

Parents perception and experience of transitioning to adulthood for their child diagnosed with an intellectual disability

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Definitions of adulthood for people with intellectual disability are often complicated, with milestones being markedly different for this population. This is then associated with difficulties for both the people with intellectual disability and their parents, who are closely involved in this transitional period. This paper aims to report on parents' perception and experience of adulthood for their son or daughter with an Intellectual Disability (ID). Qualitative data were collected through 30 – 60-minute phone interviews with eight parents of a person with an intellectual disability aged 15 or older (mean parent age = 60; mean child age = 23). Thematic analysis found that Perception of Adulthood encompassed themes of Independence and Normality. Experiences of Adulthood were categorised under Government Services, Responsibility and Social Supports. Findings of this research provide information for the growing literature around adulthood for people with intellectual disability, as well as how to amend policies and procedures for services that cater to people with intellectual disability and their parents during this transition.

Keywords: intellectual disability; adulthood; transition to adulthood; parenting; NDIS; developmental psychology

Most research on development in intellectual disability (ID) focuses on individuals with ID, defined as a disability that involves problems with general mental abilities that affect functioning in two areas: intellectual and adaptive functioning. However, there is limited research exploring parents' experiences of their child's developmental transitions and how these impact their own wellbeing. Understanding parents' experience is beneficial for both parents and their children, to enable the provision of appropriate supports across the transition to adulthood for parents of individuals with ID. Research suggests improved parent wellbeing predicts better child outcomes (Shochet *et al.* 2019). Conversely, higher levels of stress among parents of a child with ID have been associated with negative outcomes, such as higher marital distress (Norlin and Broberg 2013). Green (2007) argues, however, that research in this field focuses unduly on parent distress and its association with the burdens of having a child (subjective burden), when these burdens are imposed by society through negative attitudes and inadequate support (objective burden). This social model of disability, and its explanation of parents' perspectives and

experiences of their child's ID across the lifespan, has been little researched, particularly from an Australian viewpoint.

Arnett's (2000) model of emerging adulthood suggests that this developmental stage is characterised by explorations of identity, responsibility, independence and/or the establishment of romantic relationships/marriage. This definition is complicated, however, if the characteristics of adulthood do not line up with one's chronological age. The associated conflict between youth meeting the chronological age definition of adulthood, while lacking capacity to meet associated hallmarks that, for most, coincide with their age, complicates their identity as an adult. Moreover, the goodness-of-fit of people with intellectual disability to common definitions of adulthood can be a source of disagreement among those who care for them, with differing opinions expressed about what people with intellectual disability should or should not engage in once they reach *chronological adulthood* (Codd and Hewitt 2021). Arnett (1994) himself found that only 23% of typically developing individuals identified themselves as an 'adult' once reaching the chronological age defined as adulthood. Additionally, due to the significant emphasis on self-determination in many definitions

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of adulthood (Van Petegem *et al.* 2012), people with intellectual disability may not be perceived to have achieved this milestone, as self-determination is deemed non-applicable to those without a capacity to make (independent) decisions (Murphy *et al.* 2011).

How, then, is adulthood perceived and defined by parents of people with intellectual disability? Biswas *et al.* (2017) found parents of people with intellectual disability had varying perceptions of adulthood, with some holding a chronological view, and others focusing on developmental/social milestones. Murphy *et al.* (2011) found that parents of people with intellectual disability felt their child occupied a space between childhood and adulthood. Parents in this study emphasised self-care skills and increased independence as markers of adulthood in their children. Collectively, these studies suggest that parents of people with intellectual disability may have a perception of adulthood that is different from the societal norm, which may in turn influence how they experience the transition to adulthood of their child.

Parents' experience of their child with ID's transition to adulthood has been shown to have associations with their perception of adulthood. Pascall and Hendey (2004) found parents who have socio-normative ideas about adulthood often had their child with an ID follow a more standardised transition to adulthood (i.e. gaining employment, moving out of home). This may be feasible, even beneficial for people with intellectual disability who have mild difficulties, but is complicated for those who have more significant difficulties. For example, Biswas *et al.* (2017) found when parents compared their child to perceived norms of adulthood this led to increased worry about their child's future. Murphy *et al.* (2011) found, furthermore, that many parents perceived themselves to be ongoing support providers and caretakers for their child with ID, beyond the point of assumed adulthood. Transition to adulthood for a young person with ID is, potentially therefore, an emotionally challenging period for carers (Brown *et al.* 2020). Yet, the perceptions and experiences of their child's transition to adulthood has not to date been studied in Australian parents of a person with intellectual disability, despite there being unique aspects of the Australian socio-political context that make it an important arena in which to do this research.

For example, Leonard *et al.* (2016) discuss the importance of appropriate transition planning in terms of navigating services and programs, but to date there are no clear policies or common practices in Australia around transition planning. In addition, another finding of Biswas *et al.*'s (2017) study in the United Kingdom (UK), was that parents reported encountering barriers to seeking and receiving support from professional systems and services. In Australia, the response to parents' needs for more personalised support was the

establishment in 2016 of the National Disability Insurance Scheme (NDIS). The NDIS provides financial support for personalised plans that allocate funding according to different categories of need (i.e. transport, core supports, capacity-building). This is a more flexible funding model than the previous State-based but Federally-funded arrangement whereby services (i.e. therapies) were only accessible to people with intellectual disability through specific organisations.

The introduction of the NDIS was a significant shift in government policy and service implementation, yet its impacts on the transition to adulthood of people with intellectual disability have not yet been studied. Due to the ongoing challenges parents experience with service delivery during their child's transition to adulthood (Gillan and Coughlan 2010, Pascall and Hendey 2004) it is expected that the NDIS will affect parents' experience of transition, although the impact of this (and whether it is positive or negative) is currently unknown. The NDIS, which aims to provide more funding and assistance to those with more complex needs, works within a model that provides tailored supports to reduce an individual's future dependence on the system. It has been questioned, however, whether the NDIS will be able to uphold an individual's rights to control and choice when their disability is complex, and their presentation remains either constant or progresses in a way that is not represented through a reduced need for supports (Soldatic *et al.*, 2014). Whilst the NDIS is specific to Australia, the findings of the study could provide a case study for possible outcomes of similar initiatives in other countries.

Considering these unknowns, the current study aimed to examine parents' perceptions of adulthood for their child with an ID, as well as their experience of the child's transition to adulthood. Reflections on the impacts of the NDIS were also invited. It is hoped that the conclusions arising from the study can assist in supporting parents' personal wellbeing, contribute to the literature on emerging adulthood, and inform service delivery.

Method

Participants

Eight parents of people with intellectual disability participated in the current study. Participants were recruited via a range of disability organisations (e.g. Autism Queensland, Down Syndrome Australia, Fragile X Association of Australia and Syndromes Without A Name (SWAN) Australia) who were asked to advertise the study on their organisation website and social media platform/s in addition to snowball sampling. To be included in the study, parents needed to have a child aged 15 years or older identified as having an ID. All participants who responded to the invitation to participate were included in the research if they had a child

Table 1. Parent and child demographics.

Participant pseudonym (Age)	Child pseudonym (Age)	Relationship	Co-morbid Disability
Katie (57)	Daniel (19)	Mother	ASD
Travis (67)	Jessica (42)	Father	Psychosis
Helen (50)	Rachael (19)	Mother	Genetic disorder
Megan (53)	Melissa (20)	Mother	PWS
Sandy (61)	Nick (20) and George (17)	Mother	DS
Jane (75)	Isabella (17)	Kinship carer	DS
Belinda (63)*	Sam (27)	Mother	DS
Oliver (55)*	Sam (27)	Father	DS

Note: Autism Spectrum Disorder (ASD), Down Syndrome (DS), Prader-Willi Syndrome (PWS).

*Parents of the same child.

aged 15 years or older with ID; on this basis, two of the total applicants were excluded (as they did not have a child 15 years or older with ID) but all other applicants were included in the study. Parents of older children were included as it was considered that the transition to adulthood for people with ID may span a period of many years. The research was approved by [removed for peer review]. All participants provided informed consent.

De-identified information about the participants in the current study is presented in Table 1. The details include whether the child has another physical or mental disorder in addition to their ID diagnosis. The levels of co-morbidity evident in the children of the current sample is not unusual for this population (Goldin *et al.* 2014, Matson *et al.* 1999).

Procedure

This study adopted a descriptive-interpretive qualitative approach with thematic analysis (Braun and Clarke 2006), which is a generic approach to descriptive-interpretive qualitative research recommended by Elliot and Timulak (2021). Semi-structured interviews were conducted by the first author, who has a background working in the field of intellectual disability, behaviour support, psychology and social work. In order to maintain researcher reflexivity, the first author engaged in critical reflection throughout data collection in order to identify and deal with any biases that emerged. This was done through reflective journaling and discussions with fellow researchers. In addition, the first author was conscious of their relationship to the research topic through their previous work in the field of intellectual disability and used reflective journaling to explicitly reflect on their potential biases. This process was also used to actively critique themes identified while engaging in the coding process. Interviews were approximately 30–60 min long and were conducted individually with each participant to address the following research questions:

1. What are parents' perceptions of adulthood for their child with ID?
2. What are parents' experiences of the transition to adulthood for their child with ID?

Interviews also gathered some general information about parents' circumstances and experiences, including whether the child was relinquished from parental care, whether the parent is the sole carer, the severity of disability and the services the child has/does access. Questions were developed based on research by Biswas *et al.* (2017) which employed similar research questions, excluding questions around sexuality in order to reduce potential participant distress. Questions included:

- Do you consider your child an adult/do you believe your child will transition to adulthood?
- How did/will you know your child had/has become an adult or had/has not become an adult?
- How will/does your child's transition to adulthood affect you?
- How do/will you feel you are managing your child's transition to adulthood?

In some instances, further clarifying questions were asked to elicit more detail from participants.

Analysis

This qualitative study followed Braun and Clarke's (2019) method for thematic analysis. Thematic analysis aims to identify themes both across and within data sources (each participant interview) without being constrained to a theoretical construct, allowing patterns to be identified with less risk of bias occurring. Interviews conducted for the current study were audio-recorded and transcribed verbatim, with names of participants replaced with pseudonyms to de-identify all transcripts. Thematic analysis was used to explore the themes in the parents' perspectives about the transition to adulthood for their child with ID. First, a coding template (King 2012) was developed by analysing the data inductively. As the first author read and coded the parents' responses to the interview questions, the template was refined through discussion with the research team. Use of a coding template in this way enabled more consistent coding judgements and justification of the coding categories through comparison with previously coded data (King 2012). The coding process was iterative in that members of the research team engaged in continuous cross-checking of the coded data and

ensuring consensus was reached where there were any queries. This process reflects dialogic reliability (A°kerlind 2012) whereby agreement on final codes and themes is achieved through discussion and critique. Once coding was completed, parents' responses were collated into relevant themes.

Results

Themes that emerged from analysis of parents' reports of their perceptions and experiences of their child's transition to adulthood are outlined below.

Perception of Adulthood

Perceptions of the child with an ID's transition to adulthood fell into two major themes: 1) Independence and 2) Perceptions of Normality.

Independence

All parents spoke about the construct of independence being a key indicator of what adulthood looked like, or did not look like, for their child. Oliver suggested that the two are equivalent:

'He's growing older, he needs independence.'

Another parent, Katie, stated she disagreed with the typical, categorical concept of adulthood and instead viewed adulthood as a continuum:

'I think in terms of maximum independence, rather than adult.'

Parents in the current study reported that their child's capacity to make decisions was inherent to how they perceived their child's level of independence, and subsequently, whether they viewed their child as an 'adult'. All eight parents felt that decision-making was central to their view of adulthood. One parent, Sandy, stated that 'adulthood' was:

'I guess when you're making your own decisions and taking responsibility for those decisions that you make.'

Much of the argument around whether the child was able to make decisions and subsequently demonstrate their level of independence centred on managing risk. One parent, Megan, stated that she would know her child was an adult if:

'They can make decisions to keep themselves safe.'

Another parent, Katie again, suggested her child had reached adulthood:

'... because he's happy to make decisions on his own, or with help - with supported decisions.'

In fact, most parents posited that their child was an adult and could do most tasks and decisions with support. Oliver stating:

'Sam has the capability to do anything... he just needs a lot more support.'

For parents who did not believe their child would reach adulthood, this belief appeared linked to their

child's perceived inability to make any decisions, supported or unsupported. One parent, Helen, explained why she felt her child would never reach adulthood:

'I think it's because I have to make all of Rachael's decisions for her.'

When asked to describe what difference there was between her child's transition to adulthood and a typically developing person, one parent, Sandy, explained:

'I guess we've still got an element of certain control because they have an intellectual disability, which we wouldn't have with a child that didn't.'

Relationships with others were also referenced as an indicator of adulthood, with parents citing whether their child could independently interact with peers, form intimate relationships, and maintain friendships as key indicators of their ability to transition to adulthood. It was recognised by one parent, Travis, that his daughter was 'definitely' an adult, suggesting that this was the case because:

'She was married and was independently living with a partner for almost 20 years.'

Parents acknowledged that, while there were situations where their child did not have capacity to make and maintain relationships, their child's transition to adulthood was marked by an evolving capacity to engage in at least some relationships independently, or with support.

Perceptions of normality

Participants' perceptions of normality, compared to similar aged peers without a disability, was another theme that defined participants' ideas about their child's adulthood. For those with higher functioning children, parents perceived the similarity between their child and typically developing peers as a positive, protective factor. Katie, stated:

'He goes and you know just sits with all the other mainstream people and yeah it's fantastic.'

Several participants felt their child's adulthood was the same as for people without intellectual disability, as Belinda stated:

'I suppose in that way, in thinking about all my children, not just Sam... the move to adulthood was... my thinking about him was similar to them'

For parents who had children with lower functioning, who deviated more from the norm as the child grew older, the perception of normality was an unwanted reminder, with Helen stating:

'The gap of her being an adult to a child gets bigger as she gets older, because the more decisions you [the parent] make [for your child] as an adult, (the more) that Rachael's not doing'

Helen also noted that family provided her with a means of comparison, which further enhanced her experience of grief:

'When you see your cousins, nephews and nieces and your sister's children growing up getting a license, deciding what uni to go to, and you see the gap even broaden.'

It appears that parents of children who deviate more obviously from the societal norms of adulthood may experience this deviation as particularly distressing. Helen again stating:

'It makes me sad. It's hard one for a mum, because you see some of these things when they're an adult, but I'll carry that burden.'

Yet, another parent, Travis, argued differently:

'I don't really like the concept of normality that people should be striving for.'

In fact, some participants did not appear to connect with the normative expectations of 'adulthood'. Travis stated that whilst he had previously strived for normality for his child, he had changed his stance on this over time after realizing that it did not lead to positive outcomes:

'We were very keen for her to remain in mainstream school but that was purely out of our own ignorance rather than what was best for her, that failed completely.'

This suggests that the default social-cultural norms, and thus the concept of normality, may become internalised as individual or parental norms. The internalisation of societal norms and experience of ignorance could be countered, however, with support from community organisations with a strong value base, with Belinda stating that her expectations and definition of adulthood was shaped greatly by this:

'It's had a big influence on decision making around Sam's life ...all of that comes from those values that, you know, that we were um, exposed to.'

Another suggestion was that accommodations sit on a spectrum and are used by parents to encourage their child to meet their personal best. One parent, Katie, reported that she did not identify with traditional concepts of 'adult' and as a result, did not treat her child differently at any developmental period.

'It's funny I don't think of the term of 'adult' and 'not adult'. I treat him as an adult, ... like even from year 10.'

Some parents were acutely aware of gaps between their child's capacity and that of similar-aged peers without an intellectual disability; an awareness that appeared to cause distress. Helen reported that:

'When you see the gap gets bigger, every year she gets older, more things drop off that she is not able to do.'

Several parents suggested that their child demonstrated characteristics that were representative of both adulthood and childhood, further reiterating the complex interplay between the two developmental stages and reinforcing the concept of adulthood as more of a spectrum than a stage.

In addition to navigating the divide between adult and child, parents must also navigate a society where adulthood has a legal definition, creating a clear line whereby society holds expectations that are reflected in formal policies and procedures. For some parents, this legal definition of adulthood was a trigger to identify their child as an adult, or as someone who should be engaging in adult responsibilities, Katie reported:

'As soon as he turned 18, I ... got him registered to vote.'

Several of the participants adopted the chronological or legal definition of adulthood for their child with ID. Others, however, rejected arbitrary, legal concepts of adulthood as they are not inclusive of their child. Helen reported that:

'Technically the whole move from 17 one day turning 18, from a family perspective, you don't see any change.'

Some found the legal definition complicated access to services. Helen again:

'You are thrown into this massive pit of 'all of a sudden you're 18 and all these things change.'

Sandy argued that legal or chronological definitions of adulthood should also be rejected by those who are typically developing; that many typically developing individuals also struggle with the responsibilities of adulthood once they reach these arbitrary thresholds.

'I think a lot of people out in the community that are adults can really do with some of that help too!'

Experience of Adulthood

Data were also collected from parents regarding their lived experience of their child's transition to adulthood. These experiences grouped themselves under three categories: 1) Government Services; 2) Responsibility; and 3) Social Support.

Government services

Parents reported that their experiences with government services impacted their wellbeing. Whether services were experienced as supportive or unsupportive of parents' own definitions of adulthood for their child appeared to determine whether they were perceived as beneficial or not. Education Services (ES) were one form of government service that had been experienced as both beneficial and disadvantageous regarding, for example, provision of special education versus mainstream schooling. Many of the participants whose child had attended special school reported this experience as favourable.

Parent commentary about government services centred, however, on the transition to the NDIS. All participants reported accessing or having applied to access NDIS funding. Most parents perceived the transition to the NDIS as a positive change, with a few participants describing a comparable lack of support, historically. In

addition to offering more opportunities for their child, the NDIS was also described as enhancing parents' own wellbeing. As Helen commented:

'It's (NDIS) changed our lives... it's changed Rachael's relationship with me... (for the) better.'

Several parents suggested that the NDIS had provided more funding or more funding flexibility, thus reducing parent-carer responsibility. The flexibility of service selection also meant that parents had more power to assert their view of adulthood, and the goals they and their child had, in contrast to government-delegated services. For example, Oliver highlighted how selecting their own support workers allowed for better integration between services and parents' values and beliefs regarding adulthood, as it pertains to their child:

'We basically train them and direct them ourselves... to understand how best to deal with Sam.'

This integration provided parents with an additional level of trust; half of participants citing more positive experiences with support staff since the implementation of the NDIS.

While many participants cited the benefits of NDIS, there were suggestions that the NDIS is more complicated once a child transitions to adulthood. Many of the participants felt that leaving school was a difficult time, and this was primarily due to the cessation of ES's involvement. Helen reported that this period was not only difficult to navigate, but also a scary experience, leading to the contemplation of the future and what might be store for her child:

'You have the bubble of (ES) which was wonderful, going from safe special school, five days a week... Now, that's finished, what's next? That's scary for parents.'

The education system provides many parents with reassurance that their child is progressing developmentally and is following a curriculum aimed at increasing skills in a range of domains. It also provides, as Helen suggests, five days a week where parents do not have to worry about caretaking duties. For these parents, the end of school involves transition to full dependency on the NDIS, a relatively new service which, while providing flexibility, also lacks structure, which was noted by some parents to be a detrimental feature. Doubts about the allocation of adequate and appropriate funding was also raised as a concern by Sandy, who noted that:

'One of the stressors is just how much funding the NDIS will allow for her transition from child to adulthood.'

In contrast to ES, the NDIS does not provide a set amount of supports for a child instead allocating funding and supports based on the severity of disability, which is assessed on a six-month to yearly basis. This places an additional responsibility on parents to convey their child's level of need to access supports. The consequence of emphasizing support needs to access

funding is that parents must view their child as a person requiring significant supports. This causes struggle both internally and externally, with Jane reporting that the emphasis on needs meant she often had to work harder to advocate for her child's humanity:

'You've got to advocate the whole time within the healthcare system to get people to look at her as an individual... a continual battle'

Belinda disagreed with the concept of classification of severity, stating:

'It's never interested me, levels and that sort of thing, that's really an old-fashioned way of thinking about disability'

This position may further complicate access to funding or services that require this classification, a complication only exacerbated by the regularity of this struggle, with Helen arguing:

'Every year I have to advocate to prove that she needs this.... How challenging and ludicrous!'

This application process appeared arduous for parents in this study, with many of the participants citing difficulty navigating systems or noting that the process was time consuming. While the NDIS appeared to provide more flexibility than previous services, many of the participants mentioned that government services were still not flexible enough, and that this affected their experience of the transition to adulthood for their child. Lack of flexibility in government services also meant that often government-funded supports were either non-existent or provided an inappropriate amount of support. Katie reported the following about one support worker:

'You know we did try and work with him and say look, it's not what Daniel wants or needs... yeah so that sort of thing is just inappropriate.'

Belinda similarly cited difficulties with services, mentioning that the family no longer accessed them. Many of the participants described negative experiences with support services. Belinda's goals or ideals for her son and her perception of adulthood were not aligned with services' perception of adulthood. She also felt that the parents who 'gave in' and accepted the service's perception of adulthood for their child contributed to her own experience:

'That mindset is still out there, it's still so prevalent that whole, ... you know the total meaninglessness of life - that sort of attitude. and while that persists, then that has an impact on us too, and on Sam's life because that's really hard to fight against.'

This suggests that parents' perception of adulthood, and how much this deviates from services' perception of adulthood, affects parents' experience of the transition to adulthood for their child.

Service alignment with society's chronological definition of adulthood is another complication for parents to

navigate, affecting their experience of the transition to adulthood for their child. Helen relayed her experience of Rachael's changing supports once she turned 18:

'Six to 12 months to transition over... all of a sudden there's this guardianship thing, legality and bank accounts, I could go on and on and on... Centrelink [Government benefits], federal government supports, everything changed overnight.'

For parents who do not ascribe to chronological definitions of adulthood, institutionalized definitions of adulthood further exacerbate the discrepancy between society's ideals and parents' ideals for their child.

Responsibility

Another theme identified when discussing the experience of adulthood for parents was increased responsibility. People with intellectual disability often need more facilitation than typically developing children, further emphasized once the child has left ES. ES provide, for many individuals with ID, specialized one-to-one supports which may not be accessible in adult services, nor would staff be as well trained. Many parents report 'picking up the slack', perceiving their child's ongoing learning as a parent's responsibility during the transition to adulthood. Katie stated:

'He had to learn to catch two buses, like to get there and all this sort of stuff which was quite difficult and so [I] just put a whole lot of stuff in place so that he could do what he wanted to do'

Katie, when asked how this might be different for parents of typically developing children, stated:

'I guess the way it looks different for me is that you sort of have to tailor all the areas of his life that are going to be positive for him, it's not going to come naturally.'

The responsibility of parents to 'tailor life' possibly affects the parent's experience of their child's adulthood. This sense of ongoing responsibility likely contributed to many of the participants reporting a fear of aging and of what will happen for their child if they themselves are incapacitated.

Part of the responsibility that falls on parents of people with intellectual disability is managing risk, a role that is typically removed from parents of typically developing children who are assumed legally capable of managing their own risk by 18 years of age. Parents of people with intellectual disability are often left to navigate the murky waters of risk management, seeking to encourage independence, but without unduly elevating risk of harm. This balancing act is further complicated when parents and their child have different opinions on independence and risk, with Sandy stating:

'He can be a bit scary at times in stepping out in independence before you're [the parent] ready to [let go]'

The line between independence and parental monitoring was not clear for parents. Although some felt

they were able to manage this tension appropriately, others found navigating it was a difficult cognitive and emotional process. Helen reported that the change in her role was daunting:

'It's hard to let go of doing it for so long. It's just purely your instincts and your protection.'

Participants spoke of their child's vulnerability and the difficult process of learning to trust support providers. Helen continues:

'You have to trust the people who are looking after them to do the right thing, because they [their child] have no voice.'

Fear of abuse meant that many participants had little trust in services and felt the need to remain closely involved in their child's life. For some, their fears had been confirmed. For example, Travis talked about his daughter's ex-husband:

'Frank had some personality and behavioural issues and was very... controlling of Jessica.'

However, Travis also felt allowing his daughter to fail was important to her transition to adulthood:

'We ...allow her to have her own decisions in what she does in her life ... she got married and that was great for a while and then it didn't turn out so well. And so you just have to live with that'

The boundary between appropriate and inappropriate levels of risk was difficult for parents to navigate. Oliver describes the pull to treat his child according to his ideals around adulthood (i.e. that of independence) versus taking precautions to reduce risk:

'I'm thinking about potential risk in a place, whereas he might be able to handle it but ... I don't like him to take the chance to do that.'

Many parents reported that they felt responsible for arranging their child's housing. Most participants had their children still living at home, however many were considering future living arrangements and felt pressure to organise this. Participants reported that they were planning to supply housing to their child, with parents citing concerns about public housing. Katie reported:

'Because otherwise you'd be worried about getting them onto a you know, a waiting list and stuff like that and worrying about who he's going to share with.'

While the NDIS provides support for housing, individuals have limited choice in who they reside with, how long it will take to organise and the qualities of the property. The degree to which parents characterize the transition to adulthood by their child moving out of home is, therefore, likely to depend on their socio-economic status and ability to support their child with housing.

In addition to the financial costs of managing housing, another consequence of parents' strong sense of responsibility for their child's wellbeing is a reduction in their own independence. Sandy states:

'The fact that it sort of restricts our independence in a way because we're having to supervise them.'

Jane also commented:

'I also don't have any free time um, it's a go from 5am through to 10pm at night.'

The alleviation of responsibility associated with access to NDIS funding/funding flexibility meant, however, that some parents were able to regain degrees of independence. Helen described it thus:

'Now that physical elements are sort of taken away from me, I can balance out my life and take ... breaks.'

Social supports

Also contributing to parents' ability to manage stressors associated with their child's transition to adulthood are their social connections. Having a supportive family was cited as a protective factor by participants. Family can provide support as well as shoulder some of the responsibility, with Sandy reporting:

'It's comforting for us to know that they have got siblings who will take some care of them.'

Belinda suggested that the support she gained from her parents was part of a cycle of care where all family members provided integral support for one another:

'So, the ongoing story of parents helping their children, my mum and dad were really very big in my children's lives.'

Not all family involvement was beneficial, though. Travis stated that having a sibling was at times not an advantage for the person with intellectual disability when it came to accessing appropriate supports.

'Because she [her sister] was so close to her she actually probably camouflaged a lot of her [Jessica's] difficulties.'

Friends were also seen as integral supports, for the parents themselves and also their children. As with family support, the friendships of a person with an intellectual disability reduced the ongoing responsibility of parents, with Katie stating:

'When I see Daniel with his mates ... I just feel confident that they'll be there for life... that's when I feel most relaxed.'

Discussion

The current study provides insight regarding perceptions of adulthood among parents of people with intellectual disability, whether these differ from normative theories of adulthood, and whether their perceptions affect parents' experience of their child's transition to adulthood. The two major topics 1) Perception of Adulthood and 2) Experience of Adulthood, were well represented in the data. Within these topic areas, several themes were identified as providing insights into parents' perceptions and experiences.

Definition of adulthood

The transition to adulthood is often presented as a 'natural' progression, but the concept of adulthood is also socio-cultural-political (Liddiard and Slater 2018). Applied to those who do not follow the typical trajectory is the concept of being an 'eternal child' (Codd and Hewitt 2021) who cannot be treated as an adult due to a perceived failure to meet normative adult benchmarks (Wilkinson et al. 2015). Parents' struggle with this restrictive conceptualisation was observed in the current study via participants' differing definitions of adulthood. Most of the parents interviewed felt, however, that their child had reached adulthood or a similar milestone. One consistent theme, for example, was the importance of 'independence' as an indicator of adulthood both for their child and the general population, and all but one parent could identify their child as meeting at least some markers of independence, such as the capacity to make independent decisions. The use of independence as a criterion for adulthood is consistent with Arnett's (2000) developmental concept of 'Emerging Adulthood'.

It was suggested by other parents that, while their child did not fit into a clear developmental stage of 'adulthood', this may not be different to typically developing children/adults. This supports previous literature which has identified that both children with ID (Salt et al. 2019) and their parents (Henninger and Taylor 2014) have similar conceptualisations of adulthood to those who are typically developing.

Should adulthood, particularly for those populations that experience atypical development, even be treated as an enduring stage of development? This difficulty identifying adulthood as a clear developmental stage was noted by parents who acknowledged both that adulthood is defined by independence, and that fully independent decision-making and relationship formation may not be possible for their child. Despite these two conflicting positions, most parents in the current study still felt their child would reach adulthood. The dissonance between these two positions seemed to be navigated through the understanding that there was an in-between, a spectrum, where their child had the capacity to make at least some of their decisions independently, or that decisions could be made with the support of another person.

The responses of parents in the current study highlighted the value of conceptualising adulthood as a continuum, rather than as a categorical concept wherein one is either adult or not adult. This view of adulthood holds merit both for people with an ID and those without. Current societal constructions of adulthood are tied to chronological age and developmental milestones. This assumption that chronological age indicates capacity for independence and responsibility is challenging for those people with an intellectual disability, and

parents who attempt to measure their child against this ideal appear to experience more distress.

As some parents noted, the traditional, and/or chronological definition of adulthood is not always well suited even to those without an intellectual disability. Conceptualising adulthood as a spectrum whereby one may be an adult yet still require support is consistent with Vygotsky's Zone of Proximal Development (ZPD). Vygotsky (1987) argued that development is not a straight path or dichotomous in nature, but rather a series of qualitative, dialectic transformations that both integrate and disintegrate. Vygotsky's approach supports the social model of disability, suggesting that defects or disability are only perceived as such in a social context (Gindis 1995). Taking a spectrum view may, thus, be a more realistic and empowering approach to adulthood universally.

Categorisation and classification

While most parents felt that their child fell along an independence/adulthood spectrum, there was still a perceived need to categorise or classify their child's difficulties to facilitate access to supports within a system which requires comparisons and classifications. For some parents, comparison of their child with children without an intellectual disability was a positive experience. These parents saw their child as hovering at the edges of an adult identity, shadowed by an ID identity (Wilkinson *et al.* 2015). For others, where the difference between their child and peers without an intellectual disability was more evident, an ID identity was solidified. This solidification of ID identity, was associated with feelings of grief and, as one parent stated, a 'burden'. This is consistent with Whitney-Thomas and Hanley-Maxwell's (1996) findings that parents who had less optimistic visions for their child's future, struggled more with the transition to adulthood. Others rejected the implication that 'full adulthood' requires their child to 'grow out' of their disability; failure to do so leaving them trapped in an 'almost-adult' state (Wilkinson *et al.* 2015). Those who rejected the notion of adulthood as being categorically defined appeared to cope better with their child's transition to adulthood. Yet taking this alternative position also created issues for families trying to navigate access to services such as the NDIS or ES, where service delivery and funding is based on principles of categorisation and classification. Two parents in the current study reported, in fact, that they no longer accessed such services due to these differences in ideology.

Responsibility and managing risk

Most parents in this study felt they had an ongoing responsibility for their child with ID. Parents wanted to support their child's independence but had difficulty balancing this desire against the fear of unmanageable

risk. Children of more risk averse parents are less likely to be exposed to adult behaviours, such as drinking alcohol and sexual activity, due to parents' fears of harm. As a result, they may miss the process of experimentation during adolescence (Codd and Hewitt 2021). This was mentioned by two parents, who noted that they were hesitant to allow their child to make mistakes. One parent described an internal battle between providing care and overprotection.

The degree to which parents perceive a need to mitigate risk for their son or daughter with ID may also reflect how important they feel it is for their child to conform to societal ideals. Parents who have internalised social norms of adulthood and identify a discrepancy between these norms and their child, may be more likely to project this through the infantilisation of their child. This may lead to dependent behaviours on the part of their child, which further reinforces a belief that their child deviates from the perceived age-appropriate norms and that this is undesirable. One parent, who did not ascribe to 'normality', reported feeling confident in letting his daughter fail and learn from her mistakes. This suggests that not ascribing to social norms may have an advantage in reducing anxiety around risk management and, hence, increase the likelihood of experimentation and independence for people with intellectual disability transitioning to adulthood.

Child to adult service transition

Far from the transition to adulthood being a time of diminishing parental responsibility, parents' levels of responsibility may increase in intensity once their child leaves formal education and needs help navigating the transition to different services. These post-school services lack accessibility and quality, particularly for those with co-morbid mental health concerns (Kroese *et al.* 2013). Studies suggest there may actually be a loss of abilities acquired during the school years in the period immediately following (Gauthier-Boudreault *et al.* 2017). These findings are particularly unfortunate as research also suggests that intelligence may continue to develop in early adulthood among people with intellectual disability, in contrast to people without intellectual disabilities (Lifshitz 2020). There are also fewer options for post-school support available, with a 2009 Australian study finding there were limited full-day adult services and work experience opportunities, particularly for those with high needs (Davies and Beamish 2009).

The struggle with transitioning to adult services was reflected in the current study with parents indicating that the end of schooling was an important period, representing both a transition to adulthood for their child and an increase in parental stress. It is important to note that the transition to adulthood for people with intellectual disability also involves a transition period for parents (Wilkinson *et al.* 2015), with Leonard *et al.*

(2016) reporting over half of parents in their study perceived that the transition process had impacted on daily life and family wellbeing. During this period, parents must navigate the internal struggle brought on by managing their child's transition, including potential ongoing grief that can be triggered by the failure of the child to meet developmental milestones (Brown 2016). This is significant not only for the parents, but also for people with intellectual disability, as maternal depression has been associated with poor transition satisfaction for parents (Neece *et al.* 2009). As one parent in the current study described, also noted in Crotty (2016), families are both interconnected and interdependent, with each participant contributing to the overall wellbeing of the unit.

Strengths, limitations, and future directions

An important strength of the current study is that it highlights the importance and value of parents' input during the transition to adulthood of their child with ID. Parents' perceptions of this transition also contribute valuable insight to the ongoing literature regarding experiences of adulthood for people with intellectual disability. This includes information about how and when parents navigate the dissonance between socio-cultural discourses about adulthood and their personal expertise born of living with and supporting a young person with ID. By building a better understanding of how parents experience the adulthood of their child with ID, and the transition to adulthood for this population, the current findings can support policy development and service delivery. It is acknowledged that individual differences influence the experience of the transition to adulthood for both parent and child with ID. It is recommended, therefore, that this topic be investigated in future studies, with previous evidence suggesting that transition satisfaction is related to individual characteristics such as the mental health of people with intellectual disability (Neece *et al.* 2009).

It is also acknowledged that opinions expressed by participants in the current study may not be representative generally of Australian parents of a child with ID. The small, relatively homogenous sample limits the transferability of the current findings. In addition, it is likely that parents' experience of the transition to adulthood is time and place dependent and will differ markedly between parents whose children transition at different times and are subject to different government and social policy contexts. Further studies with more diverse samples, including parents of those with more severe classification of ID would, for example, be beneficial, as severity is the strongest predictor of not attaining adult social roles (Naarden Braun *et al.* 2006). The impacts of transition to adulthood on families of people with severe ID may thus be more profound than those reported by the current sample (Gauthier-Boudreault

et al. 2018). Further studies may also explore the factors that influence the experience of transition to adulthood for parents, and also for the young people with an intellectual disability.

Lastly, inclusion of the voices of people with intellectual disability in studies of adult development is recommended for future research. Particularly in Australia, one focus may be studying experiences of the NDIS by asking people with intellectual disability about this directly.

Conclusion

The current research provides information about parents' perception and experience of the transition to adulthood by their child with an ID. This is particularly pertinent in the current context of Australia, where there have been limited studies on the topic and a new funding scheme for disability supports was introduced in 2016. Findings showed that parents' perceptions of adulthood centred around the concepts of independence. It was also noted that parents' experience of the transition period was influenced by their interactions with government services, by a sense of ongoing responsibility, and by the availability, or lack thereof, of social supports. Assisting parents to appropriately balance management of risk with encouragement of independence is likely to reduce some of the ongoing burden of responsibility that parents experience. In Australia, even with additional provisions arising from the implementation of the NDIS, child and adult services are poorly aligned. Presently there is a gap for people with intellectual disability between end of schooling and entry into adult-oriented services, which includes moving to full reliance on the NDIS for funding support. It is the argument of the current study that bridging this gap in close collaboration with parents is essential.

All participants provided informed consent to participate in the project. The research was approved by the Queensland University of Technology Human Research Ethics Committee (approval number: 2000000059).

Disclosure statement

No potential conflict of interest was reported by the authors.

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References

- Åkerlind, G. S. 2012. Variation and communality in phenomenographic research methods. *Higher Education Research & Development*, 31, 115–127.
- Arnett, J. 1994. Are college students adults? Their conceptions of the transition to adulthood. *Journal of Adult Development*, 1, 213–224.
- Arnett, J. 2000. Emerging adulthood: A theory of development from the late teens through the twenties. *The American Psychologist*, 55, 469–480.

- Biswas, S., Tickle, A., Golijani-Moghaddam, N. and Almack, K. 2017. The transition into adulthood for children with a severe intellectual disability: Parents' views. *International Journal of Developmental Disabilities*, 63, 99–109.
- Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Braun, V. and Clarke, V. 2019. Reflecting on reflexive analysis. *Qualitative Research in Sport, Exercise and Health*, 11, 589–597.
- Brown, J. 2016. Recurrent grief in mothering a child with an intellectual disability to adulthood: Grieving is the healing. *Child & Family Social Work*, 21, 113–122.
- Brown, M., Higgins, A. and MacArthur, J. 2020. Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities. *Journal of Clinical Nursing*, 29, 195–207.
- Codd, J. and Hewitt, A. 2021. Having a son or daughter with an intellectual disability transition to adulthood: A parental perspective. *British Journal of Learning Disabilities*, 49, 39–51.
- Crotty, G. 2016. People with intellectual disabilities moving into adulthood. *Learning Disability Practice*, 19, 32–37.
- Davies, M. and Beamish, W. 2009. Transitions from school for young adults with intellectual disability: Parental perspectives on “life as an adjustment”. *Journal of Intellectual & Developmental Disability*, 34, 248–257.
- Elliot, R. and Timulak, L. 2021. *Essentials of descriptive-interpretive qualitative research: A generic approach*. American Psychological Association. <https://doi.org/10.1037/0000224-000>.
- Gauthier-Boudreault, C., Gallagher, F. and Couture, M. 2017. Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing? *Research in Developmental Disabilities*, 66, 16–26.
- Gauthier-Boudreault, C., Couture, M. and Gallagher, F. 2018. How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31, 215–223.
- Gillan, D. and Coughlan, B. 2010. Transition from special education into postschool services for young adults with intellectual disability: Irish parents' experience. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 196–203.
- Gindis, B. 1995. The social/cultural implication of disability: Vygotsky's paradigm for special education. *Educational Psychologist*, 30, 77–81.
- Goldin, R., Matson, J. and Cervantes, P. 2014. The effect of intellectual disability on the presence of comorbid symptoms in children and adolescents with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 8, 1552–1556.
- Green, S. 2007. “We're tired, not sad”: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine* (1982), 64, 150–163.
- Henninger, N. and Taylor, J. 2014. Family perspectives on a successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities*, 52, 98–111.
- King, N. 2012. Chapter 24: Doing template analysis. In: G. Symon and C. Cassel, eds. *Qualitative organizational research: Core methods and current challenges*. London: Sage Publications, Inc, pp.426–450.
- Kroese, B. S., Rose, J., Heer, K. and O'Brien, A. 2013. Mental health services for adults with intellectual disabilities- what do service users and staff think of them? *Journal of Applied Research in Intellectual Disabilities : JARID*, 26, 3–13.
- Leonard, H., Foley, K., Pikora, T., Bourke, J., Wong, K., McPherson, L., Lennox, N. and Downs, J. 2016. Transition to adulthood for young people with intellectual disability: The experiences of their families. *European Child & Adolescent Psychiatry*, 25, 1369–1381.
- Liddiard, K. and Slater, J. 2018. Like, pissing yourself is not a particularly attractive quality, let's be honest': Learning to contain through youth, adulthood, disability and sexuality. *Sexualities*, 21, 319–333.
- Lifshitz, H. 2020. *Growth and development in adulthood among persons with intellectual disability: New frontiers in theory, research, and intervention*. Switzerland: Springer Nature.
- Matson, J., LeBlanc, L., Weinheimer, B. and Cherry, K. 1999. Reliability of the Matson Evaluation of Social Skills for Individuals with Severe Retardation (MESSIER). *Behavior Modification*, 23, 647–661.
- Murphy, E., Clegg, J. and Almack, K. 2011. Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24, 61–73.
- Naarden Braun, K., Yeargin-Allsopp, M. and Lollar, D. 2006. A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: The acquisition of adult social roles. *Disability and Rehabilitation*, 28, 915–928.
- Neece, C. L., Kraemer, B. R. and Blacher, J. 2009. Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellectual and Developmental Disabilities*, 47, 31–43.
- Norlin, D. and Broberg, M. 2013. Parents of children with and without intellectual disability: Couple relationship and individual well-being. *Journal of Intellectual Disability Research : JIDR*, 57, 552–566.
- Pascall, G. and Hende, N. 2004. Disability and transition to adulthood: The politics of parenting. *Critical Social Policy*, 24, 165–186.
- Salt, E., Melville, C. and Jahoda, A. 2019. Transitioning to adulthood with a mild intellectual disability- Young people's experiences, expectations and aspirations. *Journal of Applied Research in Intellectual Disabilities : JARID*, 32, 901–912.
- Shochet, I., Siggers, B., Carrington, S., Orr, J., Wurfl, A. and Duncan, B. 2019. A strength-focused parenting intervention may be a valuable augmentation to a depression prevention focus for adolescents with autism. *Journal of Autism and Developmental Disorders*, 49, 2080–2100.
- Soldatic, K., van Toorn, G., Dowse, L. and Muir, K. 2014. Intellectual disability and complex intersections: Marginalisation under the National Disability Insurance Scheme. *Research and Practice in Intellectual and Developmental Disabilities*, 1, 6–16.
- Van Petegem, S., Beyers, W., Vansteenkiste, M. and Soenens, B. 2012. On the association between adolescent autonomy and psychosocial functioning: Examining decisional independence from a self-determination theory perspective. *Developmental Psychology*, 48, 76–88.
- Vygotsky, L. S. 1987. *The collected works of LS Vygotsky, vol. 1: Problems of general psychology*. New York: Plenum Press.
- Whitney-Thomas, J. and Hanley-Maxwell, C. 1996. Packing the parachute: Parents' experiences as their children prepare to leave high school. *Exceptional Children*, 63, 75–87.
- Wilkinson, V., Theodore, K. and Raczka, R. 2015. As normal as possible': Sexual identity development in people with intellectual disabilities transitioning to adulthood. *Sexuality and Disability*, 33, 93–105.