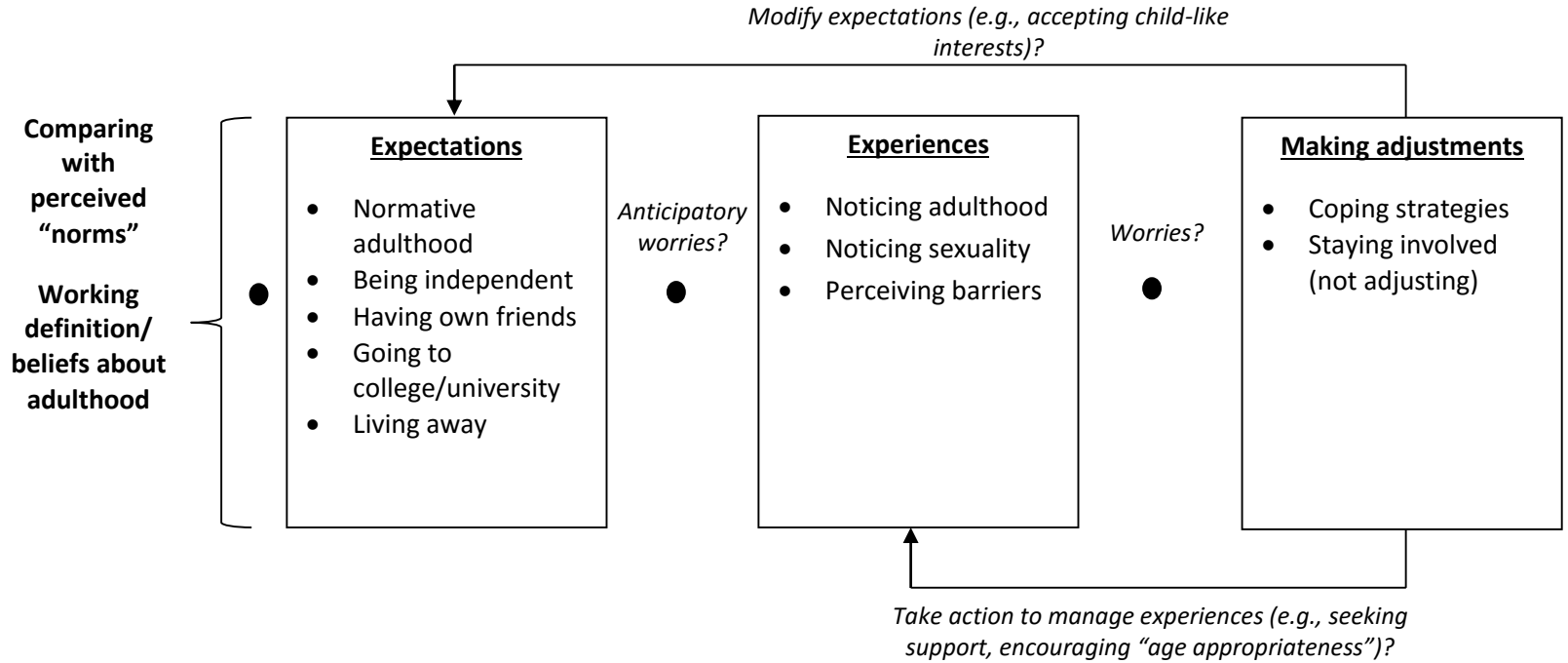
Making adjustments was a process that all parents engaged in. Parents who viewed chronological age as meaningful were likely to make adjustments that encouraged "age appropriateness" for their child. By contrast, those who did not view chronological age as important were more accepting of the incongruence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

Developing a grounded theory model

We developed a model to visually capture the inter-related processes that parents engaged in during their child's transition into adulthood. The model reflects a synthesis of the data-driven insights shared by parents in this study. It is acknowledged that this model may be applicable to parents of a child with and without an intellectual disability (see Figure 1). In summary, our model hypothesizes that parents hold definitions of adulthood, which have been derived from their views of the "normal" social world around them (i.e., influenced by family, culture, social media). Parental experiences (e.g., perceiving barriers to adulthood) may heighten parents' worries and encourage them to make adjustments to facilitate their child's adult development (e.g., encouraging "age appropriateness"). In turn, this may serve to manage their worries. Parents may also make adjustments that are more accepting of their son/daughter's "child-like" interests, which may serve to modify their

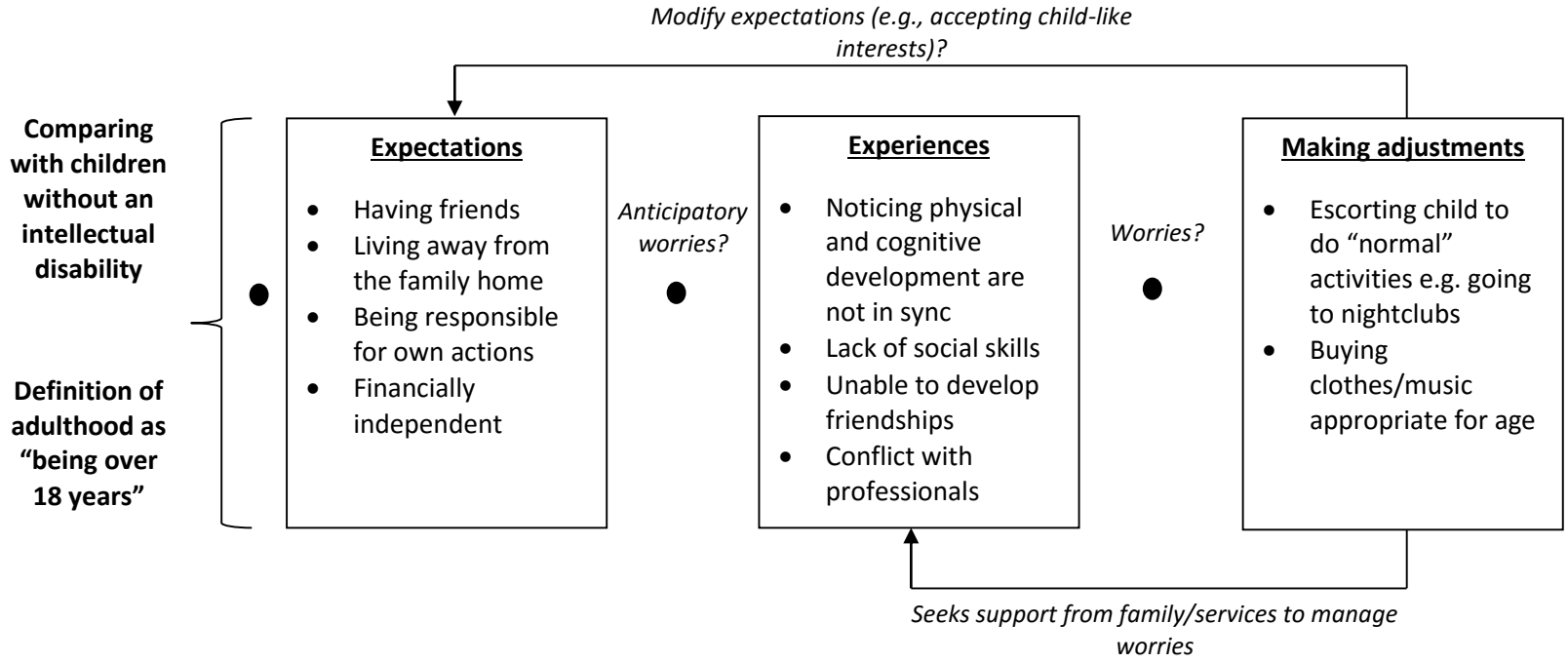
original expectations. We acknowledge that sometimes experience may challenge expectations (i.e., if reality was better than expected) and therefore we have posed certain processes (e.g., "worries?" and "making adjustments?") as *potential* processes. Thus, our model suggests that parents' adjustments are dependent upon the *quality* of their experiences.

Figure 1. A transition model of parents' views and adjustments.



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

Figure 2. An application of the model to the study findings.



Parents of a child with a severe intellectual disability are not a homogenous group. Indeed, the findings from this study highlighted contrasting parent perceptions (e.g., some parents found age to be meaningless) and so the context of the boxes in the model may vary accordingly. The findings also highlighted some exceptions where parents did not necessarily engage in all processes within the model. For example, some parents did not report noticing sexuality development in their child even when prompted during the interview. Additionally, as discussed earlier, three parents reported ways in which they did not make any adjustments i.e. staying involved in their child's care. Our model is well suited to account for variability within parents' experiences concerning their child's transition into adulthood.

Discussion

The key findings from this study are organised and discussed below in relation to the research questions.

(1) Parents' views

Conceptualizing adulthood

Parents drew upon the perceived "norms" and "adult rights" to make sense of the term "adulthood". For example, parents reflected upon their own experiences of becoming an adult and particular symbols of adulthood (e.g., celebrating 18th birthdays, "legally drinking"). This helped some to legitimize their views about the importance of chronological age when conceptualizing adulthood. For others, chronological age was less important. Some viewed age to be unhelpful as it fostered a culture of

"exclusion" within professional systems (e.g., school/college or child services). This contrast in parent views has implications for services to be open to the differences in parents' definition of adulthood. If services impose their views upon the individual with an intellectual disability (e.g., that they should be treated as adults upon turning 18) then this may cause tension with parents who view chronological age as unhelpful.

When noticing adult development in their child, parents' descriptions were closely in line with Western ideations of "independence" (Arnett, 2000). For example, parents referred to changes related to their child's behaviour (e.g., making the bed), cognitive abilities (e.g., knowing where the bus stops are) and social skills (e.g., turn-taking in conversations). At a broad level, there is some overlap of our findings with existing empirical literature focusing upon normative transitions into adulthood. Jablonski and Martino (2013) used grounded theory to explore how parents perceive adulthood status within their child. Consistent with our study, parents' conceptions of adulthood related to biological socialand legal markers.. Further markers included financial responsibility and making important life decisions (e.g., choosing which academic subjects to undertake at college or university). These markers were absent from parent data in our study. Instead, parents and professionals seemed to be responsible for managing the child's finances and life decisions. Indeed, individuals with a severe intellectual disability may never achieve normative constructs of adulthood. Thus, specific adjustments that parents make may be more pronounced (e.g., accompanying their child to a nightclub, liaising with healthcare professionals) when supporting their

child's adult development in comparison to parents of children from normative lifecycles.

Previous research highlights the notion of "relational autonomy", in which an individual fosters self-development and understanding within the content of relationships with others (Mackenzie and Stoljar, 2000). This relational model is suggested to be more suitable for the care of individuals with an intellectual disability (Widdershoven and Sohl, 1999). Based upon the current study findings, clinical interventions may aim to increase joint working in which decision-making is an interactive and triangular process (i.e., between the young person, parent and professional). Doing so would have implications for (1) broadening conceptions of autonomy in terms of it being relational and (2) understanding that adulthood for individuals with (and without) an intellectual disability is not necessarily about being able to make decisions independently but being supported to explore the options available.

Perceived barriers to adulthood: Parents vs professionals

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

Swain and Walker (2003) highlight inherent power imbalances between

parents of a child with a disability and professionals. Our findings showed that parents worried about being over-ruled by healthcare professionals in decision-making processes. Previous intellectual disabilities research found that parents often made adjustments that involved fighting with professionals in order to gain control over decisions made (Knox, 2000). "Fighting talk" (Todd and Shearn, 2003) was not apparent in our findings. Instead, we found that some parents tried to gain control over decisions by doing their own research. Stress control theories (e.g., decisional-control theory; Averill, 1973; Thompson, 1981) would argue that acquiring information serves to manage parents' feelings of uncertainty/stress about the transition period. This has implications for clinicians to work with parent perceptions and to embrace partnership practices.

(2) Parents' psychological adjustments

Making comparisons with perceived "norms"

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

One possible interpretation of parents' heightened worry can be derived from the social comparison theory (Festinger, 1954). This theory emphasizes that individuals have a drive to evaluate aspects of the self in relation to others in similar situations. This includes accomplishments, traits, possessions and aspects of significant others e.g. one's children (Gibbons and Buunk, 1999). Parents' views of how their child is managing the transition may be important for evaluating their own role as a parent. Thus, making comparisons has positive implications for understanding both parent and child (i.e., family) adjustments.

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

Accessing support

Some parents sought social support to cope with their child's transition. Accessing parent support groups provided them with emotional support

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

Some parents also sought professional support when managing the dilemmas associated with their child's sexuality development. Research suggests that sexuality development is an ambiguous area for both parents and staff (Hollins and Sinason, 2000). There is some evidence that parents of a child with an intellectual disability find it more difficult than professionals to accept their child's sexuality (Rose, 1990). However, our findings were inconsistent with this evidence. One interpretation may

be that there is a broader shift in attitude in today's society towards sexuality development in young individuals with a severe intellectual disability. Alternatively, it could be that this inconsistency was just evident in our sample. Nevertheless, parents may be misjudged by society as being "in denial" of their child's sexuality, when in reality, they may be worrying about how to best support their development. It would be helpful for future intellectual disabilities research to explore parent views towards their child's sexuality development to provide more contemporary perspectives held by parents and reduce the likelihood of their actions being misunderstood.

Clinical implications

The research questions in this study were valuable for broadening our understanding of how parents view their child's transition into adulthood, and for identifying psychological interventions to support families who may struggle to adjust to this transition. Across the study findings, it is evident that there are a number of areas that clinicians could seek to influence in order to support parents' psychological adjustments and general experiences of their child's transition into adulthood. Possible foci of intervention could include:

1. Promoting social support e.g. facilitating parent support groups in which comparisons with similar others can be made more positively.
2. Challenging parent perceptions e.g. catastrophizing beliefs around the transition process.

3. Work related to sexuality development for young people with severe intellectual disabilities.

4. Working systemically with families to embrace partnership working. This may include acknowledging parents' definition of adulthood, finding ways to negotiate what is "normal" and working towards a shared understanding with parents.

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

Strengths, limitations and research implications

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

cultures/ethnicities make adjustments for their child's transition into adulthood.

Conclusion

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

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Appendix – Evaluation of Quality

Criteria (example question)	Example of how was it was met
Fit (Do the findings fit with the researcher and participants?)	• After sharing the map, all three parents agreed with the developed categories and relationships between them. • The findings were "true" for most parents. One did not agree with the category of "making comparisons to societal norms" (Samantha)
Applicability (Do the findings offer new insight or explanations?)	• The findings offer new explanations using a social comparisons theory to understand why parents may make adjustments (e.g., encouraging "age appropriateness" in their child). • The findings offer new insight into how parents make sense of their child's adult development.
Concepts (Are the concepts developed in terms of their properties and dimensions/density and variation?)	• Concepts were developed in terms of their properties and dimensions to facilitate density/variation within the data. E.g. the "conceptual" notion of adulthood was developed in terms of its "legal" and "social" properties.
Contextualisation of concepts (Are the findings contextualised?)	• All concepts were grounded in parents' perspectives. • All participants provided contextual details (e.g., about themselves/their child) by completing a "personal details form".
Logic (Are methodological decisions made clear? Is there a logical flow of ideas?)	• The methodological decisions for using a grounded theory approach were made clear. • The final results followed a logical flow of ideas and were brought together by a core process of "making comparisons".
Depth (Do the concepts have depth/richness?)	• The descriptive details of each concept provided depth/richness. E.g. when identifying *how* parents encouraged "age appropriateness" or the types of perceived barriers.
Variation (Is there variation within the findings? Are there examples of cases that do not fit the patterns?)	• Contrasting data within some categories helped to identify variation within the findings. • A negative case analysis emerged when sharing the thematic map (see "*fit")*
Creativity (Are the findings presented in a creative and innovative manner?)	• The findings were visually presented in a creative manner.

	• A new understanding of how parents make sense of their child's transition and make adjustments was provided. • Analytic tools were used flexibly as opposed to in a dogmatic fashion.
Sensitivity (Was sensitivity demonstrated to the participants and data?)	• The interview schedule was revised three times in order to further explore concepts that had emerged from previous interviews. As such, the interview schedule became grounded in parents' views. • Data analysis shaped the research although the first author (SB) was aware of her own pre-conceived ideas/assumptions
Memos (Is there evidence of using memos throughout the research process?)	• Reflective memos were written throughout the research process.