Are We There Yet?

A study of concepts and conflicts surrounding
intellectual disability and adulthood

by

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Table of Contents

List of Tables

List of Figures

Candidate’s Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Candidate’s Name: Fiona Redgrove

Supervisor's Declaration

This is to certify that the research carried out for the doctoral thesis, "Are We There Yet? A study of concepts and conflicts surrounding intellectual disability and adulthood", was completed by Fiona Redgrove in the Disability and Community Inclusion Unit, Flinders University, Adelaide Australia. The thesis material has not been used in part or in full for any other qualification, and I confirm that the candidate has pursued this course of study in accordance with the requirements of Flinders University regulations.

Supervisor's Name: Dr Paul Jewell

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This is to certify that the research carried out in the doctoral thesis, “Are We There Yet? A study of concepts and conflicts surrounding intellectual disability and adulthood”, in the Disability and Community Inclusion Unit, Flinders University, Adelaide Australia is the original work of the candidate, except as indicated by appropriate attribution in the text and/or in the acknowledgements; that the text excluding appendices/annexes, does not exceed 100,000 words; all ethical requirements applicable to the study have been complied with as required by Flinders University of South Australia, other organisations and/or committees which had a particular association with this study, and relevant legislation.

Ethical authorisation code: 7169
Flinders University Human Ethics Committee

Candidate’s Name: Fiona Redgrove

Date: 28th November 2017

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Acknowledgements

I have enjoyed a career that spans nearly 40 years that has involved working with both children and adults with a wide range of disabilities. This thesis results from the growth I have identified from a time I once believed I was a “professional”, who was entitled to comment on the lives of people with disability and their families, to now recognising the fallacy by which I lived. I now recognise there is no way to truly and totally understand the impact of disability on those living with impairment and on their families when you have not had this experience. This thesis is the culmination of many years observing the divide between those who find themselves living with disability through personal circumstance, and those who choose to enter their worlds as professionals of one sort or another. The often dichotomous perspectives reflect the personal journeys, the different conditioning that experiences offer, and the alternate perceptions of disability held by those who engage with people with disability either through love or duty.

My perspective cannot reflect a personal experience of living with disability. It has been a personal choice to work in the field of disability. I consider myself privileged to be able to culminate my life’s work with this research project. There are many people to thank for helping me reach the end. At the forefront of this list are those I have met who have family members with disability. I have shared tears of laughter and great joy and unbridled pride and deep sadness with families over the last 40 years. These people have been my greatest teachers. My association with the Tascare Society for Children has been integral to helping me maintain connections with these families. In particular I mention Mrs Lesley Lewis, who challenged me to stop thinking like a professional. Lesley encouraged me to question my thinking in so many ways, and her experience in Social Role Valorisation, and PASSING workshops, and as the mother of a son with intellectual disability, helped me recognise my own ignorance of the reality for families. The theory I could espouse was of little interest to families engulfed in the day-to-day trials of parenting children with disabilities. I learned to listen instead!

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I would finally like to dedicate this paper to three wonderful women—my mother (Grambo), and my two wonderful daughters, Lucy and Annie. Grambo has long been an inspiration to me. I hope that in some way this journey helps inspire my girls to recognise that learning is lifelong, exciting, and fulfilling, and to be mindful that their learning is never complete. I am proud to be the daughter of a ***nonagenarian*** woman who has worked so hard in recent months to regain her independence despite strokes and falls, and I am proud to be the mother of two young women who have so much to offer the world. These three women, my sister and my husband have sustained me through this long journey. Thank you.

Preamble

“When we graduate from childhood into adulthood, we're thrown into this confusing, Cthulhu-like miasma of life, filled with social and career problems,
all with branching choices and no correct answers.”
— Felicia Day

“I believe that everyone else my age is an adult whereas I am merely in disguise.”
— Margaret Atwood

“To abandon the child ‘within’ means that the adult ‘without’ will be an adult in name only. And frankly, I can only name a handful of things that are that tragic.”
— Craig D. Lounsbrough

“People never grow up, they just learn how to act in public.”
— Bryan White

Abstract

Despite extensive research into the transition to adulthood for young people with intellectual disability, this life stage continues to offer challenges for these young people, their parents, and the staff working with those termed “young adults”. This thesis investigates the possibility that conceptualisations of adulthood differ in ways that contribute to tensions between young people, their parents, and disability support workers during this transitional phase.

The qualitative research presented here, using focus groups and semi-guided interviews, is framed by a theoretical model that offers four paradigms, or lenses, by which adulthood may be considered. Concept analysis was applied to the data. The data analysis highlights five themes where variance was found in perceptions of young people with intellectual disability as “adult”, or otherwise. These themes centred on the ideas that adults are independent and rational, that adults find acceptance in their community, and that adult life offers meaning. The final theme reflects on adulthood as either an actual or virtual observation.

This thesis highlights the difference between support workers within disability services who are guided by a prevailing ideology of human rights and empowerment, and parents who may continue to assume a paternalistic and protective relationship with their son or daughter with a disability. The research suggests that either perspective is potentially damaging to a young person with intellectual disability. The findings reflect the inadequacy of the term “adult”, and the lack of a term that better describes this developmental life stage of young people living with intellectual disability. They call for consideration to be offered to the contemporary sociological stage of “emerging adulthood” for those young people with intellectual disability who have left the dependency of childhood, but are yet to assume the enduring responsibilities of adulthood.

Chapter One
Introduction

1.1 The aim of this study

The question of when any young person has successfully transitioned from childhood to adulthood is not easily answered. This thesis explores how parents or primary unpaid carers, and Disability Support Workers (DSWs) conceptualise adulthood for young people with intellectual disability. It explores the compatibility of stakeholder conceptualisations by mapping these against one another to identify whether differences contribute to stress and conflict during the transitional phase as young people transition from childhood into their next life stage. Disability literature is replete with discussions on the difficulties of the transition process, the policies that surround this life stage, and the practices that are assumed to assure families of “successful” transition (Bigby, 2000; 2005; Clegg, Sheard, Cahill, & Osbeck, 2001; Davies & Beamish, 2009; Ferguson & Ferguson, 2000; Floyd, Costigan, & Piazza, 2009; Gillan & Coughlan, 2010; Glidden & Jobe, 2007; Hallum, 1995; Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995; Hendey & Pascall, 2001; Hudson, 2003; Janus, 2009; Kim & Turnbull, 2004; Kraemer & Blacher, 2001; Margolis & Prichard, 2008; McIntyre, Kraemer, Blacher, & Simmerman, 2004; Morningstar & Lattin, 2004; Neece, Kraemer, & Blacher, 2009; "NSW: Australian outrage at plans to sterilise disabled UK girl," 2007; Osgood, Foster, Flanagan, & Ruth, 2004; Pascall & Hendey, 2004; Pilnick, Clegg, Murphy, & Almack, 2011; Rapanaro, Bartu, & Lee, 2008; Tisdall, 2001; Whitney-Thomas & Hanley-Maxwell, 1996; Ytterhus, Wendelborg, & Lundeby, 2008). Previous research also shows that this is a worrisome time for those with intellectual disability (Forte, Jahoda, & Bagnan, 2011). This life stage has been a focus for policies and practices over the past few decades. However, there is little to be found in the literature on people with intellectual disability that targets the conceptualisation of adulthood as a possible contributing cause of the tension and complications that arise during this life stage. This study explores the perceptions of family members and those who are paid to provide support to young people with intellectual disability as they work with, and help guide the lives of young people with intellectual disability. It also offers a group of young people with intellectual disability, who are transitioning beyond Grade 12, the opportunity to voice their opinions about their status as adults.

This thesis investigates the possibility that conceptualisation of adulthood is a contributing cause of the tension and complications that arise during this life stage. It further asks whether an adequate definition of adulthood can be offered that best suits the needs and wishes of young people with intellectual disability. If no such definition exists, how then does social policy prescribe for those who live with intellectual disability? Further, how does social policy determine issues of human rights to autonomy, freedom of choice and self-determination for these young people as adult citizens? Is difference and diversity acknowledged and respected, or is adulthood simply an unquestioned, and unquestionable legal entitlement for all?

1.1.1 The context for this study

Each age and stage of life is recognised as bringing about a new set of challenges for the person passing through that stage, also for those who live with, work with, and grow with that person. Transitioning from the end of schooling to adult services is one such stage of life that can present particular challenges for young people and their families (Konstam, 2007; Tannar & Yabiku, 1999). The term “transition to adulthood” implies the existence of some idea of what is meant by the term “adult”. It infers there is a commonly held view of the criteria that constitutes adult status. The question, though, is whether this transition is simply biological or legal, or whether it is a socially constructed idea based on the criteria that the members of a community deem most important in establishing adult status (Brannen & Nilsen, 2003). It is assumed that we all grow up to be adults, but as adult status is a social concept, the criteria for achieving this status may vary from one culture to another, and can also change over time. Yet adulthood is an implicit stage in most sociological research (Arnett, 2000, 2001, 2007b; Brannen & Nilsen, 2003), offering a point of reference against which to study childhood, adolescence, or old age. It exists as an ever-present default position, and as an heuristic concept that centres many fields of analysis. Adulthood is a taken-for-granted position that has long historically established markers including employment, mortgages, children, cars, partnerships and legal rights (Peterson, 2014). Despite these markers, there is no official sociological agreement on an age that signifies the start of adulthood, only a legal one (Blatterer, 2005a).

Transitioning from childhood to adulthood is an interesting time for many and can be a challenging period of development for individuals and their parents as they negotiate new roles, new relationships, and the changing dynamics of agency that is afforded to those who acquire legal adult status, being in Australia 18 years of age. This life stage is equally interesting, but may be experienced differently, for those transitioning into adulthood with an intellectual disability. This difference may be exacerbated by the additional protection reportedly offered by parents of individuals with intellectual disability (Blomquist, Brown, Peersen, & Presler, 1998; Ferguson & Ferguson, 2000; Floyd, Costigan, & Piazza, 2009). On the other hand, this difference may equally be intensified by additional people in their world, such as support providers. Disability Support Workers (DSWs) generally play no role in the lives of young people who are not living with disability. DSWs add complexity as they are often guided by policies that require young people with intellectual disability to have the same opportunities, in ways that are parallel to those of their peers without disabilities.

1.1.2 Politics and Intellectual Disability

In what now tends to be a linguistically sensitive context in Australia, discourses on intellectual disability can attempt to render the disability in living with impairment invisible (Stiker, 1999). Halmai (2011) explains that what are now referred to as “politically correct” discourses are characterised by careful and sanitised speech about intellectual disability. Such discourses have only recently been identified, and are relatively new phenomena in relation to intellectual disability in contemporary society (Quibell, 2004). Stiker (1999) argues that there is a trend towards the erasure of disability in our culture. This view is supported by proponents of ableism who treat non-disabled individuals as the standard of “normal living”, resulting in buildings and services that are structured to serve “standard” people (Goodley, 2014; Wolbring, 2012). Stiker claims that the identification of disability in contemporary Western society is so as to be made invisible, or marked as different in order that people with disability should be made “just like everyone else”, an indication of the development of a less pluralist society, into one that is “more and more rigid” (p. 128). Stiker contends that our society no longer tolerates disability. Rather it tends to denigrate human life in seeking to “normalise” its variations, and has become ableist according to researchers and academics such as Tom Shakespeare,(see for example Shakespeare, 1998) Licia Carlson (see for example Carlson, 2010) and Dan Goodley (see for example Goodley, 2014). Such authors outline how ableist approaches offer prejudicial attitudes and discriminatory behaviours towards people with disabilities, and highlight the negative treatment received by people whose abilities do not fit cultural norms, or the preferred characteristics of a culture. Such people are labelled as “impaired”, or “not able enough”, or “not able in the right way”, and receive unequal treatment because of their apparent or assumed differences (Wolbring, 2012). Wolbring (2012) notes that definitions of ableism hinge on one’s understanding of normal ability and the rights and benefits afforded to persons deemed “normal” (p. 78). Within a culture that adheres to an ideological dominance of adulthood as a privileged position, the move to ensure people with intellectual disability are included into this centralised position has been paramount in recent decades. But the concept of “normalisation” is questioned by Stiker, who examines the desirability of sameness, suggesting that attempts to make each person identical will “cause the disabled to disappear and with them all that is lacking, in order to drown them, dissolve them in the greater and single social whole” (p. 128). Sameness might well be considered the antidote to stigma. If we eliminate difference then we address the problem of stigma by which individuals may be disqualified from social acceptance. Goffman (1976) notes:

> While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind, … He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, … it is also called a failing, a shortcoming, a handicap. It constitutes a special discrepancy between virtual and actual social identity (pp. 12-13).

Goffman talks of stigma as resulting from attributes that are incongruous with our stereotype of a particular type of person. Wolfensberger (1972) used deviance theory to explain the stigma faced by those who were seen as different, and often perceived negatively within society. Included in the aims of the “normalisation”, espoused by Nirje (1969) and Wolfensberger in the 1960s and 70s, is the goal to establish personal behaviours and characteristics that are as culturally normative as possible (Wolfensberger, 1972, p. 28), with a goal to integrate those with disabilities alongside others in the community within condition that are the same as those offered to other citizens. Based on a theory that supports dignity of risk over protection, the normalisation theory has become the foundation for deinstitutionalisation and community integration movements throughout the Western world. From this has risen the concept of community living, theoretically offering opportunities for people with disabilities to leave home and attain employment, and supporting everyone to have as “normal” a life as possible.

The normalisation theories were forerunners to self-determination and empowerment theories, but these movements have not evolved without social challenges and are in contemporary literature framed as ableist and contributing to discrimination and poor access to a life of choice (Wolbring, 2012). One such challenge is how and when people with intellectual disability transition from family life where they are recognised as children with a rightful place within their family home, to the broader community of adults, and all that this move entails (Foley, 2012). This study addresses the tensions that are known to exist between services and families of young people with intellectual disability during the years following the end of their secondary schooling, after they turn 18, by investigating the conceptualisations of adulthood that are held by stakeholders in the lives of these young people. Beyond the initial study into possible tensions between family members and DSWs, it also explores the beliefs and conceptualisations found within a sample of young people with intellectual disability who are transitioning beyond Grade 12, offering their voice to the question of their status as adults or otherwise. Consideration is given to whether the current approach is not only ineffective and not useful, but potentially damaging in its ableist underpinning when transferred in educational, support and service practices.

1.1.3 Emerging adulthood

In researching the topic of adulthood and how this may apply to young people with intellectual disabilities, the contemporary work of Jeffrey Jensen Arnett was prominent in most anthropological and sociological readings. Arnett (2000, 2001, 2007a) proposes the term "emerging adulthood" for that period from the late teens to the mid-20s (approximately ages 18-25). Arnett offers this age range as a new period of the life course in Western cultures, suggesting distinctly different developmental characteristics to those of adolescents and adults. The need to recognise this new life stage arose in response to changes that occurred from the middle of the 20th century suggesting that Erikson's postulation that adolescence was followed by young adulthood no longer applied. With median ages for marriage rising to the late 20s, and frequent job changes during the early and middle 20s, along with common pursuit of postsecondary training and education, the need for an additional life stage was recognised (Arnett, 2000, 2001; Arnett & Taber, 1994). Along with factors such as marriage, work, education and training, Arnett notes the changes in sexual mores, with the wide acceptance of premarital sex and cohabitation for young people in their 20s. Arnett's theory proposes a framework for recognising that this transitional phase between adolescence and adulthood was long enough to be considered a separate period of the life course. His studies of young people suggests that the transformation into independent adulthood occurs slowly, over many years between the completion of the secondary school years, which generally coincides loosely with the age 18, and the commencement of adult responsibilities. Arnett proposes that the period between the ages of 18 and 25 for young people is a distinct period, demographically, subjectively, and in terms of identity explorations, which differs from adolescence and young adulthood. Arnett (2000, p. 469) argues for this period to be termed "emerging adulthood", offering that it is "neither adolescence nor young adulthood but is theoretically and empirically distinct from both". Arnett's seminal work on the concept of emerging adulthood forms a platform for consideration of this transitional phase for young people with intellectual disability. Taking this position also identifies a potential approach that transcends ableist thinking and approaches to support and service practice.

Many contemporary sociologists now agree that consideration needs to be given to the recognition of a new life phase, similar to the introduction of the term “adolescence” in the early 20th century (Arnett, 2000; Blatterer, 2005a). The transition to commonly accepted cultural measures of adulthood has occurred later in the life course for many young people since the middle of the 20th century. Brannen and Nilsen (2003) explain that as the baby boomers born after the Second World War grew up, social and material conditions improved across all social classes. Changes such as greater access to upper secondary and higher education, the contraceptive pill, and the Women's Movement all contributed to the prolongation of youth for subsequent generations. Since the 1960s, age at marriage and at the birth of first child increased gradually for most social classes in Western societies. Brannen and Nilsen describe these changes as “leading to an extended phase of ‘adult independence’ before ‘adulthood proper’, and the responsibilities of parenthood arrived” (n.p.). Arnett offers the construct of a period when a young person is no longer an adolescent, nor have they met some socially constructed, and culturally recognised markers of full adult status. He describes this period of emerging adulthood as one in which progress toward independence is made rather than independence achieved. He proposes that social changes have created a distinct new stage within the life course, characterised by five core factors (Robinson, 2015 p.20):

1) identity exploration through internal and external experimentation

2) a sense of idealistic possibility

3) a feeling of being in-between adolescent and adult

4) instability in life structure, residence and relationships

5) a focus on self

While these factors may exist throughout the lifespan, they are believed to peak through this stage of emerging adulthood. Robinson (2015) quotes 2010 research by Stone, Schwartz, Broderick, and Deaton that identifies this as a “uniquely stressful part of the lifespan” (p. 20). The distinction between adolescence and the stage of emerging adulthood is made around factors such as being legally an adult, being able to transport independently, generally as a result of gaining a license, and completing secondary education. Robinson (2015) offers that these three factors combine to draw a line in the sand that once passed, shifts a person into emerging adulthood. Importantly, he also explains that this life stage is assumed to finish once a person settles into a social routine, has established roles in life, has selected a partner, has a settled home life, and has established a consistent sense of personal identity. He supports the recognition of this life course stage in the United Kingdom, quoting significant social changes, such as the rise in age of first time marriages in women from 22 in 1970 to 30 in 2012, and 24 to 32 for men over the same period. Pre-marital cohabitation has risen from 10 per cent of couples in the 1970s to 80 per cent in the year 2000, and the average age of parenthood became lower than that of first time marriages. Arnett (2000) argues that it does not make sense to suggest 18 to 29-year-olds are young adults, as they are often yet to accept established roles, in that they are often not married, do not have children, and are often not settled in stable full-time work (Zukauskiene, 2016). It now appears that parenthood outside of marriage is the norm, with the average age of first time mothers rising to 28. Zukauskiene explains that the transition period from adolescence to adulthood is significantly prolonged, with young people having a vast array of lifestyle choices, and rather than following single, uniform passages, young people now take many different routes. She offers that "pathways to adult life have become de-standardised, more flexible, heterogeneous, and differentiated" (p. 4). This prolonged period between adolescence and adulthood is, in Arnett's view, a distinctive time of life when people are neither adolescents nor adults but are in a bridging process.

1.1.4 Emerging adulthood and intellectual disability

Despite the prominence of the concept of emerging adulthood in contemporary anthropology, little thought has been given to the application of this term to young people living with intellectual disability. Floyd, Costigan and Piazza (2009) acknowledge that while Arnett's research indicates general consensus amongst teenagers, young adults, and adults in midlife, most notably marked by individualism, the idea of emerging adulthood may well differ significantly for young adults with intellectual disability. While there is some literature on specific disability types to be found, e.g., emerging adulthood and spina bifida, or developmental coordination disorder (see Kirby, Edwards, & Sugden, 2011; Zukerman, Devine, & Holmbeck, 2011), the exploration of emerging adulthood and its applicability to youth with intellectual disability is notably absent from the literature. However, the term has recently been introduced into the vernacular of disability research (see for example Henninger, 2014; Wilkinson, 2015). The term is used to describe the life stage of young people who are said to be "transitioning to adulthood". Wilkinson, Theodore and Raczka (2015) note that this stage is characterised by on-going identity negotiations. They consider whether an identity of intellectual disability overshadows the development of a sexual identity. However, little else can be found in research data about young people with intellectual disability and the stage of emerging adulthood. This thesis reveals a need for further exploration of this new life stage and its relevance and application to those with intellectual disability also transitioning from the end of the school years. Such a framework may offer a platform from which to further research the conceptualisation of adulthood by those who are transitioning, and those who are in their lives as family members or support personnel.

At the point of considering this area for research, I was teaching in a training college, and found myself faced with a quandary over whether or not to openly support a colleague in dismissing or rebuffing a father's request for information about the whereabouts of his daughter after her day at the training college had finished, information that was presumably sought with the safety and welfare of his daughter in mind. This young woman had started to go into the city after her course with some young men from another training course. These young men were not known to the father, or to the staff working with this young woman. She was then not catching the bus home that she was expected to be on, causing considerable stress to her parents. Part of this conversation is reported from memory here:

> **DSW:** *Mr Jones, what Cheryl does after she leaves here is really not my concern. She seems to be handling the buses very well, so once she leaves here, I feel sure she is able to get home when she wants to.*
>
> **Parent:** *Yes but that's the problem—it's when she wants to, and that's not always on the four o'clock bus as she should.*
>
> **DSW:** *Well Cheryl is 19, and that makes her an adult now. She is starting to make her own choices.*
>
> **Parent:** *But she's in town with people we know nothing about; she is incredibly vulnerable. She's been picked up at a bus stop before. Fortunately the police were able to find her before something really bad happened. We need her to stick to the routine so we know she is safe. Who are these men that she is walking into town with? Do you know anything about them?*
>
> **DSW:** *Yes, I know who they are, but I shouldn't discuss them with you. You need to talk to Cheryl about what she is doing after she leaves here each afternoon.*
>
> **Parent:** *You don't think I've tried! Cheryl doesn't always want to talk to us—she says you tell her she doesn't have to tell her parents anything now she's an adult! That would be fine if she could be a responsible adult, but she isn't capable of understanding the risks of wandering the streets with men she hardly knows. That's what her disability means! Her age has nothing to do with this. The fact is that she doesn't know when her actions could result in something terrible happening to her.*

As a witness to this conversation, I wanted to offer this father support in his parenting role of his daughter, whose vulnerability I recognised. Yet I felt I had a duty to support this young woman, and also my professional colleague. I found myself torn between my professional role and my genuine feeling of compassion for this father. I could empathise with his struggle to do the best for his daughter who still lived with him, and for whom he assumed responsibility, as he did not consider her yet capable of looking after herself. I could not help but wonder, in the event of any misfortune befalling his daughter, how much blame may be apportioned to him for not protecting her in light of limitations in her capacity to assess risks, to understand the intent of others, and to problem solve her way out of any difficult situation she may encounter. Simply because of his daughter's time on earth, this father was facing obstructions to his role of patriarch, protector, and caring parent. Yet there was no doubt that the respect and dignity offered to this young woman by the DSWs was well-informed and sustained by current policies that reflect best practice.

During the conversation, I noted that the term "adult" was used to defend the position assumed by the DSW, while the idea that his daughter was entitled to "adult" rights, such as privacy and self-determination, was refuted by the young woman's father. In light of the unrelenting reports of difficulties during the transition from school to the world beyond the school gates in the literature, I questioned whether the conceptualisation of adulthood as it applies to young people with intellectual disability could contribute to the conflict between the two groups of stakeholders.

1.2 Rationale for study

Challenges are widespread across families of all young people but for families of young people with intellectual disabilities the consideration of their son or daughter as a young adult is often difficult and complicated, and the source of much trepidation, conflict and grief (Baine, McDonald, Wilgosh, & Mellon, 1993; Clegg, Sheard, Cahill et al., 2001; Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995; Hudson, 2003; Jordan & Dunlap, 2001; Mellon, Wilgosh, McDonald, & Baine, 1993; Neece, Kraemer, & Blacher, 2009). Tension between stakeholders is recognised as problematic during the transitional phase from the end of school to the young person's new persona as an adult, or at least a recipient of "adult" services, once life transitions beyond the school gates. Further consideration of what it means to be an "adult" is required in order to contextualise the perception of a young person as having reached "adulthood". The road to "adulthood" for all young people is fraught with opportunities for conflict between them, their families, and their communities, but seems more precariously pitted with dilemmas when the young person has intellectual disability. At the end of 18 years of caring and support, the shift to adult services presents one of the greatest trials for parents who can find themselves regarded as tangential or inhibiting to the development of the transitioning young adult (Baine, McDonald, Wilgosh et al., 1993; Ferguson & Ferguson, 2000; Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995; Hudson, 2003; Twigg & Atkins, 1994). Further research is needed into why, despite ongoing research into the transitional phase between schooling and post-school life for young people with intellectual disability, stakeholders (families and support workers alike) still experience this as a potentially stressful transition phase. The question remains as to why there continue to be challenges for those who, presumably, share common interests which would be best served by developing harmonious relationships with one another. The on-going changes in support structures beyond the school gates require concession and compromise but, historically, this does not seem to have transpired successfully in many cases.

The principle of person-centred planning has been affirmed in recent government policy directions in Australia, with significant shifts to individualised funding models, particularly through the introduction of the National Disability Insurance Scheme (NDIS) (Kirkman, 2010). Such approaches are designed to ensure self-determination through direct funding models that allow people to determine their own services, and to have more power to make their own decisions. The shift to NDIS offers a similar shift away from people with disability as being passive recipients of government funded services to positions of greater power to "enhance the quality of life and increase the economic and social participation of people with disabilities and their families, including enhancing and protecting their rights" (Australian Government Productivity Commission, 2010 p.9). In very recent years, then, services have shifted from population-focused and population-funded delivery to individualised funding models, with Bigby and Knox (2009) quoting from the *Victorian Disability Act 2006* (Section 52), stating:

> Planning should: a) be individualised; b) be directed by the person with a disability; c) where relevant, consider the role of family and other persons in the life of the person with a disability.

While families rate a mention in these documents, the primary focus of services and planning is on the individual, first and foremost. The point at which this focus shifts from family-centred to person-centred planning, or from children's to adult services, is the 18th birthday of the young person who requires services. This would then seem to mark the arrival at a point congruent with adulthood for those who are charged with the provision of support services to the young person, considering the role of the family only "where relevant".

Whether such legislation appropriately and adequately supports these young people is unclear, and how and when the position of families is considered "relevant" within the planning for these young people could depend on the conceptualisation of the young person as an adult or otherwise. So how is adulthood defined for those with intellectual disability? The Penguin Dictionary (2004) simply notes "adulthood" as the noun form of the adjective "adult" that is defined as "fully developed and mature; grown-up". By this definition, adulthood would simply be the state of having reached that point of being fully developed, mature and grown-up. But what do terms such as "fully developed", "mature", and "grown-up", mean when used to describe humans? The suffix, "-hood", denotes the state or condition of a certain class of person such as a member of priesthood or motherhood, who is required to meet conditions for recognition as a priest or as a mother. To have reached adulthood, then, requires one to reach the state or achieve the conditions necessary for recognition as one of the class of adults. One who has reached adulthood shares with others those attributes and characteristics recognised as required for identification as an adult. However, the terms used to define the concept "adult" in dictionaries are no less unambiguous than the term "adult" itself. A conceptualisation of maturity to one may not be the same as the conceptualisation of maturity to another. This then leads to the need for a concept analysis to determine a denotative meaning of the term "adult" which may offer empirical indicators of if, how and when one enters into adulthood when one has an intellectual disability that results in the non-occurrence of normatively accepted thresholds of adulthood, such as first union, employment, or parenthood (Robette, 2010; Salmelo-Aro, Kiuri, & Eerola, 2011; Shanahan, Porfeli, & Mortimer, 2004). The question that should be addressed is whether or not there is a consensus on a definition of adulthood that satisfactorily provides for those with intellectual disability. Whether any conceptualisation of adulthood adequately serves young people with intellectual disability is unclear. If there is no workable or mutually agreeable definition, how does this affect relationships between young people with intellectual disability and their parents, and people with intellectual disability and their service providers, and finally between parents and the service providers who support their sons and daughters? This is the rationale for undertaking this research.

1.3 Overview of the study

This chapter offers a context for the study by setting out the dilemma inherent in the use of concepts such as adulthood on which to base services for young people with intellectual disability. It has presented an example of conflict between stakeholders to highlight the possibility that miscommunication and tensions may be drawn from different interpretations of the same words. These tensions are well documented, as will be outlined in the next chapter. The need for further exploration of the conceptualisation of adulthood as it applies to young people with intellectual disability is outlined. This chapter also offers definitions for use throughout this paper.

Chapter Two presents the study’s literature review. This review presents an overview of previous and contemporary parameters for consideration of adulthood within biological, legal, sociological and philosophical frameworks. It considers briefly the experiences of families of young people with intellectual disability during the transition to adulthood. It further explores the shifting paradigms and changing language in the disability sector over recent decades and the impact of these on family and DSW relationships during the transition to adulthood.

The theoretical framework underpinning the findings from this research is presented in Chapter Three. This chapter offers a conceptual framework based on Priestley’s Life Course Approach to Disability theory that outlines relationships between individuals and their community, and the relationship between nominalist and realist approaches to disability (Priestley, 2003a). A modified model presents a framework within which one may consider the concept of adulthood of young people with intellectual disability, offering four positions or domains, namely Biology, Identity, Society and Culture. Priestly describes his Life Course Approach to Disability as similar to the idea of generational location, in which generational identities may be recognised through the agency of individuals, and regulated through dialogue on “normal” life stages and progression. These stages are then governed through social policies and institutions, such as family, work and welfare. The idea of independent adulthood lies at the heart of a life stage perspective, with other categories, such as childhood, old-age or disability, seen as exemptions, or “non-adult” stages when relationships of power and conflict relegate individuals to positions outside the cultural mainstream.

The fourth chapter outlines the research design for this study. It provides a detailed description of the methodology, and how the research design corresponds to the context of the research topic and the research question. It describes the use of concept analysis applied to qualitative data collection, in order to investigate the phenomenon of adulthood as it is understood by research participants, comprising parents and DSWs from a range of disability services. It includes a focus group of 13 young people with intellectual disabilities aged 18-21, offering a voice for those transitioning beyond the secondary school system. This chapter provides details of participants, the recruitment method used in this study, the participant numbers, data collection methods and data analysis procedures. It outlines how the research evolved to include input from young people with intellectual disability. The voice of the young people, and their perspective on themselves as adults was a necessary addition to the research. The disability sector demands research address the paucity of opportunities for people with intellectual disability to offer opinions on aspects of research that directly impacts them (McDonald, Kidney, & Patka, 2013). This mandate was answered through a focus group of young people with intellectual disability on the concept of adulthood, and their understanding of this term.

The findings from the research are presented in three chapters: Chapter Five, Chapter Six, and Chapter Seven. Chapter Five presents the findings from the focus group and interviews with parents. Chapter Six presents the findings from the focus group and interviews with Disability Support Workers. Chapter Seven presents the findings from the focus group with young people with intellectual disability.

The mapping of findings from the three groups of stakeholders is presented in Chapter Eight. This chapter, which draws on analysis of the data that culminated in the identification of five key themes, or points of difference between the families interviewed, the data from the Disability Support Workers, and the data from the cohort of young people with intellectual disability. The findings found significant dichotomous viewpoints relative to the ideas that:

- Adults are independent
- Adults are rational beings
- Adult life offers meaning
- Adults are accepted members of society
- Adulthood may be actual or virtual

These key themes are discussed in detail in Chapter Nine, highlighting potential causes of tension between parents and DSWs that arise from different conceptualisations of adulthood, and overlays this discussion with views of young people living with intellectual disability offering their perspective to the debate about whether they are, or perceive themselves as adults. The discussion revisits the key themes identified from the research, and offers research translation of these themes in an attempt to address the question of the adequacy of current definitions of adulthood as they apply to young people with intellectual disability. It examines the consensus on characteristics of adulthood, but outlines those areas where stakeholders' conceptualisations deviate from one another. This chapter further considers whether an alternate definition is possible that would alleviate or dissipate the tension between stakeholders. It describes areas of discrepancy that may elucidate the differences in thinking about young people with intellectual disability and considers how stakeholders might better provide for these young people's transition from school towards a place in community that assumes a more cooperative interaction between parents and DSWs.

The final chapter, Chapter Ten, offers a case study based on a situation that involved a young woman with intellectual disability, whose family and support staff experienced conflict in their interactions with each other. The case study highlights the conundrum currently faced by parents and DSWs when issues of rights are incompatible, or at least at odds with welfare considerations as a result of jarring perceptions of young people as fully adult or otherwise. It then concludes the thesis, offering limitations of this study and offering recommendations for future study.

1.5 Definition of intellectual disability

Explanations of intellectual disability have varied historically from concepts founded on deification to those founded on defectology (Shalock, 2011). Today an intellectual disability is viewed as a disability that results from "significant limitations in intellectual functioning and adaptive behaviour and manifest during the developmental period" (Shalock, 2011 p.228).

For the purpose of this paper the definition of Intellectual Developmental Disorder as outlined in the most recent Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) (American Psychiatric Association, 2013) will be used. The DSM-5 defines Intellectual Developmental Disorder as "a disorder that includes both a current intellectual deficit and a deficit in adaptive functioning with onset during the developmental period".

The definition in the DSM-5 states that all three of the following criteria must be met:

1) Intellectual Developmental Disorder is characterised by deficits in general mental abilities such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning and learning from experience. Intellectual Developmental Disorder requires a current intellectual deficit of approximately two or more standard deviations in Intelligence Quotient (IQ) below the population mean for a person's age and cultural group, which is typically an IQ score of approximately 70 or below, measured on an individualised, standardised, culturally appropriate, psychometrically sound test.

   AND

2) The deficits in general mental abilities impair functioning in comparison to a person's age and cultural group by limiting and restricting participation and performance in one or more aspects of daily life activities, such as communication, social participation, functioning at school or at work, or personal independence at home or in community settings. The limitations result in the need for ongoing support at school, work, or independent life. Thus, Intellectual Developmental Disorder also requires a significant impairment in adaptive functioning. Typically, adaptive behaviour is measured using individualised, standardised, culturally appropriate, psychometrically sound tests.

   AND

3) Onset during the developmental period.

The American Association of Intellectual and Developmental Disabilities (AAIDD 2013) website defines intellectual disability as:

> a disability characterised by significant limitations in both **intellectual functioning** and in **adaptive behaviour**, which covers many everyday social and practical skills. This disability originates **before the age of 18**.

AAIDD notes that those assessing intellectual disability must evaluate limitations in intellectual and adaptive behaviour within the context of an individual's age, peers and culture. Further, a key point of the organisation's definition is that limitations in functioning can coexist with strengths within an individual.

This thesis concerns itself with young people whose intellectual disability was recognised and diagnosed in childhood, and not those whose problems began after this developmental period as a result of a traumatic brain injury from events such as toxic inhalation, or motor vehicle accidents.

Chapter Two
Literature Review

2.1 Introduction

This chapter commences with discussion of characteristics of people with intellectual disability and briefly outlines challenges faced by people living with this diagnosis. It then investigates the literature on concepts of adulthood and outlines the various markers of adulthood that are used in the diverse set of definitions of this phenomenon in relation to people living with and without impairment. This is followed by an exploration of contemporary perspectives on adulthood for young people and an examination of the perspectives of young people in modern society as they approach and pass through the age of 18 and beyond. It explores the spectrum of pathways that young people in general can pursue into life after childhood in contemporary society as presented in the literature. Finally studies around the general population are compared to contemporary literature on those with intellectual disability.

Chapter One outlined the need to consider how young people with intellectual disability are perceived by their families and support workers with regards to their adult status. There is a paucity of research into the conceptualisation of adulthood in the peer reviewed published literature. The need to address this area was recognised by Clegg, Sheard, Cahill and Osbeck (2001) who initially identified the potential gulf between the perceptions of parents and DSWs. In 2011, Murphy, Clegg and Almack (2011) published findings from their study into contrasting definitions of adulthood by those planning futures for young people with moderate to profound intellectual disability. Their study identified two conflicting discourses deployed by parents and support staff when discussing future plans for young people with moderate-profound intellectual disability. The findings showed that while DSWs and some parents positioned young people unequivocally as adults, most parents were reluctant to support their son’s or daughter’s right to self-determination, placing them “in a space between childhood and adulthood” (p. 71). Parents prioritised values of care and protection of their sons and daughters over the insistence on autonomy and self-reliance expressed by Transition Coordinators employed by local authority social service departments. These Transition Coordinators saw self-determination as central to adulthood, and an imperative to be addressed for young people with intellectual disability. These DSWs defined adulthood by biological age, acknowledging 18 as a point where parental responsibility was assumed to finish. Clegg et al. (2001) believe that a factor in this is that the paid disability support sector has a culture that places the adult autonomy of individuals with intellectual disability above relationships with, or wishes of, parents, and often without formal recognition of the active support role many parents do and are expected to continue to provide. Clegg et al. (2001) recognised that this systemic issue needed to be addressed by policy initiatives, as it could not be ameliorated by individual Disability Support Workers (DSWs) who are professionally bound by policies, organisational procedures, missions and values. Clegg et al. (2001) suggest that while much research has been undertaken into the institutional transition from school to adult services for young people with intellectual disability, the psychological transition has attracted little attention. Murphy et al. (2011) explain that the alternate moral positions noted by parents and DSWs are important to explore in more detail, as:

> promoting all of those who reach the age of majority to unqualified self-determination, irrespective of their capacity to reflect critically and rationally may mean abandoning the most vulnerable in our society to the consequences of choices made with only limited understanding of their implications (p. 72).

This review of the literature will highlight the gaps in this area of research, and explain why further research into the ways stakeholders perceive young people with intellectual disability as adults or otherwise may explain tensions, and have the potential to contribute to the development of policies that improve the transitional experience for all involved.

2.1.1 Characteristics of people with intellectual disability

While it is germane to use a strengths-based perspective in any description of disability, and also to be sensitive to the potential of deficit-based statements to negatively depict those with disability, for the purpose of this paper it is also necessary to acknowledge the variances between those with intellectual disability and those without. Taking a strict social model definition of disability that considers disability as based within society, and not within the person themself, may not be useful in the context of this study. Contemporary literature and policies often attempt to dedifferentiate people with specific disabilities, and include those with intellectual disability in a generic grouping of “people with disabilities” to highlight what those with intellectual disability have in common with others with disabilities (Bigby & Clement, 2010). However Bigby and Clement (2010) explain that such dedifferentiation, while arising from the dominance of an individualised perspective, suggests that people living with impairments are a homogeneous group and ignores the specific strategies that are required to support individuals with different support needs to achieve individualised and person-centred outcomes. To reflect on the concept of adulthood for those living with intellectual disability requires the articulation of the distinct characteristics and issues faced by individuals with intellectual impairments. The description below is offered for the purpose of providing a framework within which to consider the findings of this research.

The capacity of those with intellectual disability to develop to a post-formal stage of thinking and problem-solving involving higher level logic than Piaget’s stage of formal operations is potentially problematic, by definition (Commons & Richards, 2003). Such expectations would be contrary to the very definition of intellectual disability offered in the DSM-5 (American Psychiatric Association, 2013) that recognises the significant deficits in “reasoning, problem-solving, planning, abstract thinking, judgment, academic learning and learning from experience”. Wehmeyer et al. (2014) explained that in line with contemporary social model thinking, intellectual disability is currently conceptualised as a poor fit between a person’s capacities and their context. The authors describe educational and supportive services that apply Universal Design for Learning to offer interventions to enable people with intellectual disability to live and learn effectively in their communities. However, educational pedagogies developed to accommodate specific teaching and learning considerations suggests the underlying intellectual disability is a permanent attribute, which can be accommodated, but not fully eliminated. As such, the need for lifelong support in some areas of the life of people with intellectual disability is a recognised likely outcome within the disability sector (Wehmeyer, 2014).

Inherent in the diagnosis of intellectual disability is the permanence of the diagnosis, and alongside the assumption of the potential for growth and development in areas of independent living and functional skills, is the recognition of the impairment in adaptive functioning and the permanent limitations in one or more aspects of daily living (American Psychiatric Association, 2013). Studies of executive functions in people with intellectual disability note issues with speed of accessing lexical items, difficulty with working memory-related executive control at encoding, difficulty in categorising materials according to self-generated organising principles, and difficulties with inhibition and planning (Danielsson, Henry, Ronnberg, & Nilsson, 2010). As noted in Chapter One, the definition of Intellectual Developmental Disorder found in the DSM-5 states that people with intellectual disability are identified as having:

> … deficits in general mental abilities [which] impair functioning in comparison to a person’s age and cultural group limiting and restricting participation and performance in one or more aspects of daily life activities, such as communication, social participation, functioning at school or at work, or personal independence at home or in community settings.

These impairments need not define the person with intellectual disability, but they are defining attributes of intellectual disability. In earlier times David Wechsler, best known for developing several widely-used intelligence tests, including the Wechsler Intelligence Scale for Children (1949) and the Wechsler Adult Intelligence Scale (1955) defined intelligence as “the aggregate or global capacity of the individual to act purposefully, to think rationally and to deal effectively with his environment” (Plucker, 2003). Within both definitions, intelligence is closely aligned with social interaction, and engagements in community environments. In general terms, intellectual disability is defined as reduction in intellectual capacity in areas such as learning, reasoning, and/or problem-solving, with reference to adaptive behaviours in conceptual, social or practical skills. Common characteristics include difficulties understanding concepts of language and literacy, money, time and number, and the possibility of social naivety that can leave people with intellectual disability vulnerable and open to abuse. Social ineptitude may also impact on interpersonal relationships and present difficulties with social responsibility, problem-solving, and an understanding of both legal and social rules of behaviour (Parmenter, Harman, Yazbeck, & Riches, 2007). People with intellectual disability may encounter difficulties with activities of daily living such as personal care, vocational skills, accessing community facilities (transport, for example) along with difficulties with skills and understanding of the use of money, timetables, telephones or computers (Einfeld & Emerson, 2009).

It is acknowledged that within a social model of disability, disablement is seen to result from the way a society is organised, and asks that barriers to life choices be removed. The differences between people identified with intellectual disability and the population without impairment is presented here to focus this study on factors that represent individuals with intellectual disability as a heterogeneous and not homogenous group with the propensity for a more diverse lifespan development trajectory. However, it is still apposite to explore the concept of adulthood within general sociological studies to set a framework for the consideration of the concept and its application for those with intellectual disability.

2.2 The challenge of defining adulthood

The study of adult development received relatively little attention in sociological studies until Erikson in the 1950s developed his theory of stages in ego development which extended beyond the end of the adolescence and identity development, through three more stages that reflected a life course, or life cycle, rather than suggesting that development was completed once adolescence had concluded (Levinson, 1986). Erikson's theory led others, such as Marcia (1980), to offer various pathways and profiles that could be used to define the status of adulthood using identity exploration, commitment and achievement as measures of adulthood. Yet, even within a life course approach to development that abandons the idea of stages being linked to chronological age, the search for a measure of adulthood has continued.

Definitions of adulthood continue to be nebulous and illusive, and subject to the perception of the observer and the context in which membership is questioned. While definitions of the term “adult” can be found in dictionaries to include the idea of “a person who is fully grown or developed” (Allen, 2004), equally one finds complementary references to more social determinants. These include reference to those who have reached the socially accepted age of majority, or those who are determined by some cultural criteria as emotionally or mentally mature. Alternatively, the term can be used as an adjective to describe objects, places or situations as unsuitable for children, such as sexually explicit material in terms such as “an adult movie”. Indeed the idea of adulthood seems fundamentally linked to the need to make some categorical distinction between children and adults, but the need for this differentiation differs depending on whether one is making the judgement for biological, legal, social or cultural reasons.

The defining attributes, or the actual essence of “adulthood” is elusive. Blatterer (2005a) asks: “Are 35-year-olds who (still) live with their parents, ‘grown-up’? Is a childless 28-year-old single woman, who drifts from job to job, an ‘adult’?” Blatterer (2005a) acknowledges that many contemporary writers suggest that today's youth (often termed “kidults”, “adultescents”, or “delayed adults”) are in a state of prolonged adolescence and therefore not quite adults. However he poses the question that if adulthood can be delayed, what, then, is adulthood? Often in contemporary literature our current Generation Y young people are likened to boomerangs, leaving home on numerous occasions, only to return to the family home equally frequently, relying still on their parents well into their 20s for financial and emotional support (Arnett, 2000; Arnett, Ramos, & Jensen, 2001; Blatterer, 2005a; Salmelo-Aro, Kiuri, & Eerola, 2011; Urry, 1998). Blatterer (2005a, p. 1) offers:

> What is this adulthood against an understanding of which we pass such judgements, and at what point of the life-course does it begin? Despite the fact that we all take adulthood for granted, neither society nor its experts provide answers to such questions.

Blatterer (2005a) argues against the idea that adulthood is being delayed, or that adolescence is being prolonged. He believes rather that the essence of adulthood has changed, and that there is a need to redefine contemporary adulthood in view of how young people are adapting to a world that no longer provides stability and security through its labour market. Casualisation of the workforce means long-term full-time work can be out of the reach of many, with parenting and home ownership being delayed until well into the 30s for many young people. The traditional heterosexual nuclear families are no longer prevailing as the ideal adult living arrangement. As a result of these social changes the traditional objective markers of adulthood, such as independence, family and work, are often unachievable for young people until later in their life course than has traditionally been the case. But Blatterer (2005a) argues it is the disconnection between contemporary social forces and the traditional association of adulthood with stability in its various forms that makes adulthood appear to be delayed or postponed. He does not believe that young people do, in fact, delay adulthood, as to do so would be to delay personhood.

2.3 Measure of adulthood

While in non-Western cultures, adulthood is usually marked by a socially defined event such as marriage, Arnett and Taber (1994) believes that in Western cultures the “entrance to adulthood is defined and marked individually” (p. 517), based on achievement in independence, both financially and in living arrangements, along with “attainment of cognitive self-sufficiency, emotional self-reliance, and behavioural self-control”. He highlights that this process is a gradual one, which he believes may take many years. Blatterer (2005a) also explains that the classic markers of adulthood have traditionally been independence, family and work, but believes that with social trends resulting in these markers taking longer to be reached, the transition to adulthood is now more like a deferral of adulthood. Yet, as adulthood is a *sine qua non* of full personhood, it may be still necessary to try to offer a point at which adulthood is likely to emerge. Blatterer (2007, p. 779) writes:

> The very centrality of adulthood goes hand in hand with a particular ideology that is vital to the experience of not only adulthood, but to the experience of childhood and old age as well: the equation of adulthood with full personhood.

This ideological dominance was investigated by Hockey and James (1993, cited in Blatterer 2009, p. 58) through their study of forms of marginalisation based on age and ability. More recent authors concur that personhood is symbolised through autonomy, self-determination and choice, and agree that these are the essential qualities of full personhood, a requirement for full membership of society (Berry & Hardman, 1998; Billari, 2001; Kittay, 2005; Peterson, 2014; Ribbens McCarthy, 2012). The authors also explain that these aspects are “edited out” of conceptualisations of childhood or old age. Priestley (2003b) adds that they are also edited out of the conceptualisation of disability, leading in the same way to a perception of the person with a disability as a non-person. There are many terms used to describe this period of what might be regarded as "arrested adulthood", "youthhood", "half-adults", "perpetual adolescence", or "KIPPERS (Kids in parents' pockets eroding retirement savings)" (Cote, 2000, cited in Blatterer, 2005b, 2007), which are marked by predisposition to avoiding commitments. However, Blatterer (2005b) explains that such judgements use an implicit or "taken-for-granted" standard of adulthood as a benchmark for the measure of adult status:

> Its taken-for-granted status is evident in the representations and practices through which it is reproduced: working nine-to-five and beyond, dinner parties, jury duty and voting, marriages, mortgages and children, the family sedan, adultery and divorce, investment portfolios, retirement plans, life insurance, writing a will, and so forth. (p. 1)

The question then, in the absence of clear guidelines, is how to define those people who meet some of the "taken-for-granted" criteria for adulthood, but not all. For example, to Michael Jackson's biographer, he was "the man who was never a child and the child who never grew up" (cited in Buckingham, 2012). Buckingham also notes the intrigue in recent times by Hollywood film producers with the figures of child-like adults, in films such as Forrest Gump, I am Sam, Toys, and Dumb and Dumber. Such movies depict the inherent dilemma of those with disability trying to live in today's society, but who struggle with the expectations to be self-sufficient, responsible for themselves and others, and to live by society's unwritten rules. In the absence of explicit and unequivocal parameters, the question of the achievement of adulthood status remains one for further analysis in general terms, but offers a greater challenge when young people present with diverse needs that require particular deliberation and accommodation.

The last 20 years have seen a move towards "dedifferentiation" of people with intellectual disability from the broader category of people with disabilities (Clement & Bigby, 2011). This move has been associated with the promotion of social inclusion through the use of generic, mainstream services. While there has been a shift to discourses on disability that focus on "sameness" (Quibell, 2004), little can be found in the literature that connects modern determinants of adulthood for those with intellectual disability to those without disability. The question may be whether, in deliberations of the new stage of emerging adulthood, it is assumed that those with intellectual disability travel parallel pathways to their peers without intellectual disability. To this end one could expect them to take longer to bridge the divide between childhood and adulthood. However, as will be discussed further, for individuals with intellectual disability the transition to having adult status can be rapid and contemporaneous with the end of the compulsory school years, not the extended period that is assumed for those without intellectual disability. As Fyffe, Pierce, Ilsley, and Paul (2015) explain, disability policy (as opposed to carer policy) emphasises independence from family as the only way to "live like other citizens" (p. 75), and DSWs can be impatient to ensure this shift occurs. When a physical move may not be available, then some emotional or social independence can be promoted in an attempt to ensure "sameness" to other young citizens.

2.3.1 Adulthood/personhood as a measure of independence and autonomy

The notion of independence, suggesting a reduced need for protection, support or assistance as a mark of maturity and attainment of adult status has permeated through the centuries, with transition to a stage of independence generally recognised as a process. There is little agreement across cultures as to when children cross this threshold as a measure of entry into adult life. The term "independent" is subjective, and open to interpretation, with few people truly independent of others, such that they could live without some relationship with others in a social world. In relation to those with disabilities, Brisenden, himself living with vision impairment, (2000, pp. 26-27) explains:

> We do not use the term "independent" to mean someone who can do everything for themselves, but to indicate who has taken control of their life and is choosing how that life is led. … The most important factor is not the amount of physical tasks a person can perform, but the amount of control they have over their everyday routine.

Thus Brisenden suggests independence for those living with disability is considered as a point where they control the support they receive, when they choose to receive it, and from whom they choose to receive it.

Irwin (1999, p. 692) explains that "independent adulthood is the key to inclusion and relative advantage, whilst youth and later life are characterised as socially disadvantaged or marginalised positions". The reliance on other persons for support to carry out tasks of everyday living is commonly recognised as a mark of dependency, generally considered to be the mark of children and frail older people. Park (2009) calls these stages "pre-person" and "former person" stages, identified as times when people may lack consciousness, memory, language or autonomy. Many authors note the lack of autonomy by people with intellectual disability as a barrier to their consideration as full adults or to moral personhood (McMahon, 1996; Singer, 1994). Priestley (2003a) simply adds disability to the mix of non-adult categories, noting that while people with intellectual disability may be included in an age-based definition of adulthood, they stand to be excluded from the rights and responsibilities that are normally associated with adult social status. Priestley (2003a) notes that "adulthood remains relatively under-theorised as an analytical or critical concept", suggesting that our understanding of this concept may be defined "less by intrinsic adult qualities than by the shifting boundaries of neighbouring categories like childhood, youth, old age and disability" (p. 117).

2.3.2 Independence and health care needs

Those living with intellectual disability experience general health problems similar to the general population of people without disability, however many young people with intellectual disability have associated health care issues. May and Kennedy (2010, p. 4) identify some of these as "motor deficits, epilepsy, allergies, otitis media, gastroesophageal reflux disease (GERD), dysmenorrhea, sleep disturbances, seizure disorders, mental illness, vision and hearing impairments, oral health problems, and constipation". Rehm, Fuentes-Afflick, Fisher, and Chesla (2012) explored the transition to adulthood of 64 youth with developmental delays and associated health care needs and their parents, with findings indicating that adulthood by these families meant “functioning as independently as possible with appropriate supports”. Transition to adulthood for these young people was associated with developing independence and the ability to self-care, of at least the establishment of individualised support networks. Similar ideology led the development of the National Disability Insurance Scheme in Australia, resulting from the paradigm that people who require support are somehow less entitled to higher status in the community (Warr et al. 2017), but this still does not adequately address the question of when someone has achieved adulthood status. Rehm et al. (2012) reported that parents universally assumed they would remain involved in the lives of their sons and daughters during adulthood, hoping for a gradual reduction in responsibility, and more freedom for both themselves and their sons and daughters. One mother in the Rehm et al. (2012) study noted that she did not believe her job “as a mom” would ever end, assuming she would always have some support needs for which she would be required. The authors explained that the concept of adulthood had cultural overtones, with participants of African American and Asian descent envisioning interdependence and ongoing cohabitation with their sons and daughters as normal and preferable to institutionalisation.

2.3.3 Adulthood as a legal framework:

One social system in which the concept of adulthood would seem, superficially at least, relatively straightforward and easy to define is the legal system. In their broadest sense, laws are considered to be the framework in which a society functions. Laws exist in order that individuals can cooperate and live in social cohesion (Morrison, 2006). Laws describe acceptable behaviour, aimed at protecting members of a community from harm, and ensuring their rights are met. Laws are assumed to reflect the values and attitudes of the majority of members of a community, and also reflect the changes in public values and attitudes over time (Fitzroy Legal Service, 2010). Australian law signifies the transition from childhood, during which a person may be considered to be legally incompetent, to adulthood, with corresponding legal responsibilities for many aspects of life (Mathews, 2000). Laws dictate the ages at which individuals may seek license to drive, marry, smoke, purchase some items, travel abroad without parental permission, imbibe alcoholic drink, enter certain buildings unaccompanied, offer consent to medical procedures, or vote in elections. Mathews explains that these “changes in legal personality are not catalysed by merit or personal characteristics, but by the expiry of a span of time from each individual’s date of birth” (p. 27). Such a change does not account for variance in physical, emotional, psychological or intellectual development, and as such, according to Mathews (2000), may confer rights and impose responsibilities at times that are not appropriate to the developmental stage of many individuals. In a paper on children’s criminal responsibility in Australia, Mathews offers that it is “theoretically impossible and morally unjustifiable to measure criminal responsibility only by age” (p. 27).

A concept of legal adulthood is communicated, for the most part, as meaning the legal age of majority, with the bestowing of rights and obligations on legal citizens. Reaching this chronological age of majority offers a legal threshold to adulthood. It equates to the chronological point when minors are no longer legally considered as children, instead assuming control over their own actions, when the legal control and responsibility of parents or guardians no longer applies without intervention.

Joseph Goldstein, in an article on "Being Adult in Secular Law" (1978), considered the first and foremost criterion for adult status as chronological age, suggesting that the rite of passage in secular law from childhood to adulthood is simple, certain and easy to establish. He stated that once the statutory age of majority is reached, one is considered "independent" of parental control and protection, and is presumed competent to take care of oneself, and to be responsible for one's own person, one's actions and decisions. The law presumes that children under 18 are legally incompetent, and therefore parents, as their guardians, are called upon to make all-important decisions for them (Phelp & Lehman, 2005). At the age specified by law as the legal age of majority, a person acquires the full legal capacity to be bound by various documents, such as contracts and deeds that he or she makes with others. The person is no longer under the legal control, nor the legal responsibility of their parents or guardians (Australia Law Reform Commission, 2014). The age of majority has little to do with cognitive development or physical maturity, but is rather a legally static date at which point various laws bestow adult status on a young person. The United Nations Declaration of the Rights of the Child – Article 1 (United Nations, 1989), states that a child is any human being below the age of 18 years, "unless under the law applicable to the child, majority is attained earlier". At the age of majority in whichever jurisdiction they live, a person is no longer legally deemed to be a child.

However, the presence of intellectual disability raises the question of mental competency to assume legal rights normally bestowed upon adults who reach the legal age of majority, despite attempts by the United Nations to elaborate the rights of these people and establish a code of implementation that secures their rights, and counters any practices that could be considered discriminatory (Gooding, 2015).

2.3.4 Adulthood as a measure of capacity and decision-making

As already noted, within Australian jurisdiction, as well as in many countries, young people, at age 18, are assumed by the legal system to be "legally" adults, and offered the right to henceforth make their own decisions and choices. For those with intellectual disability, however, this assumption raises the issue of capacity. Despite reaching the age of license for many adult opportunities, people with intellectual disability may be disadvantaged by the question of capacity. The issue of capacity has been under review over the past 10 years. In trying to define capacity, the New South Wales Privacy Commissioner writes:

> A person has capacity if they are able to understand the general nature and effect of a particular decision or action, and can communicate their intentions or consent (or refusal of consent) to the decision or action. (Privacy New South Wales, 2004, p. 5)

The office of the NSW Privacy Commission in 2004 explained:

> There is no "one size fits all" test for whether a person has capacity in a given situation. Assessing a person's capacity involves making difficult judgements and considering complex issues. (Privacy New South Wales, 2004, p. 5)

The Commission further explains (p. 6):

> A person may not have the capacity to make decisions about certain aspects of their lives but retain the capacity to make decisions about other matters. For example, a person may not be capable of making decisions about their financial affairs or major medical treatment, but still have capacity to make decisions about basic health care and their lifestyle generally, such as where they want to live and who they want to share this information with.

In its best practice guide on privacy and people with decision-making disabilities, Privacy New South Wales outlines a number of points relative to capacity and decision-making by those with disabilities, namely that:

1) Capacity can vary widely amongst people with the same disability, and that any two people with an intellectual disability may have significantly different degrees of capacity (Privacy New South Wales, 2004).

2) Capacity may change over time and can increase as well as decrease (Privacy New South Wales, 2004).

3) Capacity should be judged relative to the nature of the decision under consideration (Privacy New South Wales, 2004).

4) Capacity may be dependent on the support available to the person making the decision, and whether such support allows them to exercise their capacity (Privacy New South Wales, 2004).

5) Capacity may be influenced by perceptions of culture and linguistic background (Privacy New South Wales, 2004).

6) 'Bad' decisions may be viewed by support personnel as indicative of a lack of capacity. "To have capacity, a person does not need to make what other people might regard as a 'good' or 'right' decision, or a decision that may be in the person's best interests" (Privacy New South Wales, 2004 p.7).

In England and Wales, the *Mental Capacity Act 2005* came into force in 2007 to provide a framework for decision-making by those who were deemed to lack capacity to make decisions for themselves. As outlined by Herissone-Kelly (2010, pp. 344-345), this act operates under five main principles:

1) A person must be assumed to have capacity unless it is established that he lacks capacity.

2) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success

3) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

4) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

5) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Herrisone-Kelly reiterates the point that is made in the *Mental Capacity Act 2005*, which was written by the NSW Government in 2004, that:

> We are not to assume that a person lacks the capacity to make a certain type of decision just because she makes a decision of that type that is unwise. Clearly, this principle acts as a check on paternalism. Equally clearly, it mirrors the distinction between substantive autonomy (determined by reference to the output of a piece of practical reasoning, i.e., by reference to the decision itself) and procedural autonomy (determined by reference to the nature of the reasoning that underlies a decision)" (p. 345).

Capacity is an assessment of the ability to make a decision, not the decision itself (Fogarty, 2009). In a paper prepared for the Intellectual Disability Rights Service (IDRS), Ben Fogarty, the Principal Solicitor for the service, writes:

> Just because a person does not agree with the decisions another person is making on moral, religious, political or opinion-based grounds, this should, in no way bear upon an inquiry into the latter's capacity. If a person wants to spend their money on sex services on a weekly basis or they want to have a certain boyfriend or girlfriend, they should be entitled to do so. IDRS has been contacted by parents of adult children with intellectual disability, saying they want to gain guardianship to stop their children associating with a person or spending their money on sex services. These are not, in and of themselves, proof that the child lacks legal capacity (p. 11).

However McKenzie and Watts (2011) point out that people involved in the daily lives of those who may lack decision-making capacity, and who may be considered legally incompetent, must decide whether to respect their decisions as competent, or to disregard their decisions on the grounds of incompetence and to act in the person's best interests. Despite reaching a chronological state of legal adulthood, one's perceived incompetence may deem them ineligible for many rights of legal adulthood, including being able to make one's own choices across all facets of life (McKenzie & Watts, 2011).

2.3.5 Adulthood and guardianship

The current philosophy on guardianship, financial management and decision-making for people with decision-making disabilities recognises that some impairment in their ability to make decisions does not mean they cannot make decisions for themselves (Fogarty, 2009). Because of the recognised impairment of capacity to reason and problem solve rationally, it has been woven into each state's guardianship legislation that people with intellectual disability and, therefore, reduced ability to make rational decisions, be authorised to receive assistive, supported or substitutive decision-making support when the question is significant or has legal consequences (NSW Government, 2008). Whether this support is assistive, when the young person's capacity to make their own decisions is considered impaired, or substitutive, when they are deemed incapable of making decisions, professionals may intervene in issues of finances, health, personal living arrangements, self-determination, along with issues of rights. While acknowledging that some people need help and support sometimes, the presumption is made that people with decision-making impairments are able to make many decisions in their lives and that decision-making is on a spectrum which sees autonomy at one end, with substitute decision-making at the other.

The idea of substitutive decision-making is partially based on the notion of cognitive inferiority, and is largely challenged in more recent legal arguments (Flynn & Arstein-Kerslake, 2014). With the introduction of the concept of legal capacity and its relationship to personhood, the rights of all persons to legal status, and to have legal agency are recognised by the state (Flynn & Arstein-Kerslake, 2014). The human rights perspective of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) requires states to recognise individuals' rights to legal capacity, regardless of any disability. This perspective promotes supported decision-making which identifies a trusted person or group of people who can support a person with intellectual disability to indicate their will and preferences. Support for decision-making does not require a formal guardianship arrangement, with informal supports available through trusted friends or family. This is considered preferable to more formal arrangements. Fogarty (2009) explains, though, that there are times when it becomes necessary to make more formal arrangements for the guardianship and financial management of people with reduced capacity. In the various states of Australia this may involve public trustees, offices of the adult guardian, protective commissioners or public advocates. It can also involve parents. Parents of young people with intellectual disability can seek to become their son/daughter's legal guardian, once the young person has turned 18 (Australian Government Department of Social Services, 2014).

For the purpose of this thesiss, the *Guardianship and Administration Act 1986* (GAB Act) (Victorian Government, 1986) is used to illustrate the purpose of guardianship provisions for people with impaired decision-making capacity. The Guardianship and Administration Act 1986 has been subject to recent review by the Victorian Law Reform Commission. The Act, under which a guardian or administrator may be appointed to support a person's decision-making as a result of their impaired or reduced capacity, operates under three basic legislative principles;

1) The means that is the least restrictive of a person's freedom to make their own decisions and choices in terms of their actions is always preferable,

2) The best interests of the person who is being supported should be paramount, and

3) Their wishes should be respected wherever possible.

However, it is acknowledged that these principles may be in conflict, and thus the role of the guardian is to find a balance between the dichotomous positions, such as the need to protect vulnerable adults, while maintaining their autonomy; to allow people to take risks and assume their rights, while bearing in mind their vulnerability; and allowing as much freedom as possible, while noting the risks inherent in this liberty (Carter 2010a).

The concept of guardianship is to make “a meaningful, beneficial difference in the life of a person with a disability” (Carter 2010b), but Carter explains that legislation “pays great attention to process, but pays little attention to the desired outcomes”. Carter (2010b) argues for there to be just one overarching principle which guides any intervention in a person’s life, and that should be the provision of a just outcome for people with disabilities, with a particular focus on human dignity. She believes the concept of human dignity should be the governing principle, but adds a complementary operational principle—that of personal and social wellbeing. Thus Carter poses a framework for fostering dignity and wellbeing as the guiding principles for the decisions of the Guardianship and Administration Board. But such a framework is still open to some interpretation. Despite the guiding principles, the end result may be the deprivation of decision-making opportunities of people despite their capacity, with caveats on the right to make decisions perceived to not be in one’s best interest, such as overindulging in alcohol, sleeping in, or eating too many doughnuts(!) (Bannerman, Sheldon, Sherman, & Harchik, 1990).

Bannerman et al. (1990) explain that while in a legal context “personal liberties include freedom of speech, freedom of religion, and other rights guaranteed by the [US] Constitution” (p. 80), other personal liberties such as being left alone, to do what one pleases, or to be free from coercion when choosing between options may be compromised by parents or service providers because of their own interests of time, money, protectiveness, and preference, rather than the choice of the person with an intellectual disability. Since the introduction of the UNCRPD in 2006 with subsequent debate on legal capacity and the concept of supported decision-making, this interference should be minimised. Flynn and Arstein-Kerslake (2014) explain that “[a] support person has a responsibility to assist the individual in getting to a place (physically and psychologically) where her decision-making capacity is optimal” (pp. 98-99), but highlights that this does not permit a support person to act against the explicit instructions of the person. Flynn and Arstein-Kerslake highlight that throughout any interactions in supported decision-making, the goal must remain the will and preference of the individual with intellectual disability, unless their actions involve self-harm. In such cases the support model can allow interference within the broader social contract that assumes no individual prefers to be harmed, and that the person would like assistance in ending this harm. However, the authors further explain that if a law is not being broken, and an individual expresses their wish to remain in a harmful situation, such as an abusive relationship, their decision must be respected, just as it should for others without disability making the same choice.

While the freedom to make decisions, even those that may have adverse consequences, is fundamental to the principles of autonomy and self-determination outlined in the UNCRPD (Carney, 2015; Ells, 2001;

Meininger, 2001; Radoilska, 2011; Radoilska & Fistein, 2010), this freedom is not always supported by family positioned to support their family members or DSWs positioned to support clients (Barron, 2001; Petner-Arrey, 2011). This rejection of the person's expressed preferences still appears prevalent, despite assertions from authors such as Lotan and Ells (2010) that the active participation of persons with intellectual disability is pivotal to ethical decision-making. Petner-Arrey's (2011) PhD research highlights many examples of the exertion of subtle control by disability support professionals such as the case of David who wanted to go for walks, but instead was always taken in the car, or who wanted to visit K-Mart, but was always taken to Wal-Mart instead. Petner-Arrey's research found that although DSWs advocated on behalf of their clients, "they also engaged in subtle, pervasive, obvious and overt control over people with intellectual disability" (p. 179).

2.4 The social construction of childhood and adulthood

In response to the demographic shifts in the transition to adulthood in the Western world, researchers in sociology and psychology such as Erikson (1950), Buhler (1972), Levinson (1976), Maslow (1966), and Valliant (1993) have in recent times proposed alternative models of adulthood characterised by individualistic characteristics. Buhler, for example, presents adulthood in terms of intentionality, goal setting, and self-actualisation. She describes intentionality as a developmental process of choosing one's life goals, working towards them, evaluating achievements and then revising or setting new goals in order to fulfil one's human potential for self-actualisation and self-determination (Peterson, 2014). Levinson proposed an early adult transitional phase lasting from age 17 to age 22, followed by an early adulthood stage up to the age of 28 (Levinson, 1986). Arnett (2004) suggests this stage may continue beyond 28, even into the early 30s, and finds that "emerging adults" define adulthood according to criteria such as taking responsibility for oneself, making independent decisions, and becoming financially independent. However, according to Park (2009), before being able to answer the question of when a child crosses the line to become an adult, we need to know who is drawing the line and why. Only then, he contends, will we be able to decide when children become adults. Park reminds us, for example, that within the Roman Catholic Church, children are considered capable of committing a mortal sin at age seven if it is possible they understand the consequences of their actions, while in Judaism, young people are considered to be adults at age 13. Even when the concept of responsibility is added to the equation for adulthood, the question may be one of "responsibility for what?" The US Constitution decrees that a man needs to be over the age of 35 to assume responsibility for governing the United States (The US Constitution with Declaration of Independence). Conversely one may be deemed by medical practitioners to be sufficiently "adult" to take responsibility for decisions relating to their sexual activities at age 15 (2007). The elusive nature and arbitrary depiction of attributes that describe a point in time when one has met the requirements for entry into adulthood present an obscure platform from which to make this judgement.

A perception of adulthood is clearly prejudiced by factors such as relationships, both personal and professional; social structures that support legal positions; cultural beliefs; and biological development. To the legal fraternity, by and large, young people enter adulthood on their 18th birthday. To social scientists such as Levinson, Buhler, Erikson or Arnett, the process of becoming an adult is recognised as a series of transitions, rather than as a function of chronological age, and to medical scientists, the biological adult status of a person reflects their full growth to a point of reproduction (Blatterer, 2005a; Ferguson & Ferguson, 2000; Hendey & Pascall, 2001; McGee Green, 2008). As noted earlier, to many ethicists the concept of adulthood is closely linked to the idea of personhood, with considerations of autonomy, consciousness, memory and self-awareness featuring in such deliberations (Park, 2009). The issue of moral personhood is a topic of much debate within the field of disability, with Piaget (see, for example, Piaget 1953) and Kohlberg (see, for example, Kohlberg, 1976) proposing that sufficient cognitive development is necessary before the development of moral capacity can be realised (Peterson, 2014). Without an understanding of why acts are considered “wrong”, then obedient or compliant behaviour cannot be considered moral or ethical. Nussbaum (2009) argues that all persons are entitled to consideration as full adults by virtue of their humanity, while others have argued that the capacity to be autonomous is necessary for gaining adult status (Singer, 1994). While ethicists such as Nussbaum, Park and Singer may offer apparently clear determinants of adulthood or personhood, how such defining attributes impact or are acknowledged by those who support young people with intellectual disability in a more practical sense has not been widely explored.

The nature of a modern Western society requires us to categorise its population to meet with the arrangements it has structured (van Krieken, Habibis, Smith, Hutchins, Martin, & Maton, 2013). Sociologists are interested in the relationship between social categories, such as age or gender, and how these affect people’s perception of themselves and the relationships between categories. Identities are built on categories (age, sex, ethnicity, gender and so forth) many of which are social constructions (Jenkins, 2014). The way societies construct who we are, or who we see ourselves as, is not rigid or fixed, but a dynamic feature of social life. Whether we see ourselves as children or adults reflects the social structures and declarations that are acknowledged and accepted by the members of the society (Jenkins, 2014; van Krieken, Habibis, Smith et al., 2013).

2.4.1 Defining children

Under the United Nations Declaration of the Rights of the Child first adopted by the General Assembly in 1959 (adopted in 1989 by the UN General Assembly as the Convention on the Rights of the Child), the definition of child includes “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier”. Within the Declaration of the Rights of the Child, it is recognised that “the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth”. Children are offered a convention of rights and strict protection in the face of their perceived vulnerability. Throughout history, children have been perceived to be defenceless, and in need of protection. Under the United Nations definition, the age 18 is a point at which childhood is presumed to cease.

However, there have also been a multitude of theories of childhood that have permeated cultures over time, including authors such as Darwin, Freud, Tiedemann, Popper and Preyer, to name but a few (Craighead & Nemeroff, 2004). Cleverley and Phillips (1987, p. 4) explain that observers of children adopt "loose theoretical frameworks" of reference similar to those of models in physical science, and these have evolved over the centuries. The authors describe how in medieval France, the concept of childhood did not exist "as a stage distinct from adulthood" but instead children were simply seen as small adults. During the 16th and 17th centuries, however, a new framework developed in which the distinct stage of "childhood" emerged. During this time, children were recognised as different to adults, and various customs and institutions evolved, such as distinctive clothing for various stages of childhood, children's games, and institutions for children's education. Cleverley and Phillips (1987) cite Lloyd de Mause (1975) as exposing the history of children to include beatings, sexual abuse, and terror, but claiming that each generation marginally improves the raising of children. This highlights to Cleverley and Phillips that the conception of children has changed over the centuries. They emphasise that the views we now take for granted about the differences between children and adults, and the role of the family in child rearing, may all have developed fairly recently, but in turn are unlikely to last forever.

John Locke, in *An Essay Concerning Human Understanding*, defends the fundamental belief that humans are born without innate ideas, and thus must derive their knowledge entirely from "external, sensible objects, or about the internal operations of our minds, perceived and reflected on by ourselves" (Locke, 1689 Bk 1, Ch 2 p.63). This belief in tabula rasa leads Locke to argue that:

> Children commonly get not those general Ideas [of the rational Faculty], nor learn the Names that stand for them, till having for a good while exercised their Reason about familiar and more particular Idea, they are by their ordinary Discourse and Actions with others, acknowledged to be capable of rational conversation.

In more recent times, the study of children's development continues to offer different perspectives and theories as to how children and adults diverge. Piaget (1896-1980) argued that children should not be considered as merely immature adults, having imperfect adult capacities, but to have discretely different ways of thinking. Piaget concerned himself with thought processes that led children to wrong answers, recognising in turn distinctly "non-adult" logic in children. Piaget concluded that the cognitive processing of children does not include the basic logical capacities of adults, citing examples such as children's inability to take other points of view, or to reverse mental operations, to understand conservation of mass and volume (Mathews, 1994). Piaget also offered that stages of development are not discrete, but did suggest that after the "formal operation" period, assumed to last from age 11 to 15, thought was perfected and the development of reflective thought completed. As explained by Bernstein (2014, p. 352), Piaget postulates that:

> Only adolescents and adults can think logically about abstractions, can speculate, and can consider what might or what ought to be. They can work in probabilities and possibilities. They can imagine other worlds, especially ideal ones. They can reason about purely verbal or logical statements. They

> can relate any element or statement to any other, manipulate variables in a scientific experiment, and deal with proportions and analogies. They can reflect on their own activity of thinking.

One criticism directed at Piaget has been his firm focus on cognitive development, while Erikson focussed his inquiry on the attainment of "ego integrity", requiring people to pass through seven stages of development, passing through stages of conflict needing to be resolved in order to become a mature adult.

> Each individual, to become a mature adult, must to a sufficient degree develop all the ego qualities mentioned, so that a wise Indian, a true gentleman, and a mature peasant share and recognise in one another the final stage of integrity. But each cultural entity, to develop the particular style of integrity suggested by its historical place, utilises a particular combination of these conflicts, along with specific provocations and prohibitions of infantile sexuality. (cited in Cleverley and Phillips, 1987, p. 89)

During the 1980s Kurth-Schai (1988) suggested three distinct images assigned to youth of the time. At one end of his childhood continuum was an image of children as victims of adult society, vulnerable and in need of protection. Buckingham (2012) concurs with these three projections of children. He describes the first projection as children under threat and endangered, reflected through the succession of investigations into child abuse, scandals about "home-alone" children, and media hype regarding abduction by paedophiles.

At the other end of his continuum, Kurth-Shai (1988) places children viewed as threats to adult society. From this perspective children are seen to be dangerous and in need of adult control. This image has been nourished over time by media exposure of youth participation in civil rights and anti-war protests during the 1960s, through to gang warfare and graffiti mobs of today. Buckingham (2012) also describes the perception of children as violent, anti-social and sexually precocious, but also highlights the role of the media in the portrayal of this image of children, suggesting that the media undoubtedly contributes to the growing sense of fear and panic in the community.

The third group identified by Kurth-Schai (1988, p. 115) are defined as children as learners of adult society. This image then presents children as "incomplete, incompetent and in need of adult guidance". Guidance then falls somewhere between protection and control, with this image of youth closely aligned to models of socialisation and enculturation theories espoused by sociologists and anthropologists during the 20th century. Buckingham (2012, p. 6) stressed the concept of childhood as a social construction, stating that:

> …'the child' is not a natural or universal category, which is simply determined by biology. Nor is it something that has a fixed meaning, in whose name appeals can unproblematically be made. On the contrary, childhood is historically, culturally and socially variable…
>
> The meaning of 'childhood' is subject to a constant process of struggle and negotiation, both in public discourse … and in interpersonal relationships, among peers and in the family.

So while the idea of the "child" is subject to negotiation and variance, the point at which this stage ends, and the next one begins may be considered a reflection of social structures, or social institutions, such as schooling. According to Buckingham (2012) the separation of children by biological age, the highly regulated nature of teacher/student relationships and the organisation of the curriculum and timetables in our schools serve to "reinforce and naturalise particular assumptions about what children are and should be" (p. 7). He stresses, though, that definitions of "children" are not necessarily consistent or coherent, but are characterised by resistance and contradiction. On the one hand, he describes the pressure exerted by parents and teachers on children to "grow up" and behave in what is considered to be a mature and responsible manner, while on the other hand, children are denied privileges on the grounds that they are not yet old enough to deserve or appreciate them.

Buckingham suggests that childhood is a "shifting, relational term, whose meaning is defined primarily through its opposition to another shifting term, 'adulthood'" (p. 7). Following this line of argument then, would lead to the idea that "adulthood" can be defined through its opposition to childhood. Kurth-Schai (1988) notes that his models assume that human development progresses predictably towards a hypothetical ideal, so that children are viewed as adults in the making. At what point this is reached is not specified; it is more recognised as a point at which a young person no longer requires control, protection or guidance by members of the adult community.

With the inherent difficulty in trying to define childhood, some have simply assumed it as the stage prior to the default position of adulthood. Waksler (1991, p. 63) offers a consideration of childhood as an absence of being "grown up", suggesting children are in fact "not something", rather than "something". Childhood may be viewed, in fact, as simply a pathway to adulthood, a time of growing towards becoming adults and full members of society, but of not being able to claim full citizenship with its access to adult rights, venues, rituals, and so forth. Alanen (2000, p. 27) offered:

> Two perspectives dominate; children are understood either as beings in a gradual process of growing up in order to become adults and members of society at some future time or, because of their present immature and socially unfinished condition, as problems and victims of, or nuisances to, the everyday running of the (adult) social order. The effect of both perspectives has been to keep children outside the proper concerns of sociology.

The dominant construction of children as pre-social individuals, though, precludes them from consideration as citizens (Buckingham, 2012). If children are defined in terms of their exclusion from adult society, then the differences that are observed to exist between adults and children while justifying the segregation of children, may equally apply to considerations of others who are not "children" but who also are observed as unable or unwilling to display those characteristics that are considered "adult". Within this definition of "children" as those excluded from adult society on the basis of their behaviour or inability to display "adult", characteristics, the conceptualisation of those with intellectual disabilities as adults can present particular challenges. Childhood is acknowledged as being about generational relationships (Alanen, 2000), with children developing largely as a result of their relationships with adults. Their status as children or adults results from defined cultural expectation of maturity and immaturity, with the binary between childhood and adulthood socially constructed.

2.4.2 Will all children become adults?

Rousseau, in Book IV: Age 15 to Age 20 of his 1762 paper *Emile*, or *Concerning Education*, (reprinted 1889) talks of the transition of the child to adult. He describes two births, the first birth into existence or life, and the second into being a human being, or a man, but recognises that for some, this transition may not occur, describing those who may remain “big children”, or “never more than children”, as a result of “arrested development”.

> Up to the age of puberty children of both sexes have little to distinguish them to the eye, the same face and form, the same complexion and voice, everything is the same; girls are children and boys are children; one name is enough for creatures so closely resembling one another. Males whose development is arrested preserve this resemblance all their lives; they are always big children; and women who never lose this resemblance seem in many respects never to be more than children.
>
> But man in general is not meant to remain always in childhood. He will leave it at the time prescribed by nature; and this moment of crisis, although very short, has long-term influences.

Rousseau recognises that this transition is not fixed in time, but is subject to determinants situated within and beyond the individual, noting that, “[t]he passage from childhood to puberty is not so clearly determined by nature that it does not vary in individuals according temperament and in peoples according to climate”. The point at which adulthood is reached is nebulous, and unformulated. It varies from person to person, and is dependent on many factors.

The fifth of Erikson’s stages acknowledges a period of “early” or “young” adulthood following the transitional phase of adolescence, purported to begin between ages 18-21 (Peterson, 2014). This period, during which people are assumed to experience the crisis of intimacy versus isolation, is a time that Erikson recognises people have resolved the “identity versus role confusion” crisis during their adolescence, and have moved on to seek companionship and love with one special person, or to become isolated from them. Robinson (2015) discusses Erikson’s views of opposites in his theory, noting the syntonic, or healthier position, which in this case is intimacy, alongside the dystonic position of isolation, which is considered highly unhealthy. Robinson (2015) highlights that both extremes are inappropriate, as too much intimacy, at the exclusion of other relationships, would not be considered healthy. The idea of intimacy includes both closeness in romantic relationships, but also commitment to career roles, with Robinson (2015) explaining that this allows young people to become “part of a larger whole and adopting the conventions of that whole, and thus means giving up on personal autonomy to some degree” (p. 19). However Robinson stresses that Erikson’s theory, devised as it was in the 1950s, reflects a time that to delay commitment to adulthood was problematic, with those who put off marriage for too long at risk of missing the opportunity for finding their permanent partner, and those who delayed their commitment to their career pathway at risk of becoming social outcasts. This is a far cry from today’s society, with delays in meeting the social norms of the 1950s no longer a priority for many people in their 20s (Robinson, 2015).

The life course perspective on human development has dominated consideration of life spans since the mid-1960s (Berry & Hardman, 1998; Billari, 2001; Peterson, 2014). Within this perspective, time on earth is rarely used as a measure of any life stage, as trajectories are more central to the analysis of life stages, and are considered to shape events in people’s lives. Billari (2001) considers five such events as markers of the transition to adulthood. These include the end of formal education, first job, leaving the family home, the first married or unmarried union, and the birth of the first child. With few contemporary societies offering explicit rites of passage to adulthood, Billari explains that the number of events that are considered to mark the passage to adulthood can vary, including events such as first sexual intercourse. He states there is a significant degree of subjectivity in selecting trajectories, noting that “[a]ny study considering only demographic events or only educational and work events is incomplete from the perspective of a transition-to-adulthood approach” (p. 121).

While it may not always be possible to state exactly when a child becomes a man or woman, the beginnings of the process within a social manifestation are generally easy to locate, with the end of schooling identified as the start of the transition period (McGee Green, 2008). This is a point at which many young people reassess their identity and stature. This applies equally for people with intellectual disability, with the kind of future they can look forward to often effectively determined for these young people at the point of leaving school. While leaving school does not necessarily elevate any young person to an adult status, it does clearly mark the end of childhood (Shepperdson, 1995). The question that remains is whether the end of childhood equates to the beginning of adulthood. The conceptualisation of adulthood becomes even more complex as a result of the shifting definitions of various life phases in recent time. As Setterson, Ottusch, and Schneider (2015) explain, over the last century simple stages, such as childhood, adolescence and adulthood have been further segmented into “early childhood”, “youth and adolescence”, “post-adolescence”, with adult stages also being subdivided into “emerging or young adulthood”, “midlife”, “third or fourth stages”, or the “young-old”, or the “old-old” (p. 1). The authors reflect on many signals that “affirm a sense of being, ‘no longer adolescents, but not quite adults’” (p. 2), acknowledging the significant cultural contradictions that exist. They note the “adultification” of children who are now exposed to adult things, such as sexual experiences, eating disorders, and exposure to other mature things such as pornography and violence. Yet there is also the “infantilisation” of young adults who the authors argue are “coddled by parents, indulged by society, and provided an extended ‘moratorium’ from serious commitments in the name of self-exploration” (p. 13).

Even the language we use to talk about this period of life suggests ambiguity, whether “adult child”, “young adult,” or “emerging adult”. How might these very labels impede the ability of individuals to embrace adulthood? At some chronological age, individuals are adult, even if they do not yet feel fully adult. What are the dangers in signalling that individuals are not adults when they are—or, likewise, in signalling that they are adults when they are not?

Setterson, Ottusch, and Schneider (2015) conclude by describing how ages and life stages are always relative, both to our former and future selves, and also to others. We will always be older or younger than others, while older than our former selves, and younger than our future selves. There are various labels attached to phases that hold cultural meanings, but Setterson et al. (2015, p. 14) finish by offering that for each individual these meanings are “both personally defined and contextually sensitive”.

2.5 Biological development, parenting and adulthood

A common sociological marker of adulthood is parenthood (Setterson, 2015). Historically the most basic marker of adulthood was puberty, considered a rite of passage. However, puberty in the 1700s and 1800s was more commonly found to occur in women at around age 15 or 16. This has gradually changed over the years. Today the onset of puberty is expected for girls around 12 years, but can start as early as age nine in Western cultures (Rogol, Clark, & Roemmich, 2000). As a result of this earlier stage of development, there has been a decoupling of reproductive capacity as a marker of adulthood. It is now recognised that individuals who are still regarded, culturally and socially, as a child may be biologically equipped for parenthood, but do not meet other social markers for adulthood simply as a result of parenting. Teenage pregnancies raise concern for the health and welfare of both the mother and child, with reported increases in risks of pregnancy complications, postnatal depression, and where the mother is married, a higher risk of marital breakdown (Spencer, 2001). Spencer reports that children of teenage mothers are also believed to run a greater risk in perinatal and later childhood outcomes, often linked to the mother’s lack of material resources and social support networks. Chen, Wen, Fleming, Rhoads, and Walker (2007) add that low birth weight, pre-term delivery and neonatal mortality are higher in teenage pregnancies, and that their findings are independent of known causes of such outcomes. Rather, they occur regardless of socio-economic status, levels of prenatal care, or inadequate weight gain during pregnancy. Chen (2007) concluded that the increased risk of adverse birth outcomes was “less likely to be secondary to socioeconomic factors and prenatal care, and more likely intrinsic to maternal youth” (p. 372). While not all teenage pregnancies are avoided, our Western culture generally works to avoid such outcomes for the vast majority of young people.

2.5.1 Intellectual disability and parenting

Many of the same concerns are expressed about people with intellectual disability beyond their teenage years. Societal attitudes have historically been reticent to support parenting rights by people with intellectual disability. Until recent decades, the rights of people with intellectual disability to assume the “adult” role of parents were negated by many myths, along with the assumed inappropriateness of sexual expression by people with intellectual disability in Western cultures. This was reflected in the practice of involuntary sterilisation which saw many women with intellectual disability have surgical sterilisation without their knowledge in their early teens (Di Guilio, 2003). The eugenics movement recommended, and even mandated in some US states, that people with intellectual disability be sterilised, based on the belief that cognitive limitations were inherited, and thus passed to any offspring of people with intellectual disability. This historical context laid the foundation for many harmful beliefs and attitudes about the sexuality of people with intellectual disability that still exist today (Di Guilio, 2003). Sexual health for people with intellectual disability has largely consisted of the prevention of pregnancy, in order to eliminate the perceived societal burden of the care of these people, and to strengthen the gene pool (Servais, 2006; Sweeney, 2007; Taylor Gomez, 2012). The practice of involuntary sterilisation of people with intellectual disability was still in place in some US states until the 1970s (Lumley & Scotti, 2001). This reliance on surgical procedures neglected other social and health needs, such as the prevention of STIs and the prevention of abuse (Marsland, Oakes, & White, 2007; Moore, 2001; Roof & Esser, 2011).

Murphy (2003) believes that attitudes began to change with the advent of the normalisation and rights movements in the 1970s (Nirje, 1994), which led to a growing empowerment of people with learning disabilities and a widening acceptance of their rights in relation to recognition of their sexual needs. However, decisions by parents and service providers to seek to access sterilisations prevail to this day. Servais (2006) cites a study by Patterson-Keels et al. (1994) which reported that 54 per cent of parents of adolescent or adult women with intellectual disability across various severity levels still believed that the possibility of pregnancy outweighed any reservations about sterilisation, with 15 per cent of parents seeking sterilisation as a means of managing menstruation. Research has shown that around 20 per cent of young Australians without intellectual disability aged 14-16, and 48 per cent of those aged 16-18, had engaged in sexual activities (Grunseit & Richters, 2000). Because of the protective and supervisory nature of relationships between parents and DSWs and the young people with intellectual disability in their care, this is highly unlikely to be the case in the cohort of adolescents with intellectual disability, although no research on this subject has been found. Women with Disabilities Australia (WWDA) reported in 2004 on information collated by the Australian Health Insurance Commission that showed that at least 1045 girls had been sterilised since the famous “Marion’s Case” in 1992, in which it was found that courts could exercise a general supervisory role to act to protect the best interests of the child. This figure counts “only those sterilisations which qualify for a Medicare benefit and for which a claim has been processed” (n.p.). This figure, then, excluded any sterilisations carried out on public patients in public hospitals by hospital doctors. WWDA believes the true figure for such procedures would be far greater than reported, and believes that many of these sterilisations would have been unlawful. More recently Frohmader and Ortoleva (2012) wrote: “Forced sterilisation of women and girls with disabilities is a practice that remains rife throughout the world, and represents grave violations of multiple human rights” (2012).

2.5.2 The question of attenuation, rights and intellectual disability

In the past decade, the idea of sterilisation for women with intellectual disability has been taken to an even more ethically questionable level. Unless there is intervention, it is generally acknowledged that people with intellectual disability are *capable* of maturing at least in a biological, or physical sense at the same chronological stage as their non-disabled peers (Ballan, 2001).This biological stage may be particularly unwelcome by parents when a child has any form of disability that is perceived to impact their capacity to cope physically or emotionally with the onset of menarche for girls (Heyman & Huckle, 1995) or with the hormonal and physical changes in boys. However, no matter how unwelcome, it will arrive regardless of intellectual development. The socio-sexual components of this stage certainly pose many more potential dilemmas for young people with intellectual disability and their families or unpaid carers than for the general population of teenagers, as will be discussed further in this thesis. Regardless of these concerns, however, this biological dimension of adulthood is rarely challenged. There may arise questions of medical or surgical intervention, such as in the case of Ashley, the "pillow angel" (Ouellette, 2008), whose parents chose to not only sterilise their daughter by removing her uterus, but to also removed her breast buds, and set out to keep her small, by closing her growth plates through high-dose oestrogen treatment. Ashley will not grow into a fully developed mature woman, but this treatment is highly controversial, and at this point, highly contentious. Her right to biological and physical maturity was removed by doctors at the Seattle Children's hospital, who argued for the use of surgery and hormones to supposedly improve her quality of life. According to Time magazine (7th Jan, 2007) the ethics committee of the Seattle Children's Hospital considered a "cost-benefit analysis and concluded that the rewards (of the procedures) outweighed the risks", which included the risk of thrombosis. Dr Daniel Gunther, one of the two doctors who performed the surgery on Ashley, claimed he understood why the case inspired such intense feelings, but noted that "visceral reactions are not an argument for or against". He commented that: "This was not a girl who was ever going to grow up. She was only going to grow bigger" (Gibbs, 2007).

The question of rights to biological adulthood has certainly been argued in light of this decision, but such a decision is rarely an option for parents of children and young people with intellectual disability who acknowledge their son or daughter's biological maturity, despite the inconvenience and challenges this presents. The question of rights to normal bodily functions has been tested in law courts in recent decades (Wilson, Carlson, Taylor, & Griffin, 1992). However, the "Pillow Angel" case defies the more normatively accepted, legally-supported perspective that, at least in a biological and physically sexual domain, all people will grow to an adult form.

However, the possibility of attenuation for children with severe intellectual disabilities is potentially growing in attraction for parents, with 70 recorded cases in the world reported in a television documentary aired in New Zealand (Roberts & Hutchinson, 2016). Most of these cases are found in the United States. The documentary highlighted the approach by parents of those with profound intellectual and physical disability to bring on early puberty through the use of hormones to stop further physical growth. This aims to allow easier management of the son/daughter, and is argued to support a better quality of life for these young people. While little is known about the additional removal of breast buds, or sterilisation of the other cases noted by Roberts, in the case of Charley Hooper in New Zealand, it seems the high dose of hormones used averted the need for clinical removal of the breast buds. In this case, a hysterectomy was reportedly performed on this girl following the hormone treatment, as a means of sterilisation (Hamilton 2014, retracted 2015).

2.6 Intellectual development and adulthood

The concept of autonomy, defined as a capacity to govern oneself, is closely aligned with concepts of self-determination and personal authority. Hockey and James (1993, cited in Blatterer, 2009, p. 58) explain that the ideas of autonomy, self-determination and choice are "the constitutive aspects of what it means to be adult, a full person and social member", adding that these qualities are "omitted from our conceptions of childhood, adolescence and old age". Blatterer (2005b) notes:

> Indeed so powerful is the association of full personhood with adulthood that adults who do not embody competence aspects of the ideal model, such as individuals with disabilities, the frail, the mentally ill, are through the process of infantilisation relegated to the marginal position of a quasi-childhood (p. 12)

He continues:

> Adulthood is a metaphor for membership in society through acknowledgement of full personhood. Adults are individuals who can be full partners in interaction because they are formally as well as informally acknowledged and validated as such.

Blatterer highlights that there remains a question over whether, or how individuals with disability are protected against the relegation to quasi-childhood, and whether or how these individuals are perceived in terms of their adult status, or indeed where they are awarded full personhood.

Even when legal and social welfare infrastructure is in place, which intends to foster participatory equality for those with intellectual disability, and their rights decreed in bills of rights such as the UNCRPD, stigmatisation and ignorance may compromise the quality of life for these people and their family. Stigma and disapproval can hinder re-categorisations of young people from children or youth into adulthood; those with intellectual disability have much to overcome before becoming culturally accepted into the "hood", or community of adults. As Goffman (1976) explains:

> Starting with the very general notion of a group of individuals who share some values and adhere to a set of social norms regarding conduct and regarding personal attributes, one can refer to any individual member who does not adhere to the norms as a deviator and to his peculiarity as a deviation. (p. 167)

Society establishes means to categorise people, and offers attributes considered ordinary or natural for each of these categories. When we meet a stranger, their initial appearance can often enable us to anticipate his "category" and attributes, and assign him a "social identity". We tend to anticipate characteristics, transforming them into expectations, although oftentimes such anticipation and expectation is not a conscious undertaking, unless there is some question of whether or not they will be fulfilled. Goffman (1976) writes of members of the lower class, who experience stigma as a result of their notable difference in speech, appearance and manner "relative to the public institutions of our society" (p. 173), thus finding themselves considered second-class citizens. Such differences in speech, appearance and manner are all too common in those with intellectual disability, equally rendering them as lesser-valued citizens, and positioning them in the category of "other".

The question is whether such "other"-ness, as described by Goffman, renders those considered "others" as non-adults. Brannen and Nilson (2003) and Peterson (2014) write of the sociological notion of the life course, and a linear progression of time, but note that there is no single life pathway. They offer that the life stage concept suggests a set of inevitable sequences, from childhood, through youth, then adulthood and old age. The stage of adulthood then confers responsibility for self and for others. When those with impaired cognition might meet such culturally recognised markers of full adult status outlined by Brannen and Nilson (2003) or Arnett (2000, 2001, 2007) is complex.

Berger (2005) and Peterson (2014) outline the changes that occur during the transition from adolescence to a mature cognition for the typical population, explaining that "adulthood" changes are multidirectional, and also more multi-contextual than during childhood and adolescence. In her text on how the human develops, differentiation is made between adolescent and adult thinking and tasks that adults are expected to accomplish, along with an acknowledgment that part of the role of an "adult" is to make certain decisions, such as whether to produce children, or regarding personal and financial decisions. Berger (p. 435) believes that adulthood must be studied from a multidisciplinary perspective, explaining that it can be "only loosely connected to chronological age". Berger (2005) further explains that many researchers take different approaches to explaining adult cognitive processes. Adult thinking is considered to be more practical, flexible and open to debate than adolescent thinking within the population of typically developing young people. Adults are assumed to be able to consider various aspects of a situation, reflecting on difficulties, but able to negotiate solutions around these. Berger (2005) highlights the comparison to adolescents who are more inclined to use quick, intuitive thought, often acting with little consideration of consequences.

In adulthood, though, conclusions and consequence are more likely to matter, with intellectual skills called upon to adapt to inconsistencies in daily life. An expectation of adulthood is the mastery of cognitive skills for monitoring one's own behaviour, and therefore an associated level of independence. With this assumption of independence goes a level of assumed responsibility. Settersten, Ottusch, and Schneider (2015) reflect on the use of chronological age as a basis for our legal system, wherein laws use ages to suggest the developmental status of young people, despite research showing chronological age to be a poor indicator of such statuses. Settersten et al. (2015) explain that many judgements on legal status are rooted in "assumptions about when young people are *cognitively* mature enough to make, 'adult', decisions" (p. 7). They expand on recent brain research that raises questions about these assumptions, showing that prefrontal cortex development—the part of the brain responsible for solving problems, understanding consequences, and regulating behaviours and emotions—continues to develop towards full maturity until age 25. Setterson et al. (2015) question the phasing in of adult rights and responsibilities, noting that the life course towards adulthood has become more ambiguous in recent decades, occurring more gradually, and in a less uniform pattern.

Mature adult thinking is considered to incorporate both subjective and objective thought. Berger (2005) offers that subjective thinking can be prejudiced, narrow and highly emotional and reflective of personal experiences and feelings. On the other hand, objective thinking can work as a “corrective” to this by providing logic and reasoning to provide solutions to problems that are both personal and practical. This path of emotion and logic is recognised by Blanchard-Fields (1999) who found that while adolescent teenagers believed in either objective or subjective reasoning, adults were able to combine these two thought processes to moderate their emotions, and to move beyond the extremes such as risk-taking, bulimia, speeding, and addictions that can typify adolescent behaviour.

A characteristic of Schaie and Willis’s (2000) post-formal operations stage of maturity is the awareness of alternate perspectives to a problem, and the possibility that problems potentially have more than one solution. Flexibility of approach to problem-solving allows for adaptability to unexpected conditions and events. Lutz and Sternberg (1999) explain that adults recognise the need to combine intellect and emotion when problem-solving, along with the need to imagine and analyse the available options. The ability, then, to consider a number of possible solutions to a problem is considered a “hallmark of post-formal thought” (Sinnot,1998, cited in Kail & Cavanaugh, 2007). It is also acknowledged that all individuals differ in this ability to problem-solve using both personal experiences and logic. The post-formal stage of thinking does not rely solely on logic or reason. It also takes into account the relativistic nature of problems and solutions and sees grey areas along with previously perceived right-or-wrong, on-or-off perspectives. Post-formal thought is considered to be flexible thinking that acknowledges the world as complex and contradictory (Schaie & Willis, 2000).

2.7 Conflict between parents and Disability Support Workers

While few studies can be found that explore conflict between parents and Disability Support Workers (DSWs) in relation to concepts of adulthood, two studies were found undertaken by Jingree and Finlay (2008, 2012) that addressed the facilitation of independence and empowerment by family carers and DSWs. In their earlier research Jingree and Finlay (2008) had found that DSWs working to support people with intellectual disability faced their own dilemmas when trying to empower their clients, with DSWs wishing to present themselves on one hand as “enlightened individuals” who positioned themselves as “facilitators of client choice”. This discourse was recognised as a guiding principle; upholding client choice was seen as a priority and taken for granted with opposition expressed at its possible infringement. However, DSWs also noted a number of “practicalities” or “unalterable realit[ies]” that had to be worked around, such as impaired cognitive abilities. These practicalities were “used as justifications for why attempts to increase client choices were unsuccessful” (p. 720). The ideal of offering choices and empowering clients was simultaneously nullified by talk of the practicalities that rendered attempts to increase autonomy impossible. Jingree and Finlay (2008) note this as an example of Wetherell and Potter’s (1992) “practical/principle rhetoric device" and offer this as an example of the gap between theory and practice. One interviewee offered:

> If the evidence is there, that you, as a resident is eating all the wrong foods and we just saying okay then because it is your rights and choices, are we killing them? Where does the fine line come in where we do have to maybe say, 'No, you can't do that.'? (p. 718)

Support staff acknowledged that increasing rights and choices may also increase risks, and struggled with the idea of a fine line between supporting risk taking and their duty of care. Their concern for the "practicalities" as internal factors positioned their clients as "incapable, irresponsible and vulnerable" (p. 720), and allowed the support staff to blame the client in cases where their efforts to increase choice and control were unsuccessful. Other DSWs described environmental or social barriers to choice, such as lack of support staff, or difficulties with transport. This ability to apportion blame to other factors allowed the DSWs to present themselves as doing their best to uphold empowering practices. Jingree and Findlay (2008) explain that such apportioning of blame aligns with the individual model of disability and is incompatible with the notion of empowerment within the social model of disability, but note the practical/principle rhetorical talk used extreme cases as additional persuasion of their challenges. The example noted above is such an extreme example where the idea of "killing" clients is used to substantiate the interviewee's concerns about increasing autonomy. Jingree and Finlay (2008) note this use of extreme cases was frequent, with only rare cases of positive examples of empowerment.

Many of the DSWs recognised risk as a feature of increasing client autonomy, which led to personal growth, but despite talk of everyone being "human", or "all the same", the commentary of the support staff was pitted with "we" (the support workers) comments and "they" (service users) comments. Such "they" comments "produced constructions of incapacity and vulnerability" (p. 722), effectively closing down opportunities for them to manage their own risks. Essentially, in respect to the empowerment of service users, DSWs tried to position themselves between identities of being facilitators of independence on one hand, while being responsible and answerable professionals on the other. Thus opportunities to offer complete choice and control were not available, with limitations on independence determined by constraints of health and safety. This was referred to by Jingree and Finlay (2008) as "bounded empowerment". While this may not suit people without intellectual disability, it was argued by support staff to offer service users short-term autonomy, while recognising that DSWs are directed by a duty of care to act in the best interest of their clients, thus often restricting their choices.

Jingree and Findlay's later paper (2012) used critical discursive psychology to examine focus group discussions involving family carers of sons/daughters or siblings with intellectual disability. Their study explored family carers' thoughts on empowerment and the facilitation of independence of their family member with intellectual disability. Jingree and Finlay (2012) found that parents invoked empowerment talk for three reasons:

1) as a resource to construct the facilitation of independence as an abstract, irresponsible, politically correct professional trend;

2) dilemmatically with meritocratic or practical arguments to undermine notions of facilitating choices; and

3) as a resource to construct new service developments as contrary to the preferences of people with learning disabilities (p. 412).

This research by Jingree and Findlay (2012) noted that parents were found to describe their family member with intellectual disability as “unable to cope”. Family carers described stark contrasts between their practices with their family member and the practices of DSWs. Family carers ascribed those with intellectual disability as “flawed and irresponsible”, and rarely spoke positively about policies that targeted empowerment of their family member. These family carers defended their positions by offering that the family member with intellectual disability was unable to cope, and unaware of choices, and suggested their child or sibling lived in a “fantasy world”, or was “living in a bubble” (p. 425). Such comments supported the family carers’ belief that it was pointless to offer choice to their son/daughter/sibling, and that policies supporting this were “fanciful and irresponsible” (p. 425).

Further, family carers positioned themselves as having a more “realistic” understanding of their family member, believing that service policies were based on:

> abstract and unrealistic ideologies about empowerment and as so driven by political correctness that they had adopted irresponsible practices and failed to understand the “true” needs and wishes of their son/daughter. (p. 425)

The findings of Jingree and Finlay (2008, 2012) align with concerns expressed by Almack, Clegg and Murphy (2009) who examined the concerns of parents about the risk of accidents or abuse of their sons or daughters with “relatively severe” intellectual disability during their transition from special schools in England. Parents expressed concerns about the vulnerability of their sons and daughters as they move into the “adult world”. Their concerns were considered in view of the increase in policies that promote possibilities for people with intellectual disability to express and pursue their own preferences and aspirations. According to Jingree and Finlay, parents were found to have real challenges negotiating the perception of being “over-protective”, and alternatively “letting go” through trusting others to act in their son/daughter’s best interest and to “safely” negotiate risk. In the study by Jingree and Finlay (2008) parents acknowledge the tensions offered by these “dual imperatives” (p. 291), and the trials of being regarded as “paranoid” or alternatively being prudent in calculating the risks involved in “letting go” (p. 291). Parents identified a number of risks during the transition to adult services, for their sons/daughters with intellectual disability, including sexual, physical, emotional and financial abuse. Parents also identified vulnerability in new environments, with poor sense of direction, poor road sense and the risk of social isolation. While identifying a tendency to over-protectiveness, parents could also justify this by recognising their sense of responsibility and the potential to be seen at fault should they be seen to offer their son/daughter too much independence. One mother could offer that her son would have a more fulfilling life if he was not “wrapped in cotton wool”, and recognised the risk of stifling her son’s development towards adulthood, even in light of his lack of awareness of road safety. While trying to support his independence, she also acknowledged that in the event of any harm coming to her son, this tragedy would be “chargeable to her account” (p. 293). So the potential for being judged negatively may stem from either over-protectiveness or failure to provide adequate protection. Clearly parents see themselves potentially “damned if they do, or damned if they don’t!”

Another common concern expressed by parents in the Almack et al. (2009) study include the choice of young people with intellectual disability to do nothing other than sit around home, risking social isolation, and health issues. Parents were also concerned about the constraints this placed upon them, as they were unable to return to work, or to lead their own lives. Parents expressed the belief that they knew their children best, and their lifetime relationship with their son/daughter positioned them best to decide on the “best—and least risky—course of action for their offspring’s future”. As one mother stated:

> Yes they are adult and they have a voice but sometimes William agrees to things without understanding what he is agreeing, it’s the carers [support staff] and parents who actually know what it is because we’ve got it 24/7, not social services and that’s the difference. I think that gives you an overall summing up (William’s father) (Almack et al. 2009, p. 295).

Unfortunately the abuse of people with intellectual disability continues to significantly influence beliefs around independence or protection (Fisher, Baird, Currey, & Hodapp, 2016; Fyson & Kitson, 2007) . In light of abuse of residents in Cornwall, UK, in 2006, Fyson and Kitson (2007) reflect on the need for better linkages between legislation and policies that support and promote choice and independence, alongside those measures in place to support vulnerable adults.

> Promotion of independence and choice for people with learning disabilities is an admirable aim, and an understandable reaction against decades of provision that have demeaned and dehumanised this group of people. Admirable as they may seem at first glance, independence and choice now run the risk of being fetishized to the point where they become the *sine qua non* of learning disability services: concepts beyond questioning. We believe that, in order to better protect vulnerable adults from abuse, these beliefs can and should be challenged. That is not to say that we would wish a return to services in which people with learning disabilities are locked away from the rest of society and have no choice or independence, but rather a plea for a recognition of the obvious (if unspoken) reality that if these people were able to be fully independent and to make important life choices without support then they would not be receiving state-funded services in the first place
> (pp. 433-434).

While service policies are founded on ideals of independence and autonomy, such that the recognition of an element of control within the support relationship between support staff and service users is overlooked, Fyson and Kitson (2007) believe a dangerous gap exists in which abusers can find an "all-too-comfortable niche" (p. 434). Carolyn Frohmader, Executive Director of Women with Disabilities Australia submitted the following in 2015 to the Senate Community Affairs References Committee for inquiry and report into "*Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*":

> These are not isolated stories. We hear stories like these every single day—not once a week, not once a month, but every single day. Just last night, as I was packing my suitcase in order to fly here to speak to you today, my phone rang. It was a woman with disability trapped in the laundry of her home, hiding behind the washing machine whilst her husband—her carer—raged outside the laundry door, threatening to kill her. Again this is not an isolated incident. Every day, every night, every weekend we hear these stories. So today we stand united to say to you that people with disability in Australia represent the most detained, restrained and violated sector of our population. They are significantly overrepresented in prisons, institutionalised and segregated within communities, locked up in schools, confined in mental health facilities, incarcerated in detention centres and trapped within their own homes (Frohmader 2015).

Emotive as it may be, public commentary such as this naturally impacts parents' capacity to "let go" of the caring, supportive role they experience their sons/daughters with intellectual disability who they perceive as vulnerable, in need of support, and possibly not as independent members of adulthood. The idea that independence, autonomy and self-determination are indeed the *sine qua non* of the service industry whose policies support human rights and adult principles presents a murky and dilemmatic transitional journey for all involved—support staff, family members, and young people with intellectual disability.

2.7 Summary

Despite the call from Clegg, Sheard, Cahill, and Osbeck in 2001 to explore the conceptualisation of adulthood and the potential difference in understanding of this concept by parents and support staff in disability services, this review of literature shows that the call has received only minimal attention. The potential for tension between families and support staff during the years after secondary school remains, and it is not clear whether conceptualisations of adulthood contribute to this conflict.

While acknowledging that people living with intellectual disability have unique characteristics and challenges, the literature shows current approaches to disability respect the common rights of all people regardless of these differences. These rights are implemented through service policies that reflect their recognition under the UNCRPD.

The idea of adulthood is fluid and changes over time. It is therefore difficult to define this concept in anything other than a legal framework which offers a legally static date for assumption of legal capacity and legal status. This point catapults a person from childhood to a new legal status. However, this new status raises the question of capacity or understanding of the nature and effect of decisions and actions. The concept of legal capacity offers the individual the opportunity to make decisions deemed either “good” or “bad”. Bad decisions, or decisions considered by others as not in the best interest of a person can be seen as indicative of a lack of capacity to make decisions, and can invoke a paternalistic response from parents or support staff.

Current philosophy recognises that impairment in abilities to make decisions does not mean people are incapable of making decisions, instead recognising that support may be needed in the process of realising self-determination. This support can be from trusted family, friends or support staff but is preferable when offered by circles of support (Wistow, Perkins, Knapp, Bauer, & Bonin, 2016) or family who are understood to best know the will and preference of the person with intellectual disability. The principles guiding support are based on sanctioning a person’s freedom, protecting the best interest of the client, and respecting their wishes. These principles however can result in conflict and may require intervention by guardians to find a balanced outcome. This balance requires consideration of human dignity, personal and social wellbeing, along with the right to make decisions whether these are in one’s best interest or not. The outcome can be seen to involve a measure of freedom alongside a duty to ensure safety and wellbeing, but the right to make one’s own choices and decisions is considered paramount.

The idea of adulthood is constructed often for social convenience, but socially and culturally this concept shifts in response to demographic changes in Western cultures over time. Children remain defined by the United Nations as those under 18, or until they reach a country’s age of majority. Children are recognised as needing safeguards, but definitions of adulthood are not so clear, and the essence of adulthood is often elusive.

Adulthood can be aligned with social rites or rituals, but is more often recognised as a transitional process, that Arnett (Arnett, 2000, 2001, 2007a, 2007b) says may last from age 18 until well into a person’s 30s. The traditional determinants or identifying characteristics of adulthood such as independence, autonomy, self-determination or responsibility are no longer assumed by many young people who stay at home and dependent on their parents for much longer than previous generations. These determinants are also subjective and may ignore inter-personal relationships, and the interdependence between members of communities.

The right of people with intellectual disability to make their own decisions is the subject of the UNCRPD, yet there are examples provided of cases where a basic right to physical growth to maturity can be denied children based on their intellectual disability. Parents are also known to attempt to restrict their son or daughter’s right to sexual expression and reproduction. On the other hand there is evidence offered of DSWs engaging in subtle or overt control over people in their care. While rights exist in theory, in policy documents, and in international conventions, parents of young people with intellectual disability still see their sons and daughters as vulnerable to abuse or neglect at the hands of support staff. For this reason, parents are reluctant to relinquish their sons and daughters to the support from disability services, and as such are regarded as over-protective with their actions deemed contrary to the best interests of the young person. This situation remains at the centre of the tension identified between parents and support staff during the transition to adult services, but how, or whether, this tension is compounded by differing conceptualisations of adulthood, and how young people with intellectual disabilities are perceived as adults or otherwise has not been investigated. It is not known whether there is a definition of adulthood that could be potentially useful in addressing this challenging time for all involved. This gap in knowledge is the subject of this thesis.

Chapter Three
Theoretical Framework

3.1 Introduction

This chapter offers a theoretical framework with which to analyse the data collected through the research interviews and focus groups in relation to the perception of adulthood. This framework offers a number of concepts that are viewed as both discrete and closely linked that influence perceptions of young people as adults or otherwise. These are used by the general population in most Western communities, but offer different perspectives that are dependent on the relationship between the person under consideration as an adult, and the person making the judgement. There is currently much written in the literature about the concept of emerging adulthood as it applies in the Western world to describe the current shift from traditional markers of adulthood. This concept has been discussed in the literature review. However, this concept has not yet been applied to those with intellectual disabilities in the extensive discussions on sociological changes in our community. Literature offering a broad framework upon which to consider young people with intellectual disability as adults is sparse, and thus it is necessary to develop an original framework for the purpose of this thesis. As no more appropriate theoretical framework could be found as a platform for analysis of the data collected in this research, this framework has been developed based on the work of Mark Priestley (Priestley, 2000, 2001, 2003a, 2010).

Swanson (2013 p.173) explains that a theoretical framework offers “the structure that can hold or support a theory of a research study”. The development of the theoretical framework for this thesis is intended to explain the research problem that exists. It aims to theorise the possible difficulty that may exist in finding a mutually agreeable and universally accepted definition of adulthood as it applies to young people with a disability.

3.2 Priestley’s Life Course Approach to Disability

One of the few authors found to consider how social categories of disability intersect with the generational system is Mark Priestley. He describes how the “concept of adulthood lies at the heart of [the] generational system” (p. 116), and explains how constructions of adulthood “frame our understanding of citizenship and rights”. His book, *A Life Course Approach to Disability,* outlines the need to consider the life course approach as an alternative framework for thinking about disability as “it highlights how disabling societies and practices affect people of different generations” (p. 1), but adds that it also allows us to see more clearly how societies organise “generational boundaries”, and how this shapes our understanding of disability within a social community. Priestley considers four paradigms as a framework within which to consider disability.

This study applies a parallel approach to that taken by Priestley. It similarly constructs a framework that uses four paradigms, or lenses to consider adulthood. The framework developed here considers conceptualisations of adulthood within four paradigms aligned loosely to those described by Priestley as contributing to an understanding of how disability is produced. It investigates concepts of adulthood within four domains and explores the relative weight given to these domains by young people with intellectual disability, their parents, and support staff. It considers conceptualisations alongside current policies and social structure and examines their compatibility.

Priestley first describes the assumed relationship between an individual and society, and secondly the relationship between materialist, or idealist dimensions of social theory. He outlines four positions within which he explains contemporary theories of disability. The first two positions relate to the properties of an individual, which he explains are “nominalist positions” as they are social phenomena, which may, in fact, have no “real” existence outside perceptions and interpretations of them. The other two positions are concerned with the “properties of collectives” and contrast with the first two positions in that they are “realist” approaches. Priestley claims that such approaches suggest that “social phenomena do have ‘real’ existence beyond our observations and interpretations—that they exist independently of the individuals who experience them” (Priestley, 2010 p.76).

Priestley’s model of the four paradigms for disability theory can be seen in Figure 3.1.

Position 1 requires observation and classification of material individuals, or bodies, and is classically empiricist. This requires the analysis of the individual in objective terms, with minimal influence of subjective values, and involves basic biological or genetic determinism.

Position 2 again focuses on the study of the individual, but focuses on voluntaristic action, rather than biology. It reflects analysis of “experiences, beliefs and interpretations of individual actors” (p. 77). It does not concern itself with the interactions between individuals, but rather considers one’s own imagination of their intentions and actions. While meanings may be shared by members of groups, Priestley acknowledges the need to interpret the actions of individuals in order to “arrive at a meaningful perception of social realities” (p. 78). Such concerns are common in feminist, anti-racist and postmodern studies, with individual realism illustrating how “the personal, the private and the reflexive can also be political” (p. 78).

Position 3 considers the “structure” of the society, rather than the “agency”. It suggests that social phenomena are real and material, and that social structures exist objectively beyond an individual. Priestley aligns this position with Hegelian and Marxist analyses that reflect social relations that are determined by a “mode of production within a specific historical context” (p. 78), and offers the material relations of power as units of analysis for this position.

Position 4 also views social phenomena as having objective reality outside the individual, but locates its analysis within idealist society, rather than material society. In this position, Priestley offers that “social reality exists more in ideas than in material relations of power” (p. 78). Priestley aligns this position with Durkheim’s study of “culture” which embodies objective idealism and positive sociology. This theory analyses cultural values and representations as measures of disability.

Table 3.1 Priestley's four approaches to disability theory

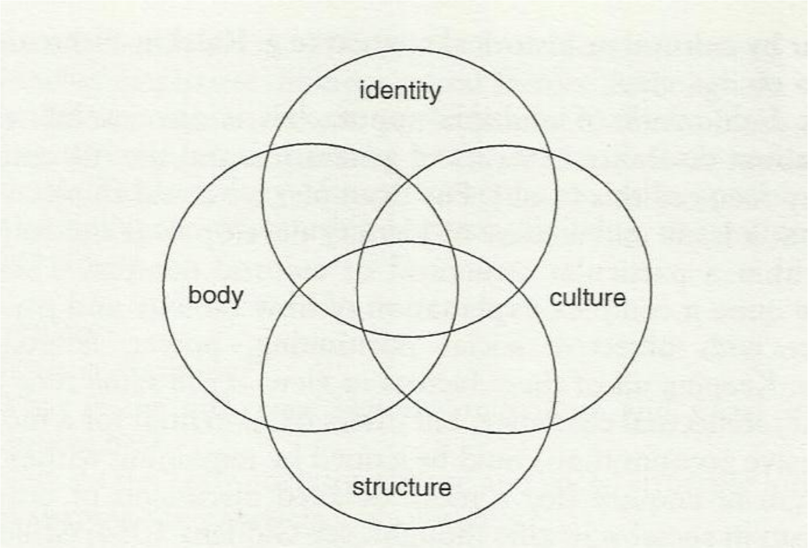
	Materialist	**Idealist**
Individual	**Position 1** Individual materialist models Disability is the physical product of biology acting upon the functioning of material individuals (bodies) The units of analysis are impaired bodies	**Position 2** Individual idealist models Disability is the product of voluntaristic individuals (disabled and non-disabled) engaged in the creation of identities and the negotiation of roles. The units of analysis are beliefs and identities
Social	**Position 3** Social creationist models Disability is the material product of socio-economic relations developing within a specific historical context The units of analysis are disabling barriers and material relations of power	**Position 4** Social constructionist models Disability is the idealist product of societal development within a specific cultural context The units of analysis are cultural values and representations

Figure 3.1 presents the complexity identified by the interaction of Priestley's four paradigms. He explains that the four theoretical approaches to disability should not be seen as discrete, but rather as overlapping areas of consideration. By way of example Priestley offers the question of how far the adoption of disability identities is influenced by "embodied experiences" (p. 17), as opposed to cultural or historical contexts. He explains:

> We could think about the way that a body and a sense of identity develop over the course of a life, within a particular structural or cultural context. This would involve quite a complex explanation of how biology and psychology interact with objective social positioning, power, language and culture. (p. 18)

Keeping in mind all these factors offers a more comprehensive perspective than could be achieved through reflecting on any one paradigm; it provides a perspective on the dynamic relationship between biology, psychology, culture and structure.

Figure 3.1 Priestley's model of disability



3.3 Adaptation of Priestley's framework

The four paradigms used as the structural framework for this research are adapted from Priestley's approach to disability theory, but are amended to reflect contexts within which one may consider the concept of adulthood:

- **Position 1** (Biology) considers adulthood as a result of biology or genetics that determines the state of maturation that may be classified through simply observation of the body, with knowledge determined by classical empiricism.

- **Position 2** (Identity) considers voluntaristic actions of the individual. It considers the notion of self, the creation of identity, the negotiation of roles with significant others, and the interpretation of individual actions to determine a meaningful perception of social realities.

- **Position 3** (Society) aligns with social creationist models that consider adulthood as a product of social structures, markers, determinants and practices that exist within an historical context. These may reflect relations of power arising from political economies, or patriarchic or legal conditions.

- **Position 4** (Culture) offers an idealist, rather than materialist consideration of social phenomena that provides an ontological basis for consideration as an adult. From this perspective, adulthood is recognised as a social construct within specific cultural contexts. Adulthood is a product of specific cultural conditions.

Table 3.2 Redgrove's four approaches to adulthood theory

	Materialist	**Idealist**
Individual	**Position 1 (Biology)** Individual biological models Adulthood is the resultant product of biology acting upon the functioning of material individuals (bodies) The units of analysis are chronology and human biology (physical and sexual development)	**Position 2 (Identity)** Individual idealist models Adulthood is the product of identity achievement by individuals through the negotiation of roles with significant others The units of analysis are beliefs and identities
Social	**Position 3 (Society)** Social creationist models Adulthood is the product of socio-economic structures that exist within a specific historical context The units of analysis are societal markers, determinants and practices.	**Position 4 (Culture)** Social constructionist models Adulthood is the idealist product of societal development within a specific cultural context The units of analysis are cultural values and representations

Figure 3.2 Model of possible conceptualisations of adulthood.

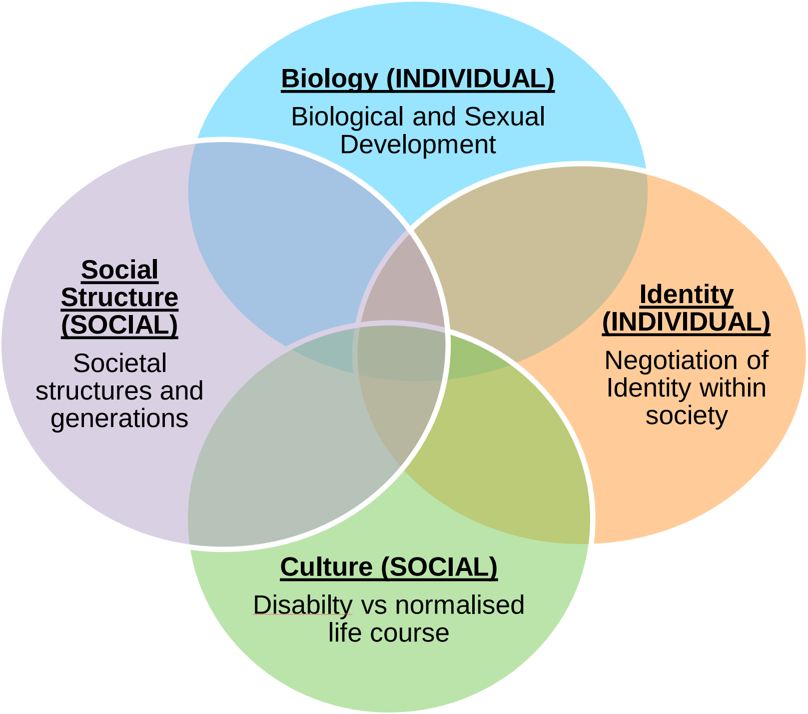


Figure 3.2 shows how no one position stands in isolation to the other three positions. Just as Priestley explains that there is considerable overlap between approaches to disability, individual perspectives on adulthood are also embedded in social structures and cultural beliefs. Identities, for example, are negotiated

and developed within social contexts, and form as a result of cultural and structural forces. So the illustration above highlights the overlap between conceptualisations of adulthood, and is perhaps a more useful model of the framework for this research. This framework of multiple approaches to adulthood is outlined in more detail below, outlining how we may consider adulthood as a social structure, or a result of biological or sexual development, or a cultural achievement, or the achievement of adult identity. The resultant framework for adulthood is consequently recognised as a complex combination of biology and psychology, interacting with social structures, power, language and culture. Each paradigm will now be discussed individually in more detail.

3.3.1 Position 1: Biological/sexual adulthood

The concept of biological adulthood may be considered the least complex domain to define for members of the animal kingdom (Arnett, 2001). The term “adulthood” may be used to refer to the biological status of any animal, including people, reflecting their full growth to a point of reproduction. For humans, biological adulthood may start at around age 10, or even earlier for young girls, with the onset of puberty now not uncommon in girls aged eight in the United States and other Western countries (Lee, Guo, & Kuliln, 2001; Papadimitriou, 2016). The onset of puberty that occurs usually between ages 10 and 12, (but may occur from 8-18) with the changes in hormonal levels, can be a challenging time physically as well as emotionally for many young people, offering bodily changes that present new trials for the young person and those around them. This life stage, known in Western cultures since the early 20th century as “adolescence” is recognised as a cultural milestone, as much as a physical determinant of a new life stage for those who reach it. Biological processes at the onset of puberty produce changes in brain development, contribute to height and weight gains, and changes in body contours (Santrock, 2009). The biological variances stimulate changes in motor skill development and cognitive processes, such as changes to thought patterns. These biological processes also influence changes in relationships with other people, emotional responses, and can contribute to altered personality (Santrock, 2009). Along with the enlargement of breasts and penises, the growth of pubic and facial hair, deepening of the voice and the onset of menses, this life stage is often marked by an easily recognised pursuit of independence and greater time spent apart from the family for most young people.

However, while young people may outwardly finish developing physically, with the capacity for sexual reproduction sometimes as early as 12 or 13 (Papadimitriou, 2016), this concept of adulthood is rarely assigned to young humans in today’s Western cultures due to the more complex sociological aspects of sexual behaviours that may not develop parallel to physical biological adulthood. It is even less likely to be assigned to those with intellectual disability. Intellectual disability that arises from either exogenous causes such as alcohol and drug abuse, malnutrition or infections during pregnancy, or from genetic aetiology such as Down syndrome or similar, may impact brain development in ways that suggest incompatibility between the physical reproduction of children and the social responsibility required to safely raise these children (Greenwood & Wilkinson, 2013). Parenthood is unlikely to be considered a marker of adulthood for those with intellectual disability, and in fact raises more concerns than celebrations for families alongside the fear that they may have to assume responsibility for any offspring produced (Cuskelly, 2006; Cuskelly & Bryde, 2004).

3.3.2 Position 2: Identity and adulthood

During and beyond adolescence young people are assumed to develop identities and relationships leading to the stage Erikson called Ego Identity versus Identity Diffusion. Erikson's seminal theory emphasised identity development as the fundamental development occurring during adolescence, noting the need for revision of this identity an important task to be undertaken during adulthood (Erikson, 1950). Erikson considered identity to be a subjective feeling of "sameness and continuity across time and across contexts… best represented by a single bipolar dimension, ranging from identity synthesis to identity confusion" (Luyckx, Schwartz, Goossens, Beyers, & Missotten, 2011 p.3). Erikson described *identity synthesis* as a "reworking of childhood identifications into a larger and self-determined set of ideals, values, and goals", whereas "*identity confusion* represents an inability to develop a workable set of goals and commitments on which to base an adult identity" (Luyckx, Schwartz, Goossens et al., 2011 p.3).

Exploring more closely Erikson's stage of Ego Identity versus Identity Diffusion, James Marcia studied males enrolled in US College courses, and proposed a model of four alternate profiles of those young males who passed through the stages proposed by Erikson. Marcia (1980) identified four statuses of young adults, which he referred to as;

1) Identity achievement: in which the adolescent has moved through the identity crisis, has made a commitment to their identified role, and consequently has achieved their identity.

2) Identity Moratorium: in which the adolescent is in crisis, with identity options being explored, but no firm commitment to any being made

3) Identity Foreclosure: in which the adolescent conforms to the expectations or desires of others about their future, and does not explore alternate options

4) Identity Diffusion: characterised by a lack of direction, no sense of choice, and no attempt to commit to an identity.

It is accepted that within Marcia's stage theory of identity development, an accumulation of experiences offering choices and personal decision-making and providing disequilibrium in identity actually assist in the construction of a final identity, and a commitment to an identified role. However, Baker (2009) points out that, as many young people with intellectual disability have lower rates of social activity than the general population, it logically follows that the development of identity will be slower than noted in the general population.

Further, Baker (2009) identifies that due to the nature of intellectual disability, some experiences that are central to the development of identity may be more difficult to understand or interpret for young people with intellectual disability. By way of example, Baker notes:

> …successful resolution of Erikson's intimacy versus isolation stage requires the cognitive ability to attach meaning and valence to events and then compare the relevant stimulus categories of alone and together, which may be beyond the cognitive scope of some individuals with intellectual or developmental disabilities (n.p.).

Of particular concern to Baker is the possible lack of inductive reasoning skills in people with intellectual disability, which allow people to generate their identity. He explains that inductive reasoning involves "the coding of multiple similar exemplars into a common rule/category" (n.p.). Relating this to the development of identity, a person may subsequently induce features of themselves into a unified sense of identity. Baker offers an example of assuming an identity as a Christian as requiring the inductive reasoning to organise the different elements of religious belief into a statement, such as "I am a Christian".

A further concern expressed by Baker is that many people with intellectual disability have a pattern of compliance. This concern is supported by the Victorian Advocacy League for Individuals with Disabilities (2011) who note in their Advocacy Guidelines:

> Many people with intellectual disability who have limited understanding and experience might be overly compliant with or unduly influenced by the views and opinions of others (p. 4)

As a result of this over-compliant nature, Baker fears that many young people with intellectual disability remain in Marcia's state of Identity Foreclosure, and do not move through the stages of identity development. By passing straight into a stage of foreclosure, their "identity" as a person with a disability may be determined by their parents and/or the system that sees them on a pathway from school into disability services, with little prospect of an alternate lifestyle, or the development of anything other than a socially or culturally "disabled" identity. Others may leave school in a stage of diffusion—with no sense that they have choices, nor the willingness to make a commitment to an identity commensurate with consideration as an adult (Baker, 2009). However, Disability Support Workers (DSWs) in disability services may attempt to shift these people to a stage of identity moratorium by encouraging investigation of choices and supporting the exploration of these. They can offer young people with intellectual disability the opportunity to consider alternate housing options; to explore social experiences; and to understand their rights as people in the community with rights to access information and social occasions.

How life stages that describe the growth and development of the majority of the population translate for those with intellectual disability, whose lives require support and supervision has not been widely explored in the literature (Baker, 2009; Thompson, Schalock, Agosta, Teninty, & Fortune, 2014). Whether, in fact, young people with intellectual disability are supported to experience crises and explore a range of identities before committing to their chosen one, and whether this process of identity exploration runs a parallel pathway to that of young people without intellectual disability is not well researched. The path to settling down and becoming one's own person may well be moderated by the need to accommodate support and supervision, and the need to negotiate decision-making with others, either family or support staff. The environment that provides the framework for exploration of adult identities is potentially limited, and the protection against perceived harm may be similarly restrictive for those unable to autonomously negotiate the consequences of their actions.

3.3.3 Position 3: Social organisation and social structures:

The third lens through which adulthood may be considered reflects our need for social organisation and the establishment of social structures. Societies are generally understood to be the aggregate of people who live together in some form of ordered community within a specific geographic territory with shared customs, laws and organisations (Bernardi, Gonzalez, & Requena, 2007). Henry and Sundstrom (2016) note that there is general agreement amongst scholars that civil society is "an arena of activity that is distinguished from the private realm of family", but one that is bound by legal orders, or shared rules. A scan of definitions in various dictionaries widely acknowledges the term *society* as a group of persons gathered for religious, cultural, political, or other purposes, referencing the structured system of human organisation that offers a measure of protection, continuity, security and identity for its members (see, for example, Oxford Reference, 2017). Within any given social structure are institutions that are considered self-sufficient in so far as they offer relatively enduring clusters of values, norms, statuses and roles. The idea of "structure" in its most general sense, is described by Bernadi, Gonzalez and Requena (2007 p.162) as "a set of relations between elements that has some measure of coherence and stability". Social structure is recognised as a heavily abstract concept that can be applied to any set of relationships where a degree of order is perceived. Within any social structure will be found social systems in which interrelationships exist between individuals, groups and institutions in such a way as to form a coherent whole (Layder, 2015). In order to help meet the basic needs of any society, social institutions exist centred on families, religion, the law, politics, economics, education, science, medicine, the military and the mass media, amongst others. Society is made up of these social systems, within which the social position of individuals can determine their behaviour (Layder, 2015).

Social structure may be considered to be those rules and practices that, within a geographical location, influence the actions and outcomes of social actors (Bernardi, Gonzalez, & Requena, 2007). Piaget (1936) identified three important characteristics that define the concept of structures across scientific fields and disciplines. Firstly, a structure is a totality whose properties cannot be reduced to the simple properties of its constituent elements. Secondly, a structure is a system with its own laws to support its functioning, and thirdly, Piaget recognised that structures are self-regulating entities that maintain themselves throughout time. These characteristics influence the understanding of the term "social structures" in modern sociology, although Bernadi, Gonzalez, and Requena (2007) argue for recognition of two disparate visions of social structure, one that focuses on institutional vision, and the other on relational vision. Their first vision is that of institutional social structure, and refers to different levels of social structures, and the analysis of relations that support them. This institutional structure reflects the norms, beliefs and values that regulate social actions, and define its members' expectations of behaviour. The second vision of relational social structures considers opportunities for freedom and creativity that are allowed by social structures, along with the influence of individuals to modify the social structure. In this approach the question that is considered is the relationship between social structures and individual actions. It is focused on social relationships that connect individuals, groups, organisations, communities and societies. The societal domain within this theoretical framework considers institutional social structures, while the relational interactions are considered in more detail under the fourth position, that of the conceptualisation of adulthood as a cultural phenomenon.

3.3.4 Position 4: Cultural determinants of adulthood

The fourth lens that is identified as a paradigm for adulthood is that of culture, as opposed to sociological measures. The meaning of the term "culture" is subject to debate within anthropology (Prinz, 2011). Prinz notes that the first influential definition of culture was offered by Edward Tylor in 1871 who offered that culture is "that complex whole which includes knowledge, belief, art, law, morals, custom, and any other capabilities and habits acquired by man as a member of society." Over time the pairing of psychological items such as beliefs, and external items, such as art, have raised concern by various authors, with some more recent definitions choosing between either the internal and external factors noted in Tylor's definition. While Margaret Meade stated in 1953 that culture is "the total shared, learned behaviour of a society or a subgroup" (cited in Prinz, 2011), more recently Gertz (1973, cited in Prinz, 2011) offered culture as defined as "an historically transmitted pattern of meanings embodied in symbols". Within such a view, culture can be considered to be like a text, within which culture is explored through the investigation of symbols. Such interpretations, according to Gertz, involve the production of "thick descriptions" in which "behavioural practices are described in sufficient detail to trace inferential associations between observed events" (Prinz, 2011, n.p.) Prinz also cites Richerson and Boyd (1995), who defined culture as "information capable of affecting individuals' behaviour that they acquire from other members of their species through teaching, imitation, and other forms of social transmission." This idea that culture is information shared amongst members of a community or social group, and shared in virtue of belonging to that group, is the definition that is assumed for this framework. Within such a definition, culture is a set of learned behaviours and beliefs that characterise a group of people, is socially transmitted, and changes over time. It encompasses a set of beliefs, and can include the foods, religion and family grouping within any group of people. It may include dress codes, the way in which people address each other, and typical behavioural patterns of those within the group. To really understand a culture, one must delve into underlying assumptions about how things really are (Prinz, 2011). Often these are unconscious to the members of the group, simply learned responses that result from adopted values, which subsequently lead to behaviours that become the norms for the group (Spencer-Oatey, 2012). Spencer-Oatey offers that values gradually transform over time into an assumption about how things really are, becoming so powerful that people are considered "insane" or "ignorant" for questioning them.

Cultural expectations offer clear rules under which individuals are guided in how to capacitate and constrain actions. Culture may be considered to have trait-like units that develop and spread as they are passed on within a community. Richard Dawkins (1976) characterised such trait-like units as “memes” that are passed on by imitation. Dawkins describes a “meme” as the cultural equivalent of DNA, explaining that cultural information is copied from brain to brain in a similar fashion to information passing genetically from one to another. Memes can be trendy words, such as “awesome”, that become popular within a culture, or tunes that are heard, whistled and passed on, or religions, which are more complex memes, but which can flourish amongst members of a community (Hudson Union Society, 2013). The changing meaning of words, such as “gay”, or “cool”, or “awesome”, can also be recognised as memes, taking on new meaning within a culture through passing on new ideas between its members. The social construction of these terms reflects new cultural assumptions, new “taken-for-granted” cultural meanings. “Adulthood” within a cultural framework is a meme that reflects cultural assumptions, and is communicated amongst members of a community.

3.4 Cultural and social construction of lifespan stages

The onset of adolescence has been loosely assumed to coincide with puberty, but this biological framework has been challenged in recent times by the argument that adolescence involves, to a greater or lesser extent, some degree of social construction (Hudson, 2003). Hudson (2003 p. 259) explains that this social construction “is closely allied with a social model of disability”, asking that even if adolescents do go through a period of inner turmoil as is commonly assumed during this stage, “is this the result of unalterable biological law, or by adjustments necessitated by particular environments, cultures and moments in history?” If there is, then, a question raised over whether adolescence is a social construct, it would seem reasonable to assume that the beginning and ending of this life stage is dependent on cultural and familial attitudes.

The challenge within this research was to investigate the cultural assumptions about adulthood that occur in the community. The idea of a new life stage, that of adolescence, was introduced in 1904 by Stanley Hall, a time he described as one of “storm and stress”, a turbulent time during which “the higher and more completely human traits are now born" (Hall, 1916 p. xiii). The introduction of this new term exemplifies the evolving nature of recognised developmental stages within cultures. As outlined in Chapter One and Chapter Two, we find that 110 years later Developmental Psychologist, Jeffrey Jensen Arnett and other sociologists (see for example Blatterer, 2005b; Konstam, 2007; Zukauskiene, 2016), are asking us to consider yet another life stage, that of emerging adulthood as a new and distinctly different stage between adolescence and adulthood. Much of Arnett’s argument for this new life stage considers the changes in the technological world, and applies to those aged 18 to 25 who are yet to become parents, yet to live in their own homes, and are not financially independent. These emerging adults can also be considered as the “failure to launch” sons and daughters, with parents seemingly happy to assume the role of parenting their children well into the 20s. This then changes the underlying assumptions that are held within our culture about what constitutes an adult.

Cultural considerations or determinants differ from the clear arrangements imposed on members of a community as social structures. Culture is certainly learned from one's social environment, and at any one time, a person may be a member of a number of cultural groups, requiring several layers of mental programming to assume one's position in gender groups, generational groups, social class groups, occupational groups or family groups. The degree to which people conform to cultural expectations and act in accordance with the values and behaviours of a culture, the more they share that culture. Marsumoto (1996) explains:

> culture is as much an individual, psychological construct as it is a social construct. To some extent, culture exists in each and every one of us individually as much as it exists as a global, social construct. Individual differences in culture can be observed among people in the degree to which they adopt and engage in the attitudes, values, beliefs, and behaviours that, by consensus, constitute their culture. If you act in accordance with those values or behaviours, then that culture resides in you; if you do not share those values or behaviours, then you do not share that culture. (p.18)

The degree to which young people with intellectual disabilities share the values and behaviours of their culture impacts their acceptance within that culture, and their belonging to that culture. Our cultural perspective on adulthood, and how people conform to the cultural values, attitudes and beliefs we have about adulthood, can determine membership of adulthood. Arnett (2000, 2001) explains that qualities of character, such as self-responsibility, autonomy, financial independence and self-direction in decision-making, are associated with adult status. Similarly, the Network on Transitions to Adulthood Policy Brief states that perhaps "most important to the discussion of what constitutes 'adulthood', traditional social roles—getting married, starting a career, having children—still matter greatly" (Osgood, Foster, Flanagan et al., 2004). How the lack of such roles or qualities impacts the status as adults of those who do not become autonomous, independent people, or who are unlikely to marry and have children needs further exploration. It is such qualities, roles, beliefs and values that are explored through the cultural lens of the theoretical framework for this thesis.

3.5 Conclusion

This chapter has outlined the theoretical framework that underpins the research in this study. Adapted from Priestley's Life Course Approach to Disability, it assumes four perspectives from which adulthood may be measured, these being biological, identity, social and cultural. Priestley (2003) recognises that there has been a tendency to think about young people with intellectual disability as developing within separate, parallel fields which emphasise their transitions within specialist domains such as educational, health or social services. Priestley (2003, p. 113) offers that there is "a sense in which disability has been constructed as a kind of liminal yet enduring adolescence" that renders young people with intellectual disability in a kind of "time-warp" beyond childhood, but not yet fully adult. He discusses a "nether world of repeated, unresolved transitions in which true adult status is neither envisaged nor attained". Yet 14 years on, and with Australia rolling out the National Disability Insurance Scheme (NDIS) in which these young people are presumed to become self-determining consumers with the power to more freely choose their lifestyle, the question of their attainment of adulthood status merits further exploration. As highlighted in their service charter, one of the specific aims of the NDIS is to “enhance the independence, social and economic participation of people with disability and their carers”. The focus on human rights that now demands support policies and practices recognise the fundamental freedoms of all citizens may well be reflected in contemporary conceptualisations of adulthood. However, this should not be presumed. Priestley believes “disability and youth both exist at the margins of adult citizenship” (2003, p. 114). The design of this theoretical framework is considered appropriate for exploring whether this is still the case. It is not assumed that all interviewees will share the same perceptions of young people with intellectual disability as adults, but this framework offers a means of analysing the domains by which these young people are, or are not, considered to have attained adult status, and thereby offer the context in which to compare and contrast conceptualisations.

Chapter Four
Research Design and Methodology

4.1 Introduction

The purpose of this research is to explore and map the conceptualisation of adulthood by parents of young people with intellectual disability, Disability Support Workers (DSWs) working with young people with intellectual disability, and the young people with intellectual disability themselves. The qualitative design of the research for this thesis corresponds to the context of the research topic and the research question. Employing a qualitative approach to data collection and a concept analysis to the data, this research aims to investigate stakeholder meaning of the concept of adulthood to young adults living with intellectual disability. The investigation of the concept of adulthood as it applies to young adults with intellectual disability aims to gain understanding and insight into its conceptualisation by young people with intellectual disability aged 18 to 25, and to those stakeholders in their lives who are parents or support staff. An outline of the methods used in this study is provided. It includes three focus groups; one consisting of parents, one consisting of DSWs, and one consisting of young people with intellectual disability. There are also individual semi-structured interviews undertaken with parents and DSWs. This chapter presents descriptions of participants, the methods of data collection and the principles of concept analysis. Issues of trustworthiness, ethics and potential bias are outlined. Previous chapters have provided a discussion of the literature and the theoretical background and framework for this study into the conceptualisation of adulthood as it applies to people with intellectual disability. The review of the literature identified gaps in the research and unlike the plentiful study into the transition to adulthood, there is a paucity of literature exploring stakeholder understanding of the concept and phenomenon of adulthood in young people with intellectual disability.

The term “adulthood” is used in everyday conversations between parents, DSWs, and the community at large with an underlying assumption that it offers the same connotations to all parties involved in communication around this notion. The scarcity of considered examination of this concept offers a focussed research context and the opportunity to undertake a concept analysis of the term ‘adult’, its synonyms, such as “grown up”, “mature”, “fully developed”, or “fully grown”, and their application in reference to people with intellectual disability. This chapter presents the research design used to approach this question of how stakeholders conceptualise adulthood for young people with intellectual disability, the methods used to collect the data, to analysis and interrogate the data, and to map the variances in conceptualisations offered by stakeholders.

4.1.1 Research questions

In order to develop an effective research methodology, Cresswell (2003) offers that the first step has to be the development of research questions that allow the researcher to gather the kind of information they require to address the research objectives. The purpose of this research is to investigate the conceptualisation of adulthood by young people with intellectual disability, and by the key stakeholders in their lives, namely their parents and their disability support workers, and to compare these conceptualisations in order to identify whether they are compatible, or sources of conflict between these groups. Thus the research questions to be addressed are:

1) What does 'being an adult' mean to
    a) Parents
    b) Disability Support Workers
    c) Young people with intellectual disability?
2) Do members of these three groups of stakeholders describe similar conceptualisations? In what ways are conceptualisations similar, and how do they differ?
3) If differences between perceptions held by parents and Disability Support Workers exist, do these provide an explanation for conflict between these two groups once young people with intellectual disability turn 18?

4.2 Paradigm and methodology

4.2.1 Interpretivist paradigm

A paradigm, or worldview, is explained by Guba (1990 p.17) as a “basic set of beliefs that guide actions”. A paradigm is generally considered to be a philosophical and theoretical framework that includes beliefs and values that are shared by members of a community, and that can act as a guide to breaking down the complexity of the real world (Kuhn, 1970). It dictates the kinds of problems that should be addressed by scientists, and the types of explanations that are acceptable to them. This study presents research undertaken using a framework that assumed the existence of multiple perspectives, and equally assumed that these perspectives are value-laden. It assumes an investigative approach to explore the views and actions of different groups within the community, seeking insights into the way each person sees their world. It assumes that different groups of people reflect different cultural beliefs that are derived from the influences which have shaped their culture (Minichiello, Sullivan, Greenwood, & Axford, 2004). The aim of the interpretivist qualitative approach is to understand the participants’ ways of believing and acting, and to build a picture of the culture of each group. In this research it is recognised that the groups under investigation, namely the parents of young people with intellectual disability, the support staff working with these young people, and the young people themselves, will each have different experiences and ways of acting because of these experiences. For this reason, an interpretative paradigm was employed in which knowledge is established through the meanings attached to the concept under investigation and the context within which it is explored.

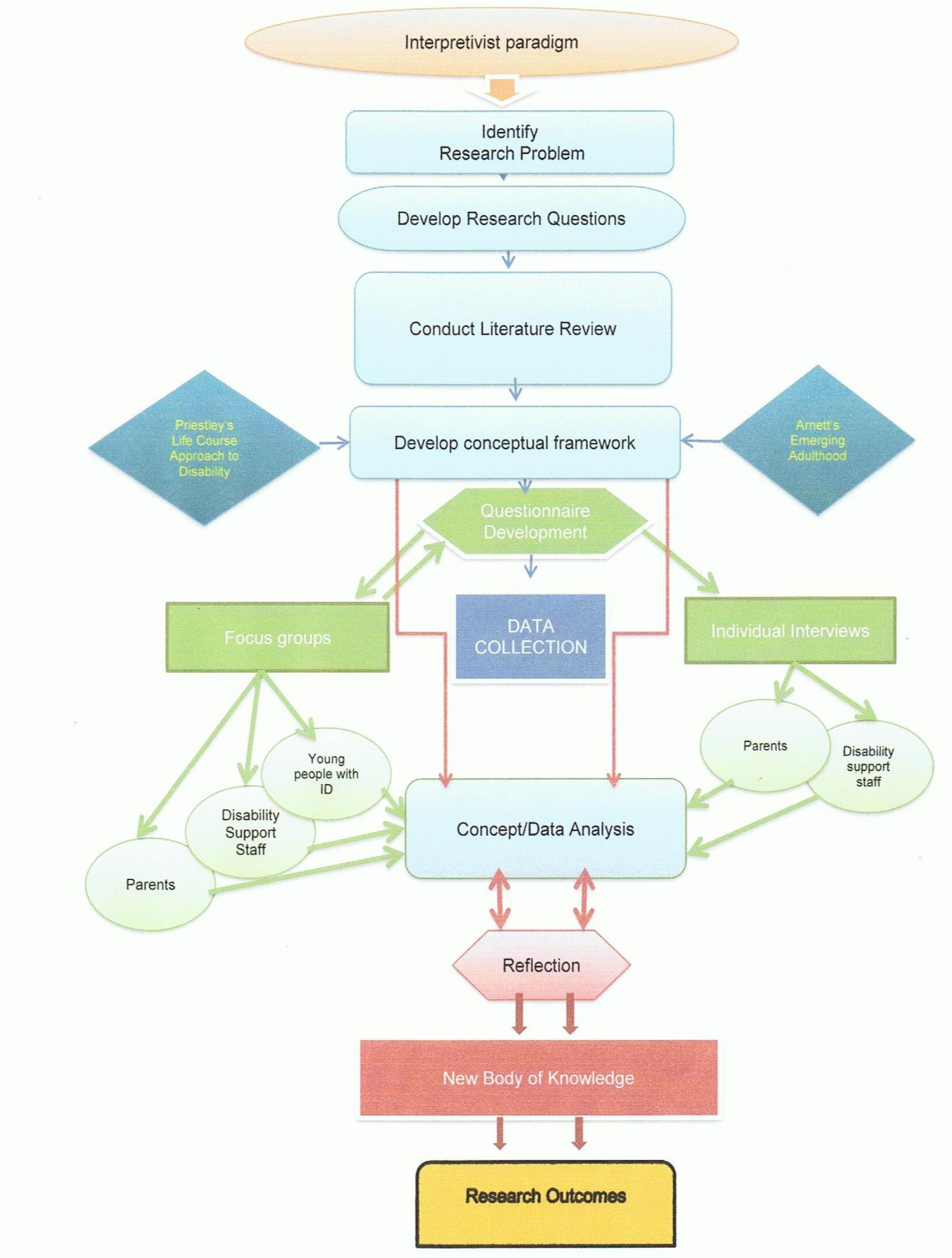
The purpose of research within an interpretive paradigm is usually to understand the subjective meaning that people recognise as guiding their actions, and to interpret and understand the reasons behind those actions (Klein & Myers, 1999 p.69). The intent of this research was to understand the meaning that groups assign to the concept referred to by terms such as “adult”, or “adulthood”, or “grown up”, and how this assigned meaning guided their perception of themselves (in the case of the young people with intellectual disability) or others as adults or non-adults, and their actions relative to this perception. For this reason, an interpretive approach was chosen for the research design. Such an approach to research recognises that reality is socially constructed (Mertens, 2005) and therefore relies upon the participant's own perception of the subject of the investigation. From their reality, each person creates their own definition of adulthood, assigning defining qualities and determining those who meet the requirements for classification as adults.

The term "paradigm", originating from the Greek word *paradeigma,* was used by Thomas Kuhn (1970) to denote a conceptual framework shared by a community of scientists that offered a model for exploring problems and offering solutions. According to Kuhn, paradigms have two aspects. The first applies within normal scientific research as experiments that are likely to be emulated. The second applies to shared preconceptions that guide the collection of evidence. It is conceived here that conceptions of adulthood can fall within different experiences and perspectives, and subsequent different realities. These different perspectives need to be interrogated and interpreted through qualitative research that leads to a better insight into the phenomenon of adulthood as it applies to young people with intellectual disability. In the absence of any more appropriate theory on which to base the research, this study required the development of its own theoretical framework with which to guide its research. This theoretical framework was outlined in Chapter Three. It forms the framework on which the research questions were developed.

4.2.2 Research design

Research design involves a clear focus on the purpose of the study, the research questions, and the information required to answer these questions. It also considers the strategies that will be most effective for collecting this information. The design for this research is depicted in Figure 4.1, which indicates links, conceptual relationships, and the influences between the various aspects of the research process. As mentioned in Chapter One, interest in this research stemmed from the tension noted in the literature and observed in personal conversations with and between parents and DSWs. The research questions and objectives were designed with this tension in mind, in order to develop an understanding of the experiences of those young people with intellectual disability, their parents and support staff, as they journey beyond the age of 18 and into this world where they are referred to as "adults". Guided by the underpinning interpretive paradigm, both focus groups and individual interviews were used for the collection of information required to address the research question. Following the collection of data, conceptualisations from the three cohorts of stakeholders were presented. From these findings, a discussion of emerging key themes will be offered in Chapter Five, Chapter Six, and Chapter Seven. A mapping of the similarities and differences in stakeholder conceptualisations is presented in Chapter Eight. These similarities and differences are discussed in depth in Chapter Nine, with the conclusions, limitations and recommendations from this research presented in Chapter Ten.

Figure 4.1 Research design



4.2.3 Qualitative research

Qualitative research explores information that may not be quantified through traditional quantitative research methods. It explores people's opinions or observed trends (Patton, 2002a). Patton explains that qualitative research offers a framework for people to respond in ways that accurately represent their own perception and experiences of a particular phenomenon. Denzin and Lincoln (1994) contend that interpretive qualitative research locates the observer in the world, using interviews, conversations, recordings and self-reflection to interpret the world, and to understanding phenomena, and the meanings people bring to them, in a naturalistic setting.

Qualitative research aims to depict a world in which reality is a socially constructed, complex and ever-changing perception. Researchers who undertake interpretive qualitative research thus recognise that they may be dealing with multiple realities (Lincoln & Guba, 1985). Within qualitative research, expert knowledge is believed to be situated in local communities, and rooted in interactional sites. Hence qualitative researchers explore through interactions with participants their perceptions and understandings of their worlds. To understand these constructed realities, the researcher takes an "inside view" from listening to the participants and interpreting the data collected from interactions.

For this study, rich data and profound meaning were sought from the perspective of parents of young people with intellectual disability, support workers who worked with these young people, and from the young people with intellectual disability themselves. Individual interviewees would naturally have a diverse range of experiences, various realities, and numerous understandings and ideas about adulthood. They would also have diverse thoughts on the impacts and consequences of those experiences. If this study had simply relied on surveys and statistics in isolation, the multifaceted, individualised human experiences that arises from qualitative research may have been portrayed wrongly as simple and widely generalisable (Todres, 1998). Creswell (2003) states that in cases where minimal research exists, or limited theories have been developed, qualitative research is particularly appropriate. In qualitative studies, questions often starts with a *how* or *what,* as do the research questions of this current study, examples of which would be:

> *How do parents/family members, disability agency management teams, and direct service support staff (stakeholders) define adulthood, autonomy, self-determination and quality of life for themselves, and for young adults with intellectual disabilities?*
>
> OR
>
> *What are the guiding principles that influence stakeholders in the support, abrogation or limitation of the adult rights of young people with intellectual disabilities?*

The characteristics of qualitative research and their suitability for this research are listed in Table 4.1. This outlines the framework offered by Cresswell (2003) that demonstrates why an interpretive, qualitative approach is, therefore, an appropriate approach for this study.

Table 4.1 Characteristics of qualitative research (Creswell, 2003)

Characteristics	Applicability to this research
Researcher as the key instrument of data collection	Yes
Data collected as words or pictures	Yes, as words
Outcomes as process rather than product	Yes
Analysis of data inductively, attention to particulars	Yes
Focus on participants' perspectives, their meaning	Yes
Use of expressive language	Yes
Persuasion of researcher by reason	Yes
Scientific method approach (inductive-bottom-up). Researcher generates rich and detailed explanation from data collected	Yes
Research objective is description and exploration	Yes
View of human behaviour: Behaviour is fluid, situational and personal	Yes
Behaviour is studied in natural environments, the context in which behaviour occurs	Yes

4.2.4 Concept analysis

Concept analysis has been a prevalent research method since it was popularised by Wilson in 1963, and advanced by Walker and Avant (1983). It has been widely used to develop and clarify the knowledge base of nursing since this time, with Rodgers (1989) noting the need to resolve conceptual problems as a component of intellectual advancement of nursing practice. Nursing has long had an interest in clarifying and intellectualising its conceptual framework and to this end concept analysis offers an approach that:

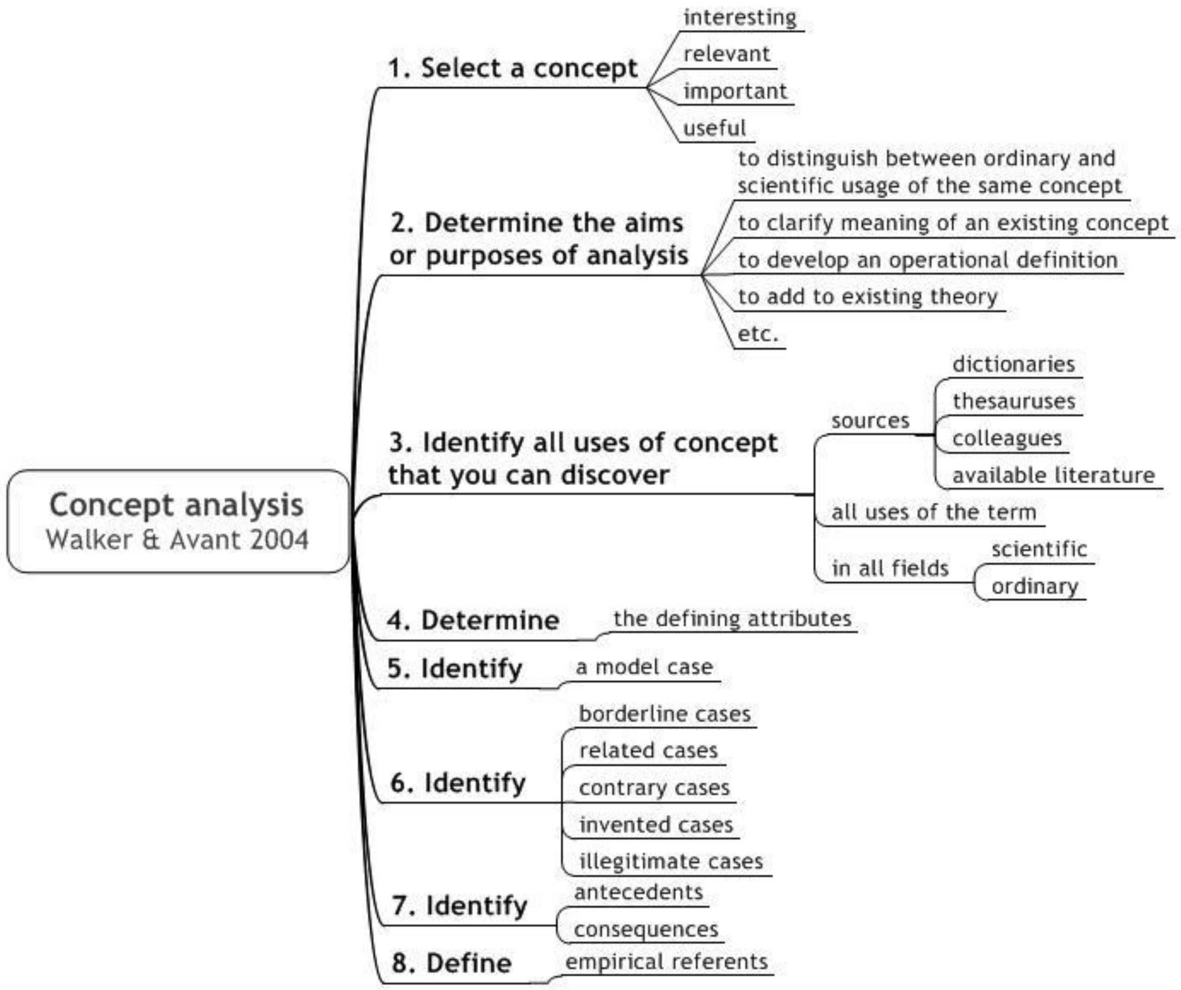
> … overcomes problems concerning the separation of the mental and physical realms of reality, that recognises the dynamic and interrelated nature of the world, and that presents concepts as offering a pragmatic contribution to the resolution of existing and significant problems (Rodgers, 1989 p. 334).

While it is imperative that a study concerning the lived experience of people with disability and their support networks should not be seen within a medical model, the recognition of some aspect of either care or support within these relationships allows this research methodology to be appropriate for this study. Earvolino-Ramirez (2007 p. 74) believes concept analysis is “applicable and relevant to terms that have been used across disciplines, for long or short periods of time, and in emerging and evolving areas of research”. The use of concept analysis in no way suggests the author’s positioning of disability support in a nursing context, but rather reflects the belief that as a research methodology, it is relevant to the study of the concept of adulthood in the context of disability support agencies and networks. It is important to acknowledge the contextual framework is positioned firmly in a social model of disability, with due reference to the human rights model, but equally recognises that support needs offer relationships that may be reflective of empowerment models in contemporary health care perspectives (Falk-Rafael, 2001).

Concepts are regarded as important to the development of knowledge and to “promote the organisation of experience, facilitate communication among individuals, and enable the cognitive recall of phenomena that may not be immediately present” (Rodgers, 1989 p.330). Botes (2002, p. 32) explains that “[c]oncepts as lingual constructions are the most elementary symbolic construction by which people classify or categorise reality”. Concepts carry meaning, and provide tools with which people can make sense of, and offer meaning to their worlds. When the defining attributes of a concept are not clearly recognised, the ability of the concept to assist in communication is greatly impaired. In such cases, it can be difficult to distinguish one occurrence from another that is not an example of the concept. Rodgers adds that it is also difficult to differentiate between “the concept of interest and other concepts that may be related” (p. 330). This can create barriers when attempts are made to label an event or phenomenon as an example of a concept, resulting in impaired communication, “as questions regarding vague or ambiguous concepts are met with confused responses that are dependent upon individual and often *ad hoc* interpretations” (p. 330).

Adapted from Wilson’s method of concept analysis, containing 13 steps, Walker and Avant offered an eight-step approach to concept analysis founded on realism. In their model, concepts are viewed as static entities, independent of context, and with clear and distinct boundaries. Rigid boundaries are considered to define the “truth” of a concept. Walker and Avant offer linear steps for constructing cases in which deductive analysis results in a definition of a concept that can be measured empirically. This process was presented diagrammatically by Nuopponen (2010 p.9) (see Figure 4.2)

Figure 4.2: Walker and Avant's Eight-Step Model of Conceptual Analysis



Rodgers (1989) was critical of the deductive approach of Walker and Avant, claiming it failed to acknowledge the vast interrelationships in the world, suggested a static view of the world in which concepts did not change over time, and stayed constant across contexts. Rodgers' modified evolutionary view presents a concept as "an abstraction that is expressed in some form, either discursive or non-discursive". While acknowledging the valuable contribution to nursing knowledge gained from Walker and Avant's methods, Rodgers believed that the method of concept analysis had not been well understood, and argued that researchers had not explored the philosophical foundations and implications of conducting concept analysis. Thus, Rodgers asserted, it was not clear how concept analysis actually contributed to "further intellectual progression" (p. 331), as, while a conceptual definition may be determined, the actual value of this definition is not self-evident. Consequently, Rodgers called for an "exploration and critical examination of the philosophical foundations and implications of the method" (p. 331) as it was employed in nursing research. She offered an evolutionary model of concept analysis which modified the analysis model espoused by Walker and Avant, and which was founded on relativism, rather than realism, further explaining that:

> Through socialisation and repeated public interaction, a concept becomes associated with a particular set of attributes that constitute the definition of the concept. Concepts are publicly manifested through certain behaviours, with linguistic behaviours being one significant form of manifestation.

> Concepts, therefore, are generally expressed in statements that indicate what are considered to be the attributes. (p. 332)

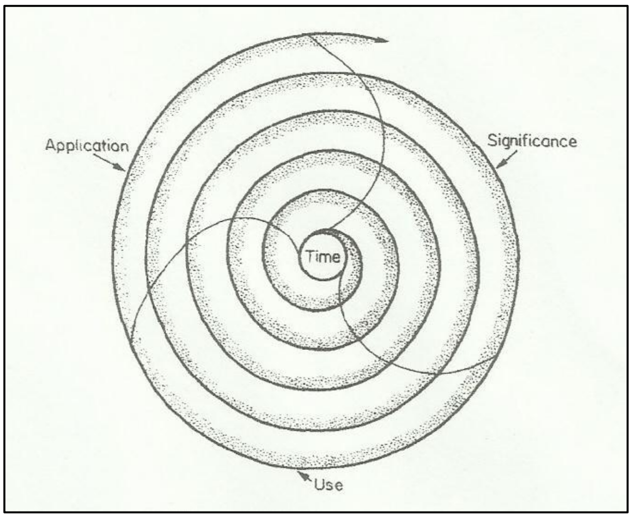
The evolutionary view of concepts recognises strengths, limitations and variations that can enhance the contribution they make to the attainment of intellectual goals. It recognises the attributes of a concept as a cluster of situations or phenomena that, when offered together, are appraised in reference to their similarity to a concept, rather than strict correspondence to fixed sets of necessary conditions (Rodgers, 1989)

The method of analysis described by Rodgers (1989, p. 333) involves the following steps:

1) Identify and name the concept of interest
2) Identify surrogate terms and relevant uses of the concept
3) Identify and select an appropriate realm (sample) for data collection
4) Identify the attributes of the concept
5) Identify the references, antecedents, and consequences of the concept, if possible
6) Identify concepts that are related to the concept of interest
7) Identify a model case of the concept.

Rodgers' Evolutionary Model presents cyclical phases that are influenced by significance, use and application of a concept. Within this model, concepts are viewed as dynamic and evolving phenomena that are not constrained by identifiable boundaries, and may change over time. While concepts of adulthood within legal or biological frameworks are recognised as constrained by boundaries such as chronological age, or physical maturation, the social and cultural frameworks are not similarly constrained and are constructed uniquely by each individual. Within these frameworks concepts may have multiple meanings, are considered subjectively, and recognised as contextually based. As noted in Chapter Two, Berger (2005) explains adulthood must be studied from a multidisciplinary perspective, and should only be very loosely connected to age.

Figure 4.3 Rodgers' model of concept analysis



The research in this thesis employed Rodgers' model of concept analysis to inductively identify those characteristics of adulthood articulated or tacitly referred to by interviewees. It assumes that rather than being solely a concept characterised by rigid sets of conditions that are unchangeable over time, as may apply biologically, chronologically or legally, the concept of adulthood requires additional analysis of the mental or private experiences of those for whom this term is applicable and pertinent. It considers that people may be directly or indirectly affected, with their quality of life influenced by discourses of adulthood and its applicability to those with intellectual disability. Rodgers' concept analysis draws from the writings of Wittgenstein, who argued that "words get their meaning in use, rather than by having some inner meaning that is hooked into them, and dissoluble from them" (cited in Baldwin, 2008). Baldwin offers an example of the modern day use of the word "mouse" in the new electronic world. She explains that words can be used in different ways, depending on context. Assuming a dispositional perspective allows for investigation of the behaviours or capabilities that may result from a person's use of the concept of adulthood. The development of concept analysis has contributed widely to the body of knowledge in nursing research. While recognising clearly that this research is not aligned with (but may further contribute to) studies of nursing, it acknowledges concept analysis as a pragmatic and rigorous approach to defining concepts that can further develop the body of knowledge in the disability field.

4.2.5 Identification of the concept

The concept of adulthood was selected for its potential relevance, importance and usefulness in addressing the conflict identified amongst stakeholders in the lives of young people with intellectual disability and outlined in the initial literature review. While the topic of the transition to adulthood is prevalent in research literature, it appears that the term "adulthood" is assumed to involve some common defining attributes understood by those who use the term, but this research considers the validity of this assumption through the mapping of conceptualisations, and comparison of similarities and differences.

4.2.6 Summary

This research explored the stated research questions using Rodgers' Evolutionary Model of Concept Analysis. In order to determine whether families and disability support workers use conflicting frameworks in decision-making processes with, or on behalf of young adults with intellectual disability, clearly one needs to analyse which frameworks form the basis for these decisions. Rodgers' Evolutionary Model of Concept Analysis focuses on the use of concepts, which claims to offer presentation of attributes that aid in the organisation of human existence (1989). Rodgers' contextual perspective recognises that concepts may appear to be in competition or conflict, with the individuals who use the concept being unable to articulate its attributes or the situation in which it is applicable. This may hinder "efforts towards further knowledge development" (p. 333). The aim of the analysis in this research was to identify the attributes of the concept of adulthood through attention to its common use by various stakeholders in dialogue, thus offering clarification that illuminates points of similarity and tension. The concept of adulthood was analysed from the interview data from participants within the milieu of interactions and decision-making with young people with intellectual disability. Defining attributes, those characteristics that occur repeatedly in the interview data, were identified, compared and contrasted between the three groups of participants. A model case is presented to offer a brief situational description that highlights how conceptualisations are dependent on defining attributes that may differ as a result of contextualisation.

4.3 Participants

Three separate and discrete cohorts of participants were sought for this research. The first group consisted of parents of young people with intellectual disability aged 18-25, the second group consisted of DSWs working directly with, or responsible for services to young people with intellectual disability aged 18-25, and the final group consisted of young people with intellectual disability aged 18-25. Focus group meetings were conducted for each group of participants, with individual interviews conducted with parents and DSWs (see Table 4.2). The rationale for the use of a focus group as the research methodology of choice for young people with intellectual disability is outlined later in this chapter. Acknowledging that these young people had much to offer on this topic, and the right to be heard, the use of a focus group approach was considered to offer appropriate support and opportunity for these people to voice their thoughts and opinions on the concept of adulthood through interaction with each other and the facilitator.

Table 4.2 Numbers of research participants

Participant Type	Focus Group	Individual Interviews	Total
Parent	7	14	21
Disability Support Worker	5	12	17
Young person with intellectual disability	13	0	13

4.3.1 Participant Group 1: Parents

The primary method of research for this study was a series of semi-structured interviews with parents of young people with intellectual disability, using an interview guide and open-ended questions. A purposive convenience sampling method was employed to select subjects for this research. Families of young people with intellectual disability were invited to participate in this research through notices placed in newsletters and on the websites of the Tascare Society for Children and the Association of Children with Disability in Tasmania. Both organisations offer regular newsletters that are circulated to families of children and young adults with disability through mail-outs and via their websites. The purpose of the research was outlined in notices placed in these newsletters, with parents and primary unpaid carers invited to contact the researcher via a Flinders University email, or by phone to the researcher's mobile number. This approach elicited an initial 15 respondents. Through snowballing of information via these initial respondents, the number of potential interviewees extended to 25 parents who expressed their willingness to participate in the research. Grandparents, siblings, or other family members who had assumed guardianship for young people with intellectual disability, were invited to participate in the research. However, finally all respondents in this study were parents of young people with intellectual disability, with no unpaid primary carers responding to either the initial invitation or to any snowballed information about the research. All but one parent had a child who they identified as having a degree of intellectual disability and aged 18-25. One parent was the mother of a 17-year-old daughter with intellectual disability who was to turn 18 within three months of the invitation. This mother explained that she was very concerned about how things were going to change when her daughter turned 18. She asked to be included in the research, and was invited by the researcher to be part of the focus group discussion. Other respondents were invited to participate in either an individual interview, or to be a part of an initial focus group discussion on the topic. Six parents chose to be part of the initial focus group discussion, bringing the number of focus group participants to seven in total.

Of the remaining 18 respondents, 14 participated in an individual interview. Four of the respondents who initially indicated their willingness to participate became unavailable or unwilling to continue with the interview process. In total, then, seven parents participated in an initial focus group, and 14 parents participated in semi-structured individual interviews.

The question of "how many interviews is enough?" is a persistent issue for qualitative researchers. Sample size is mentioned in the literature, with a variety of rationales offered to assist in justifying the selected sample size. Some factors mentioned include the expertise of the interviewer, the opportunity to interview, availability of contacts, and specificity of the sample group (Patton, 2002b). Baker and Edwards (n.d.) reflect on the writings of 14 prominent qualitative methodologists and conclude that the only answer to this is that "it depends" on:

> … epistemological and methodological questions about the nature and purpose of the research: whether the focus of the objectives and of analysis is on commonality or difference or uniqueness or complexity or comparison or instance (p. 42).

For this research, a number of factors contributed to the final number of interviews undertaken. Initial plans were to continue interviewing until a saturation point was reached where it was believed no new informational themes were being observed in the data (Guest, Bunce, & Johnson, 2006). During the time frame available for the research though, difficulties were encountered in recruiting additional participants, and eventually the 21 parents (seven focus group participants and 14 interviews) were considered sufficient for the purpose of this study. It was believed that there was good depth and breadth of sampling within this cohort of parents from which to collect data for analysis, and no new informational themes had been found in the last three interviews conducted. Details of participants are noted in Table 4.3.

Table 4.3 Participant Group 1: Parents

Pseudonym	Focus group	Individual interview	Age & gender of son/daughter with intellectual disability	Diagnosis of service recipient	Primary service/s accessed	Siblings (age and gender)
Hilda	X		M 22	Intellectual Disability/Cerebral Palsy Mild Autism Epilepsy	Recreation/ Community access	F 15
Rodney	X		F 21	Rhett syndrome	Occasional in home respite	M 23
Holly	X		M 20	Intellectual Disability Autistic traits	Training college	M 23
Tanya	X		M 19	Intellectual Disability Autistic traits	Training college	F 23 F 17
Priscilla	X		M 22	Global Developmental Delay Epilepsy	Community Access/Recreation program	M 25 F 15
Charles	X		M 19	Down syndrome	Community Access/Recreation	M 24 F 21
Faye	X		F 17	Global Developmental Delay	Secondary schooling	F 28 F 25 F 20
Cassie		X	F 22	Down syndrome	Community Access	M 28 M 26
Doreen		X	M 24	Global Developmental Delay	Group home	M 27 M 21

Pseudonym	Focus group	Individual interview	Age & gender of son/daughter with intellectual disability	Diagnosis of service recipient	Primary service/s accessed	Siblings (age and gender)
Margie		X	M 22	Global Developmental Delay Epilepsy	Community access	M 24 F 22
Peter		X	M 22	Global Developmental Delay Epilepsy	Community Access/Recreation program	M 25 F 15
Colin		X	F 20	Chromosomal abnormality	Training college	M 17 F 15
Wendy		X	M 23	Down syndrome	Open employment (voluntary)	F 26 F 21
Rupert		X	F 21	Prader-Willi syndrome	Recreation service	F 19 F 17 M 13
Michael		X	M 22	Global Developmental Delay Epilepsy	Community Access/Recreation program	F 18
Sheila		X	F 23	Angelman's syndrome	Community Access/Recreation program	M 27 F 25
Theresa		X	F 19	Global Developmental Delay	Training College	-
Barbara		X	F 20	Down syndrome	Training College	M 35 F 29
Heather		X	M 22	Intellectual Disability Autistic traits	Open employment (part-time)	M 25
Cathy		X	M 20	Intellectual Disability Autistic traits	8 hours open employment and part-time training	F 24
Barry		X	M 21	Down syndrome	Community Access, works with family on farm	M 29 F 27 F 24

4.3.2 Participant Group 2: Disability Support Workers

The recruitment of Disability Support Workers (DSWs) was first undertaken through approaching the executive officers of two large disability support agencies in Tasmania that provide a range of services, including both accommodation and day programs for young people with intellectual disabilities aged 18-25 years. The executive officers were asked to disseminate invitations to participate in this research to staff at staff meetings. The invitations included information regarding opportunities to participate in a focus group meeting or to be offered an individual interview. This recruitment strategy resulted in six initial respondents, with snowballing, (that is, the passing on of research details to others who may be interested) resulting in a further six respondents who indicated willingness as participants. To elicit more participants, TasTAFE trainers who were responsible for staff training to disability support agencies in Tasmania were asked to disseminate information about the research project to training participants. This resulted in a further eight respondents. These final 20 respondents offered a good representative cohort of DSWs employed across training, accommodation, recreational, and employment services, with 10 respondents working across two or more areas or service providers. However, three respondents became unavailable for interviews, leaving five members of the focus group, and 12 individual interviewees. Three managers/executive officers offered to participate in the research, and were invited to join the focus group meeting along with two other respondents who offered their preference to participate in a focus group over an individual interview. As presented in Table 4.4 the senior staff represented a combined 80 years of experience in the disability sector, and six interviewees had over 10 years of experience each. The other six interviewees had experience ranging from two to eight years.

Table 4.4 Participant Group 2: Disability Support Workers

Pseudonym	Focus group	Interview	Service type	Years of experience in disability services
Deb (46)	*		EO (executive officer), training services	22
Matt (52)	*		EO, accommodation and day support	28
Carmen (55)	*		Manager, recreation services	30
Jackson (35)	*		Community access trainer (transport) DSW, weekend respite services	12
Herman (34)	*		DSW, recreation services	15
Ellen (42)		*	Teacher/vocational training	14
Mark (38)		*	DSW, training provider	16
Rick (32)		*	DSW, team leader: day options Casual DSW, accommodation services (weekends)	8
Sacha (26)		*	DSW, day options service Community access trainer (transport)	4
Myf (27)		*	DSW, day options service Casual DSW, accommodation support	3
Linda (34)		*	Teacher aide, training college	6
Tina (45)		*	Casual DSW, supported employment	17

Neville (40)		*	Casual DSW, recreational service Casual DSW, accommodation support	10
Shane (38)		*	Trainer, recreational services	13
Patrick (52)		*	DSW, accommodation services	21
Abbey (31)		*	DSW, accommodation services DSW, weekend respite services	5
Martin (23)		*	DSW, community access Teacher assistant (special needs) part-time	2

4.3.3 Participant Group 3: Young people with intellectual disability

After initially collecting data, then comparing and contrasting the conceptualisations of adulthood by parents and disability support staff working with young people with intellectual disability, this research turned its attention to capturing the voice of the young people themselves in this complex dilemma. An invitation was extended to a representative group of young people with intellectual disabilities to present their thoughts and consideration of the concept of adulthood and how it applied to them. The question of methodology led to consideration of whether to interview potential participants individually or to apply a group interview technique to obtain narratives for concept analysis. The decision was made to use an existing group of students with intellectual disability incorporating focus group methodology for reasons explained in section 4.5.4.1 later in this chapter. Gill et al. (2008) note that as interaction is a key to a successful focus group, sometimes using a pre-existing group which is more familiar to participants can better facilitate discussions, and offers participants the ability to challenge one another more comfortably.

The focus group for this research consisted of 13 willing participants who were enrolled in the Work Pathways program at the Tasmanian Institute of TAFE, aged between 18 and 21 years, who had completed their secondary schooling, and were enrolled in either a Certificate I in Transition Education, or a Certificate I in Work Education. These students identified as having a level of disability (a prerequisite for enrolment in the course) with many having complex needs, including (but not limited to) intellectual disability, autism, visual impairment, social disadvantage, verbal communication limitations, and physical disability. As the students represented diversity in social status, diagnosis, familial demographics, disability, and intellectual capacity, it was appropriate to invite this cohort of students to participate in a focus group for this research. At the time of the focus group the participants had been together as a student cohort for just two months. In total, members of this group had attended five different secondary colleges in Southern Tasmania, some knowing one another from special education units they had attended together, but there were also participants from the private school sector who did not know the other participants prior to enrolment in their tertiary education course.

All 13 members of the focus group, aged 18-21, had diagnoses of intellectual disability, with the degree of intellectual disability ranging from quite mild (four with accompanying formal diagnoses of autism), to moderate, including two young people with Down syndrome and one with Bobble Head Doll syndrome.

Other students had more general diagnoses of global developmental delay, or simply intellectual disability. Two students used assistive communication devices—one relying on a voice synthesiser, the other using an iPad when his words were indecipherable. The focus group was conducted during normal class time, and one hour was allocated to the discussion. Participant details are outlined in Table 4.5.

Table 4.5 Participant Group 3: Young people with intellectual disability

Pseudonym	Disability type	Age
Noah	ADHD, Autism and intellectual disability (moderate)	20
Audrey	Intellectual disability (mild) with autistic traits	19
Wendy	Global Developmental Delay (moderate)	20
Cyril	Autism and intellectual disability (mild)	20
Sally	Intellectual Disability (moderate)	19
Gerry	Intellectual Disability (moderate)	19
Thomas	Intellectual Disability (and autistic traits)	20
Lesley	Autism and intellectual disability (mild/moderate)	21
Richard	Intellectual disability (moderate) and language disorder	20
Lauren	Intellectual disability (moderate)	18
Jacquie	Intellectual disability (mild)	19
Jay	Global Developmental Delays (moderate) with severe speech impediment (uses AAC)	20
Barbara	Intellectual disability (mild)	21

4.4 Data collection methods

Focus groups interviews are a recognised method of collecting qualitative data to explore or explain social phenomena (St John, 2004). They allow researchers to yield interactive data, to gain a clear view of participants' thinking, language and reality, and to explore variation, diversity or consensus on a topic. They allow access and insight into ideas, beliefs, attitudes and opinions, and provide participants the opportunity to clarify or qualify their agreement with ideas as they are discussed. They can prompt participants to analyse notions that they may not have otherwise considered which fosters a greater focus on participants' points of view (St John, 2004). In short, focus groups are a widely accepted method in qualitative research.

The composition of a focus group is an essential consideration in order to have the best quality of discussion from which to generate useful information. The initial focus groups conducted with, a) a group of seven parents and, b) a group of five disability support workers, were designed to identify issues to form the basis of the research questions for this research, as well as to develop the open-ended questions for individual interviews (Grbich, 1999). Gill, Stewart, Treasure and Chadwick (2008) suggest there is no "best" solution to group composition, but as the group mix will impact the data collected, it is important to consider factors such as the mix of ages, the sex of participants, and if appropriate, the social and professional status of participants.

4.4.1 Focus groups

4.4.1.1 Focus group: Participant Group 1: Parents

The parent focus group comprised seven parents of young people, aged 17-22 years, with intellectual disability. Grbich (1999) explains that the facilitator has control over three important aspects of the focus group process; the location, the physical environment and the composition of the group. The parent focus group was conducted in the meeting room of a Tasmanian organisation that supports families of children with disability, and was a familiar environment for five of the seven participants. The room was equipped with white board and markers along with butcher paper for collecting data. The focus group was also audio recorded for later transcription. It was held in the evening to maximise the opportunity for participants to attend, and a supper and coffee was provided. The group was purposefully selected to include parents of children from a range of situations, from those with mild to moderate intellectual disability who were attending college or further training, to others attending recreational programs, and the father of a young woman with severe intellectual disability who did not attend any programs for people with disability.

4.4.1.2 Focus group: Participant Group 2: Disability Support Workers

The composition of the disability support workers' focus group was also purposefully designed to include two executive officers and one management level employee within a recreational service along with two DSWs, one a social trainer who works predominantly with community access training, and another DSW in a recreational service with 15 years' experience in the disability sector. This focus group was conducted during one afternoon in the back (private) space at a central café, and afternoon tea was provided. This was considered to be a comfortable venue in which to conduct this meeting, with butcher paper used to record ideas, and the meeting audio recorded for transcribing afterwards. As Grbich (1999) explains, it is important that the location is relatively close to participants' working or living places to avoid extensive travelling, and should be separate to any participants' workplace. This was achieved for both focus group meetings. The venues also met the need for the rooms to be large enough to seat the group comfortably so that all participants could see one another, but not so large as to create an echo in the room, or to allow more shy participants to shrink into the background. The rooms were minimally decorated and did not present any significant distractions for participants.

4.4.1.3 Similarities in parent and Disability Support Worker focus group participants

Both the parent focus group and the DSW focus group presented a relative mix of ages, although due to the similarity in age of the sons and daughters in the parent group, there was some constraint on the diversity of age of participants. Participants in the parent group ranged in age from 40-56, all within what could be described as a middle-aged cohort. Ages of the participants in the DSW focus group ranged in age from 33-54, and included one participant who could be described in Arnett's terms as a young adult. The others were also in the middle-aged cohort. Grbich (1999) explains that when the composition of a focus group includes friends, this can inhibit participation due to loyalty or confidentiality. While certainly some members of both groups knew each other, there were no known “friendships”. It became clear in the parent focus group meeting that parents had shared similar experiences with support groups, or schools, and were known to each other through such links, but no firm friendships existed to deter participation by group members. Both groups also had a gender mix, with the parent group made up of five women and two men, and the DSW group comprising three women and two men.

No formal feedback was offered to participants following the focus group meetings, as Grbich explains that the numbers involved in focus group meetings are viewed as providing instant verification and adequate cross-referencing. At the conclusion of both focus groups, participants were invited to share phone numbers and email addresses to further their own discussions on the topic of adulthood and young people with intellectual disability.

Recordings of both focus group meetings were transcribed verbatim. The analysis of the data from focus groups took into account the interactive nature of the discussion. Gill et al. (2008) suggest that in group discussions individuals may challenge each other, or justify their remarks because of the group setting, in ways they may not in simple one person interviews. The analysis of data generated in focus groups must take such dynamics into account. Familiarisation of the data was achieved from reviewing the audio recordings of the focus groups, and from reading the transcriptions in their entirety. A number of themes, ideas and concepts from this data arose from the transcript. These were identified from the original context and rearranged under various themes using NVivo, as described earlier in this chapter, allowing the data to be reduced to key ideas drawn from frequently used words and phrases.

4.4.1.4 Rationale for use of focus group with young people with intellectual disability

There has been little attention paid to the use of focus groups with people with intellectual disability (Kaehne & O'Connell, 2010). It is important that the choice to use focus group as a research methodology is founded on the belief that it will achieve the purpose of the research project. Focus groups can be used as the major approach to generating data, and in this research, this is the only methodology used with young people with intellectual disability. The rationale for this is that focus groups allow research participants to “feel relaxed, develop a sense of ownership of the discussion and increase the potential to explore topics from different angles” (Kaehne & O'Connell, 2010, p. 133). Another advantage noted of the focus group approach is that it can be used to assist in overcoming literacy, language, cultural and/or power differences between the researcher and those being researched (St John, 2004). The use of focus group research for people with intellectual disability also addresses an important objective of current research policy, which is to include and empower participants, based on the concern that research should not be conducted on people, but rather undertaken with their active participation. As Kroll, Barbour and Harris (2007, p.690) explain, people with disabilities are “often treated as research objects … rather than as active participants”. The use of focus groups aligns with the need for research in this field to be sensitive to emancipatory and participatory principles. Kaehne and O'Connell (2010) note that emancipatory and participatory research paradigms can differ significantly, but that they both aspire to include those with intellectual disability in research processes. The authors cite Northway (1998) as stating that at the heart of participatory research is the commitment to forego the research agenda, and "allow ambiguity" (p. 135).

This research aims to obtain data on the experiences of participants in a social context, which lends itself ideally to the use of focus group methodology. Participants with intellectual disability are believed to enjoy the opportunity to share their thoughts and ideas with others who have similar characteristics (Kroll, Barbour, & Harris, 2007), provided the research is well planned, and skilfully executed.

4.4.1.5 Risks and limitations

While focus groups are widely accepted as a qualitative research method, the use of such groups for research with people with intellectual disability has received less attention than other research groups (Kaehne & O'Connell, 2010). While the somewhat loose format of a focus group is considered to be an advantage over semi-structured interviews, this also offers some unpredictability for facilitator and participants alike, and it is up to the facilitator to ensure the focus group is an enjoyable experience for all participants in order to elicit valuable data. Focus groups require participants be willing and able to share their opinions within the group, with a willingness also to listen and reflect on the opinions of others. This subsequently requires reflection of their own ideas in light of the contribution of others. Kaehne and O'Connell (2010) note that it is for reasons such as this, that there may be an over-representation of fairly articulate people with intellectual disability in focus group research. These are more likely to represent the population with mild levels of intellectual disability, as those with more severe limitations in receptive and expressive communication will have difficulty participating meaningfully unless the facilitator is particularly skilled in interview techniques. There are, therefore, limitations on the data collected in focus groups involving participants with intellectual disability. Such data should not purport to be representative of the full population of people living with intellectual disability, but be acknowledged as the voice of those with mild or moderate intellectual disability only.

While there are recognised limitations in focus groups as a general research methodology, such as having one or two dominant individuals who may restrict the opportunity of others to freely participate, of the group dynamics obscuring controversial perspectives (Smithson, 2000), there are other more specific concerns when these focus groups involve people with intellectual disability. Concerns raised by Kaehne and O'Connell (2010, p, 137) include:

1) the effect of intellectual impairment and the ability of participants to respond to and reflect on other people's viewpoints and engage in a debate;

2) the role of advocates or facilitators in focus group discussions;

3) the issue of eliciting views from pre-existing groups and the associated problem of over-researching existing groups and

4) the ethical implications of the (lack of) capacity of research to change lives.

These concerns have been considered in relation to this research and due attention offered to each possibility.

1) The effect of intellectual impairment and the ability of participants to respond to and reflect on other people's viewpoints and engage in a debate

The requirement to reflect on other people's arguments and engage with opposing views can place significant cognitive and emotional demands on participants of a focus group. Participants are expected to have the capacity to reflect on their own views and the views of other participants. They are also expected to engage communicatively with others in the focus group and explore issues that arise in the discussion with minimal guidance from the facilitator.

The focus group was conducted in the final hour and 15 minutes of a Health and Relationship class that normally ran from 9 am to 12 noon. In the two weekly classes prior to the focus group, students were given 30 minute opportunities to work in small groups to brainstorm and develop a mind map of ideas they have about the concept of adulthood. These activities were not supervised by the researcher, but were supported by Vocational Education and Training Student Assistants (VETSAs), who were asked to simply assist the students present any ideas they had, but not to guide their thinking on the matter. Students were encouraged to either contribute to a group mind map or to construct their own, noting (either with words or pictures) on butcher's paper, any thoughts they had about their achievement of adult status, or otherwise, and what this means to them. During the focus group session, students were invited to refer to their mind maps to raise points they had identified, agree with comments made by fellow students, or to draw attention to something they considered differed from, or expanded upon the thoughts of others. All students were individually invited by the facilitator to offer contributions to the discussion, and to reflect upon and comment on the ideas put forward by their peers. Students were reminded when necessary that it is acceptable to have their own ideas, as their experiences are not the same as all the other students, and were commended for sharing alternate perspectives. An example of this was when one participant, Lesley, adamantly stated that you can't be an adult while you are still a teenager, so when you were "eight-EEN, or nine-TEEN", (emphasis on the "teen") you were not an adult, and you could not be considered an adult until you were at least 20. Others argued that you were supposed to be an adult when you were 18, as this was when you voted, and could go to into public bars without your parents, and so forth, but this young man would not accept that these things made you an adult, as you were still a teenager. Lesley was supported to hear the opinions of his classmates, and eventually came to realise that it was fine to hold firm to his opinion, but that others may form different opinions.

2) The role of advocates or facilitators in focus group discussions

No advocates were used during this research, as the students had an established relationship with the facilitator of their focus group thus negating the need for advocates or support persons to be present to interpret contributions by individual members. Due to the researcher’s teacher-student relationship with the participants, another staff member in the program was requested to facilitate this focus group. This full time staff member was also well known to the students, has over 15 years’ experience teaching students with disability, and was comfortable to undertake the role of facilitator. The facilitator also believed there was no need for any student to be accompanied by an advocate in this process. Kaehne and O’Connell (2010) found that in cases where topics had been discussed with advocates in groups prior to focus group meetings, well-rehearsed responses were commonplace, with advocates facilitating “right” responses to questions raised by the facilitator. In this research, students had the opportunity to consider the topic of adulthood prior to the focus meeting, but in the absence of advocates or other staff, the responses were those of the young people themselves, and not directly influenced by outside stakeholders during the focus group meeting. It is acknowledged that the climate of the educational environment in which these students study encourages the concept of being an “adult learning environment” in which the “adult learners” are encouraged to take responsibility, wherever possible, for their own learning, and to be as independent as possible. However, the program also offers a ratio of 8.5 staff (FTE) to 28 students, allowing learning support, and assistance with personal care, and community and workplace access to be available as needed. The students were able to call upon the assistance of two teacher aides if required in the development of their mind maps, but the staff members were instructed to support the students’ own creations and thoughts, and not to enter into discussions about their own thoughts about the concept of adulthood.

3) The issue of eliciting views from pre-existing groups and the associated problem of over-researching existing groups

Kaehne and O’Connell (2010) call for researchers to be aware of rehearsed answers in focus groups with people with intellectual disability. This is thought to be the result of participants offering “right”, answers based on what advocates or family members have previously sanctioned as true or factual answers to some questions. The authors explain that some responses are preconceived and deemed accurate, with participants seemingly “versed” in their responses. To counter this concern, the facilitator should check that issues such as those to be discussed in the focus group have not previously been the focus for the group of participants, and in cases where this may have happened, they need to probe the “quality and validity” of the responses (p. 141). This is undertaken through exploring why a particular view exists. Drawing on the previous example of the idea of “teen”-agers not being adults, Lesley was questioned on where this idea had come from. He responded that it just made sense, but not that he had been encouraged to think this way by anyone in particular, adding, “Well, you are a child, then you’re a teenager, then you’re an adult”, suggesting that this was a concept he had logically deduced over time, and that this made more sense to him than the idea of being an adult and a teenager at the same time.

4) The ethical implications of the (lack of) capacity of research to change lives

The challenge of enlisting participants into research when this may upset or traumatise them, through being asked to discuss things that require recalling or reliving traumatic events, is of considerable ethical concern to researchers, more particularly when the participants may have limited social networks. A second concern is where the same participants are used repeatedly for research, yet there is no improvement to their quality of life as a result. The cohort of students who were invited to participate in this research had no previous experience of participation in focus groups for research purposes, and all participants except one who were invited to participate agreed to take part in the focus group. It was anticipated that a discussion on adulthood and anticipated changes in the participants' lifestyle may invoke some discomfort or anxiety amongst students. In the event of any student indicating verbally or non-verbally that they were uncomfortable with any aspect of the discussion, the TAFE College counsellors were on stand-by to offer counselling to these students.

One student declined the invitation to participate. This was preceded by a phone call from his mother explaining that the idea of becoming an adult was causing this young person anxiety. She explained that his behaviour at home was indicative of heightened stress over comments he had overheard from staff in the first three weeks of his enrolment about "learning in an adult environment", and "being treated like an adult", now that he was attending an "adult" learning institution. This anxiety was significant in itself, and this student's reluctance to participate warrants further consideration during the discussion in Chapter Nine.

The focus group was undertaken within the familiar context of a regular classroom discussion, to ensure students were comfortable with other participants, who constituted their regular learning group. It is therefore believed that this focus group methodology resulted in the gathering of valid data from participants. The limitations that have been identified in the literature about the use of this methodology for people with intellectual disabilities are acknowledged. As far as possible, these concerns were addressed so as to offer the research participants the opportunity to discuss their experiences in a safe and comfortable environment that allowed open and honest conversation.

Table 4.6 Guiding Questions, Focus Group Three: Young people with intellectual disability

Semi structured focus group guiding questions for young people with intellectual disability
What do you think makes someone an adult?
When do people become adults?
What things change when you are an adult?
What can adults do that children can't?
Do you think of yourself as an adult yet?

4.4.1.6 Qualities of the researcher

The role of facilitator is fundamental to success of focus groups, particularly for focus groups of disadvantaged people or marginalised groups. Grbich (1999) explains the qualities that are required for a good focus group interviewer, including: empathy, enthusiasm, confidence, a good sense of humour, a capacity to be non-judgemental, a clarity of expression, a capacity to end long-winded contributions without offending participants, an ability to encourage reticent participants and a capacity to intervene effectively in heated arguments. It was felt by the researcher appropriate that the researcher facilitated the focus groups for parents and DSWs, and the researcher felt extremely comfortable to do so.

4.4.2 Interviews

In contemporary research in the social sciences, narratives offer an interpretive approach through inviting participants to tell their stories. The narrative paradigm is based on the idea of narrative rationality, which Fisher (1987) claims guides all human communication as the main device for making sense of social action. Narratives can offer examples of causal thinking that explore questions of human agency and serve as bridges between people’s experiences and the norms they cultivate (Fisher, 1987; Sandelowski, 1991). The interview guides for this research encouraged participants to use personal narratives or draw from their own experiences in order to consider their understanding of the terms “adult” or “adulthood”. This approach lends itself to interpretive analysis of the data presented to identify characteristics that help to define adulthood for the interviewees. Narratives allow knowledge and conceptualisations to emerge as the stories unfold, and are essentially individual constructions of human experiences.

Interview questions were initially developed as a result of data analysed from focus groups meetings. Questions were developed as tools that could be used to collect responses to gather credible data that was relevant to the research questions. Interview guides were constructed to assist in directing conversations towards the areas of research if and when necessary, and to offer follow-up questions once the interviewee had completed their response to the previous question when required. When the interviewee veered away from the question posed, probing questions were offered to try to have the interviewee clarify or elaborate on their initial response. It is understood that people can hold two sets of ideas; theories that are espoused, and theories that are applied in practical situations. People can offer explicit attitudinal explanations, while exhibiting their implicit attitudes through their behaviours and approaches in real-world situations. Even though people may espouse theories that they claim guide their actions, these may not always be observed in their daily actions. For these reasons, interview questions were designed to investigate people’s beliefs, and also to examine actions in more practical applications. Interview guiding questions are presented in Table 4.6, Parents and Table 4.7, Disability Support Workers.

Table 4.7 Interview Guide Participant Group 1: Parents

1) When you think about your son/daughter now that they have reached the age of 18 or over, how do you measure their adult status? Do you now, (or when will you) see your son/daughter as an adult?
2) What does the term “adult” mean to you, and how does it apply to your son or daughter with intellectual disability?
3) How do you manage situations if/when your son/daughter wants to do things that may be considered “child-like”, such as listen to children’s songs, or watch children’s TV programs or wear clothes that depict child-associated images?
4) What sorts of things is your son/daughter doing now they are over 18 that differ from what he/she was doing before he/she was 18? How have your lives changed over this time? How have you adapted to any of these changes?
5) What do you want most for your son/daughter to get from their lives? How do you measure their quality of life and how does this compare to how you measure your own quality of life or that of your other children without intellectual disability?
6) How important is it to encourage your son/daughter to take risks, to go out of his/her comfort zone? What factors have led you to think this way?
7) What guides your thinking when you are either making decisions for, or helping your son/daughter make decisions about things in his/her life

(Probes: If your son/daughter has to make an important decision and asks for your support in the process, are you influenced by what he/she wants to do, of by what you believe is in his/her best interest? What other factors may you take into consideration when supporting him/her to make a decision?)

   a) If your son/daughter wanted to try something new, such as travelling to training/work on their own, but you thought it was too risky, in that they could be bullied, or get lost, or someone could steal items from them, what would you do?
   b) What about other activities generally associated with adulthood, such as adult movies, going to pubs with friends, attending nightclubs, or casinos, and gambling on horses, accessing sex workers, or voting. How do you feel about your son/daughter engaging in these types of activities? Does this apply to all people with intellectual disability?

8) The transitional phase when sons and daughters are moving beyond the school years is regarded as stressful for all families, regardless of whether the young people have intellectual disability or not. How do you think your experience compares with that of other families of children without intellectual disability, or your own experiences with your children without disabilities? Are their similarities or differences that you can identify?

Table 4.8 Interview Guide Participant Group 2: Disability Support Workers

1) Can you tell me about any training, either pre-service or in-service, you have received in relation to working with young people with intellectual disability and their families?
2) How do you feel about supporting a client to uphold their adult rights if you think they are not making choices that are in their best interests (e.g., food, smoking, financial expenditure etc.)?
3) What framework do you use to measure their quality of life?
4) If a young person wanted to listen to music or wear clothes that you considered inappropriate for their age, what would guide your response to this person?

5) The young people you are supporting are regarded legally as adults. How do you see these clients in terms of adulthood? Does your concept of adulthood apply to the young people you work with?
6) Can you reflect on any differences that you recognise between how services operate when they are supporting children and how they compare with services that support young people with intellectual disability after they have finished their school years, (after age 18)?
7) Services to the young people (over 18) that you support are generally regarded as person-centred. When you are supporting these people, how much consideration do you believe should be given to these young people as free agents, and how much consideration do you think should be given to their relationship to their family?
8) A young person with moderate intellectual disability (19) who lives at home with his parents, believes he could catch a bus home from work without you. He's been doing this for six months with you. You agree he should be safe, although there are some guys on the bus who might give him a bit of a tough time with teasing if you're not there. What principles would you draw on to support your decision about whether to let him go home without you?
9) His parents are adamant that he is unsafe and vulnerable to abuse, and do not want him travelling alone. He asks you to go and tell his parents that he is perfectly safe. He says he hates being treated like a baby. How would you feel in this situation, and why? What are the most important principles to be considered in this case? (prompts—safety, dignity, rights to take risks, respect for parents' wishes etc.
10) How important do you consider it is to support your clients to take risks—to go beyond their comfort zones and try new things? What if they don't want to? If you think it is important, how do you support your clients to do this?
11) Can you describe any situation where you, or any staff you know, have felt uncomfortable about supporting a person to act in a way that is supported by their rights? In such a situation, what would guide your actions? (Probes—this may involve choices about diet (e.g. Prader-Willi) smoking, financial expenditure, accessing pornography, sex workers, sex aids, gambling, relationships etc.)

4.5.2.1 Transcription processes

Each interview with a parent or a disability support worker was recorded using the researcher's digital voice recorder. As soon as practical after each interview a transcription of the interview was undertaken into a word processor document that was stored on the researcher's computer, secured with a password. Interviews were initially transcribed verbatim, ensuring that that data collected through narratives was transcribed as fully as possible. While transcribing can appear to be a straight-forward process, Bailey (2008) points out that it involves the researcher's judgement about what to include and what not to include. Bailey explains that the level of detail included in transcriptions requires balance between readability and the accuracy of a transcript. Transcribing involves close observation through repeated careful listening to recordings to ensure familiarity with the data, and to ensure that what is recorded is an accurate depiction of what is actually in the interview, and not what is expected to emerge during the interview. This process was a very lengthy process, with some utterances interpreted through analysis of the context and the interaction between the researcher and the interviewee during the process. There were times that contextual information helped in the interpretation of the recorded material, however wherever possible, the interview was transcribed as accurately and responsibly as possible. Transcriptions of interviews were then sent to each participant for review, who were asked to check their narratives for meaning, and to ensure that the transcriptions depicted their meanings accurately.

4.5 Organisation of data

Data analysis involved an on-going iterative process from the commencement of data collection to the conclusion of this study (Veal, 2006). Data analysis aims to make primary data "readable" for subsequent investigation by the researcher. Analysing qualitative research is undertaken by coding and categorising patterns in the data, and eventually classifying themes. In this study the parents', DSWs', and young people with intellectual disability's responses to questions were recorded, and subsequently transcribed. The transcriptions were spot checked for accuracy, and then became the units of analysis. These transcripts were returned to the participants as part of the process of ensuring accuracy of meaning. It also allowed participants to add any further understandings they may have considered since their interview had taken place.

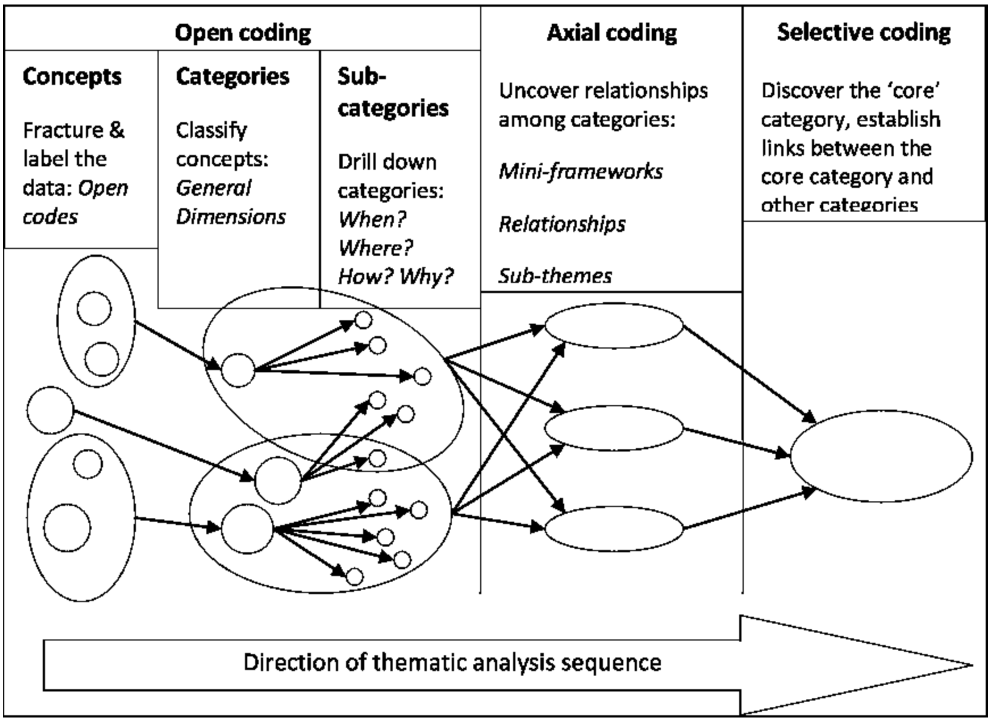
After the initial data had been checked and analysed, a qualitative software package was used to assist the research with further analysis of the interviews. NVivo 10 software was chosen as the tool for organising the data and thus assisting with the analysis process. Computer assisted qualitative data analysis systems (such as NVivo 10) have been promoted "to facilitate an accurate and transparent data analysis process whilst also providing a quick and simple way of counting who said what and when, which in turn provides a reliable, general picture of the data" (Welsh, 2002, p.3). It has been claimed that qualitative research lacks the validity and reliability of quantitative analysis, but clearly these are distinct differences between the two types of research. Programs such as NVivo allow researchers to systematically analyse their data with a level of control that was once considered the domain of quantitative researchers alone. The advantage of qualitative research is that it commits to understanding social phenomena from the interviewee's perspective, recognising reality as what people believe it to be. It concerns itself with the meaning people attach to their experiences in their own lives.

4.5.1 Coding

The analytic process was based on immersion in the data, with the words and phrases of the participants guiding the development of codes. To ensure a high level of familiarity with the data, the transcripts were read and re-read. A constant comparative analysis was undertaken, a method of analysis that was created by Glaser and Strauss (1967). Glaser and Strauss suggested that constant comparison of one piece of data with another helps to identify the relationship between two data sets. The similarities and differences between them can therefore be examined. This information is then used to classify, or code, the data to a category. Incidents of data that are similar can then be grouped together under a category. Although the incidents of data are coded under the same category, it is probable that they will uncover different properties and dimensions of a category, thus bringing out different aspects of the same phenomenon (Corbin & Strauss, 2008). Constant comparison can be undertaken deductively, with codes identified prior to analysis, then looked for in the data. Alternatively comparison can be inductive, with codes emerging from the data (Leech & Onwuegbuzie, 2007). In this study, codes were developed using both methods of analysis. Once codes were identified they were given short descriptors; for example, the code “independence” was described as any mention of living in one’s own home, travelling unaccompanied, being able to undertake activities of daily living (ADLs) without assistance, or any other situation that did not require supervision or support. Similarly, the code “employment” was used to describe an activity that was undertaken for payment in open employment or in a supported setting. For the purpose of this paper, volunteering activities were considered as acceptance in the community, and not as employment. The researcher took pains to compare each new portion of data with previous codes, so similar topics would be labelled with the same code.

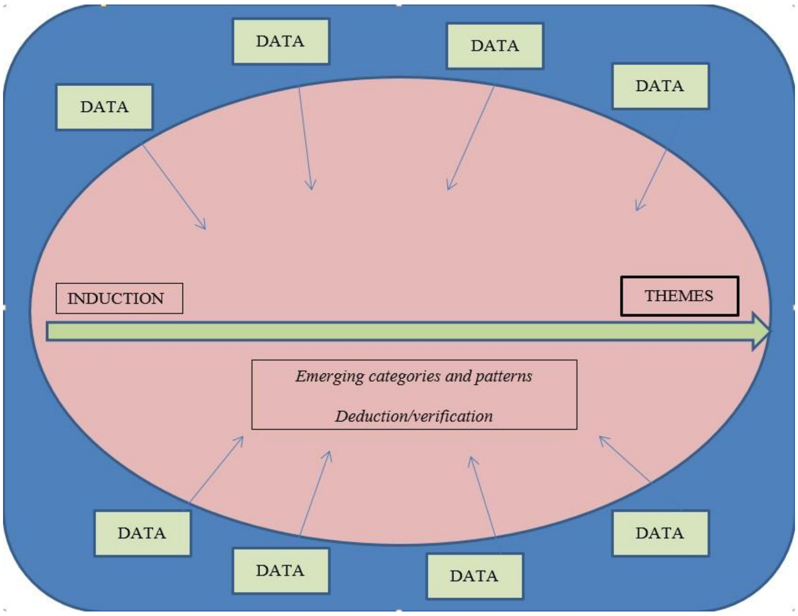
Following this process of open coding was the process of axial coding, or the formation of categories. Axial coding starts to put data back together in new ways (Strauss & Corbin, 1990, p. 97). Topics were grouped into provisional categories when they seemed to relate to the same or similar content (Lincoln & Guba, 1985). Categories became increasingly complex and inclusive. Finally, selective coding ensued: this was the integrative process of selecting the core category, systematically relating it to other categories, validating those relationships and filling in categories that needed further refinement and development (Strauss & Corbin, 1990, p. 116). Harwood’s diagrammatic representation of the analytic process in Figure 4.4 captures the process involved during the different coding stages.

Figure 4.4 The analytic process (adapted from Harwood, 2002, p. 76)



As the first step towards better understanding, organising and displaying the data, a matrix was assembled, a process generally regarded as one aspect of the complete analysis (Patton, 2002). The first sweep of the data resulted that had been mentioned by interviewees. These were listed and grouped together into 16 preliminary categories which appeared to encapsulate a topic group. In the same way that the initial codes had been identified, these categories were also identified either inductively (e.g., independence, rational thinking, cognition) or deductively (e.g., meaning from participation, membership in society or the reality or projection of adulthood).

Figure 4.5 Inductive and deductive thematic analysis process



At times there was lack of clarity about where a particular topic would fit, and consequently some topics were listed in more than one category. However, five major themes were eventually identified and labelled as “general dimensions”. The first two general dimensions, *Adults are independent beings,* and *Adults are rational beings*, emerged inductively from the data. These were obvious major themes that were identified by the occurrence and repetition of many relevant topics. On the other hand, the third, fourth and final general dimensions, *Adult life offers meaning, Adults are accepted members of society, and Adulthood may be actual or virtual,* were determined deductively. Examples of the process of coding, the development of general dimensions, the associated preliminary categories, and the identification of key themes are included in the findings (see figures 5.2 and 6.5). It became useful in communicating the findings as a whole and could now also be used for describing individual conceptualisations. While there is limited research detailing the use of matrices in qualitative research, together with steps that can be undertaken in the categorisation process—such as rules for inclusion (Miles & Huberman, 1994), one clear message is that researchers must be cautious that the data is not artificially altered to fit the categories and fill out the matrix (Patton, 2002). Thus, general dimensions, categories, and codes—other than those that had been deductively pre-determined—were identified to holistically reflect the interview data (Patton, 2002).

4.5.2 Refining the matrix

Analysis of qualitative data requires skill, vision, and integrity on the part of the researcher (Pope, Ziebland, & Mays, 2000). Initial indexing of data can produce “fuzzy categories” which require further refinement. The matrix of categories, although initially useful, proved to be a cumbersome and fairly unmanageable document which needed further refinement. Consequently, some initial concepts were renamed or subsumed within other codes, or occasionally deleted if they were considered extraneous or better represented by a related code. Codes that seemed similar were merged to form broader and more manageable sub-themes. Themes can be described as conceptual linking of expressions, and come both from the data (inductively) and from the researcher’s previous theoretical understanding of the phenomenon under study (deductively) (Patton, 2002a). Identifying themes and sub- themes deductively was done by referring to the literature and the pre-existing theoretical model (see Figure 4.5).

An example of this is shown in the way that the topics listed below “Adults are independent beings”, were organised deductively. This theme was deduced from comments made by both parents and DSWs that reflected capacity to undertake some activities without support. These comments described aspects of:

- Thinking independently
- “Moving on” or Moving out of home/having own home
- Having one’s own finances
- Managing personal items
- Confidence and “Letting Go”
- Doing things for themselves
- Income and money management
- Being capable in activities of daily living
- Having a capacity for self-protection
- Coping emotionally with daily experiences

The idea that adulthood for people with intellectual disability could be considered either as real (or actual) or artificial (or virtual) was deduced from the use of words such as:

- Appearance
- Acceptance
- Reality or Realistically
- Idealist or Ideally
- Able-ist or disable-ist
- Normality (e.g., “where normal people go”)
- Politically correct

Or phrases such as:

- Feel-good gestures

- Presents as, or seems like …
- How they think it should be, (but it's not)
- Them and us
- Training organisations "building them up for nothing" or "just passing time".
- Forcing issues of adulthood
- Because they are adults, they should …
- Adulthood not an age, but a condition

4.6 Research design limitations and potential bias

The family members and disability support workers involved in interviews and focus groups were limited to those who responded to calls for voluntary participation through parent-focussed or industry newsletters, and through snowballing via other parents or support workers. Twenty one (21) parents volunteered their time for focus group involvement or individual interviews, including one married couple. The severity of their son/daughters' disabilities ranged from mild levels of intellectual disability to one young woman and one young man, both with a profound level of intellectual disability. Many had associated disabilities or conditions, including vision impairment, cerebral palsy, epilepsy, autism, diabetes, or mental health issues, but each was recognised as having a significant intellectual disability. Each of the young people who participated had received special education services either in mainstream school or in special schools, and were currently engaged with specialised education, or with specialist disability services such as recreational, employment, or accommodation agencies, and all were eligible for registration with the National Disability Insurance Scheme.

The findings in this research offer a diversity of subjective positions which, along with the interpretive nature of quantitative research, makes it impossible to provide a complete and binding commentary on some facets of the questions under investigation. For this reason it is important that the information in these findings is not simplistically generalised to wider populations, but that further research is undertaken to provide comparative analysis and to allow for an assumed critical mass of research to confirm key trends and differences identified through this research.

4.7.1 Positioning of the researcher

Bias is defined as "an inclination or prejudice for or against one person or group, especially in a way considered to be unfair" by the Oxford Dictionaries online (www.oxforddictionaries.com). The Merriam-Webster on-line dictionary defines bias as "a tendency to believe that some people, ideas, etc., are better than others that usually results in treating some people unfairly" (www.merriam-webster.com). Patton suggests that value-free interpretive research is impossible, acknowledging, along with Denzin and Lincoln (2000) that as qualitative research is driven by ideology, each researcher brings their own pre-conceptions and interpretations to the data analysis, regardless of the methodology. Smith and Noble (2014) explain that understanding research bias is important for a number of reasons. Firstly, they suggest that bias exists across all research, regardless of research design, and is difficult to eliminate. Secondly, bias can exist at every stage of the research process, and finally, bias impacts the validity and reliability of any research findings and contribute to misinterpretation of data. Yet Strauss and Corbin (1990) assert that bias is not only inevitable, but is in fact desirable. This is based on the premise that the researcher is the primary instrument of investigation, and therefore any data collected will be biased. To this end, it is important that the researcher is sensitive to the data, and considers their bias in their analysis of the data in order to make appropriate analytical decisions. Personal bias is acknowledged in this study due to the researcher's past history of support and advocacy of families, thus acknowledging empathy for their situation. However, conversely, the researcher has worked also in the disability sector with young people with intellectual disability, and equally understands the situation of disability support workers. The researcher has worked for eight years in the training sector, guiding disability service employees through training packages centred on working with families, and has been aware of concerns expressed over many years relating to the challenges of remaining client-focussed in the face of family attempts at intervention. In light of the recognition of personal views, and assumptions, the researcher took every precaution, in collaboration and confirmation with the supervisors, to ensure these were not imposed upon interviewees, and that any themes identified from the data were not pre-determined. The data was also forwarded to the researcher's primary supervisor for corroboration of findings, and to ensure the identified themes were not prejudiced.

Chapter Five

Findings from Parent Focus Group and Individual Interviews

5.1 Introduction

This chapter will present the findings from the parents' focus group and the individual interviews undertaken with the parents of young people with intellectual disability. It will describe the data collected and the analysis process that lead to the categorisation of the data, and the induction and deduction of five key themes identified from the initial focus group, which were subsequently explored in the individual interviews.

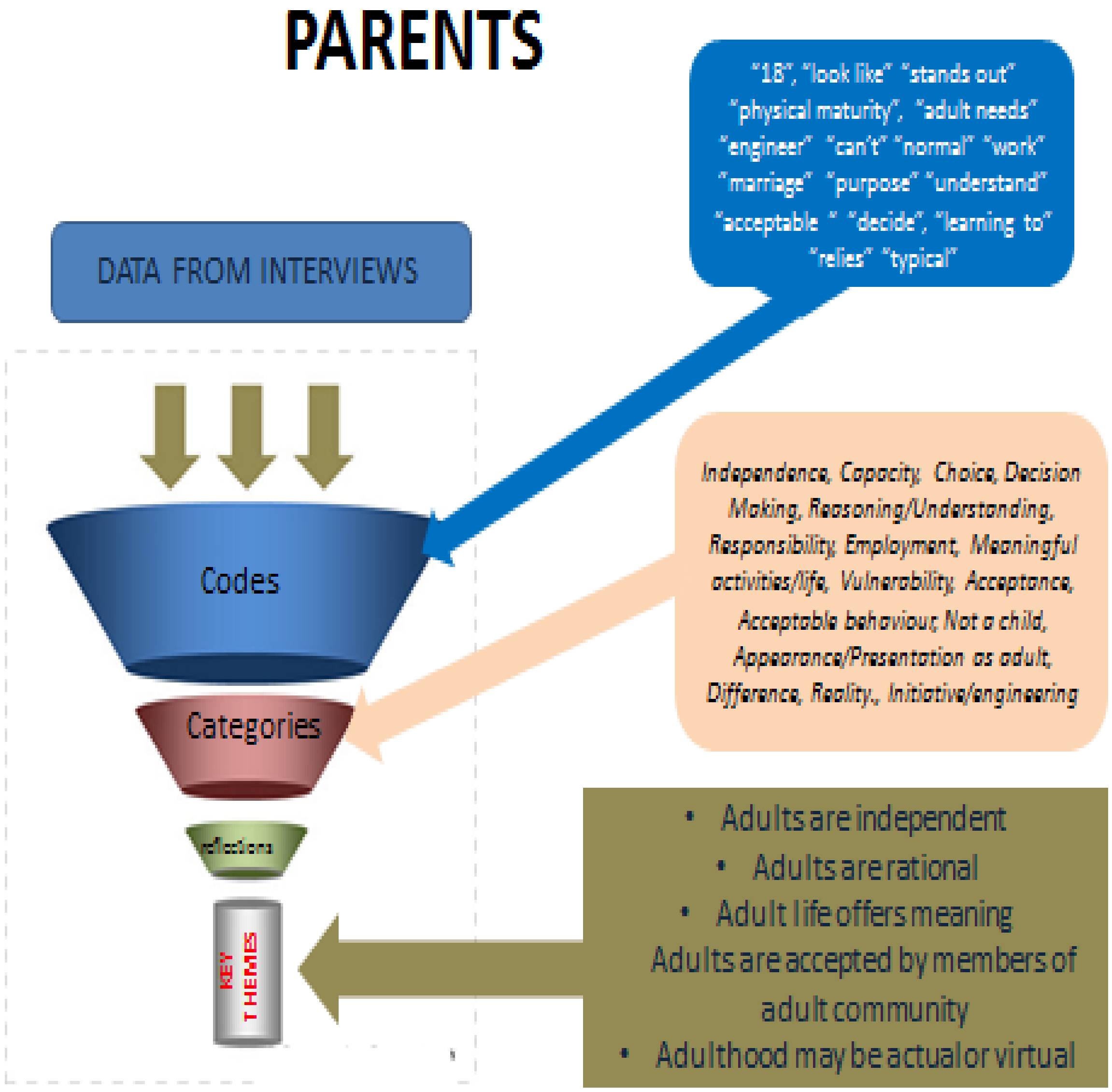
5.1.1 The focus group meeting

The focus group meeting of seven parents was conducted in an evening session with in-home respite services offered through the Carer Respite Centre to allow parents to attend while their son or daughter was supported in their home. Four parents knew each other through organisational associations, while three parents had not previously met any other participants. The group's sons and daughters had a range of diagnosed conditions. All had a significant level of intellectual disability impacting their lives, with associated diagnoses of Down syndrome, cerebral palsy, autism, Rhett syndrome, PDD-NOS, and Global Developmental Delay. The focus group was conducted over approximately 90 minutes with a short break after the first hour. The session was video recorded, and the conversation subsequently transcribed. The transcription became the data for content analysis, which included open coding, creating categories, and finally abstraction, through the generation of categories which grouped smaller categories with similar ideas and incidents into an overarching theme.

5.1.2 Focus group issues, themes and coding

Overall, the transcript from the 90 minute discussion produced very rich data from which a number of categories arose. A categorisation matrix was developed, with all data in the transcript reviewed for content and coded according to words and phrases. From coding and categorising patterns, a number of categories arose from the narratives of participants. Inductive content analysis, supported by NVivo software, identified frequently occurring terms, which were subsequently classified into a smaller number of content categories. For example, the term "vulnerability" was considered a category that encompassed terms such as "bullied", "ripped off", "taken advantage of", or "susceptible". The process of analysing the data to identify codes, then categories, and then through reflection to identify the key themes is illustrated in Figure 5.1.

Figure 5.1 Analysis process



The 16 categories that emerged from the initial coding, along with examples of compelling and powerful quotes are included in Table 5.1 to illustrate how these categories were identified.

Table 5.1 Categories emerging from parents' focus group

Category	Examples of quotes
Independence	• *It's still to emerge whether H can live independently.* • *My hope and dream I suppose, is that he would live independently* • *I guess the idea of being able to think and act independently plays some part in the definition of adulthood.*

Category	**Examples of quotes**
Capacity	- *He's had lots of good options and he's pretty capable, you know, within the limitations of his disabilities, he's a pretty capable human being.* - *There's no way she could bring up a child.* - *She is so low in terms of cognitive capacity, and is not likely to ever break away from her family*
Choice/lack of choice	- *They can make the choice to be poor, whereas for a kid with a disability, their life is always being planned and structured.* - *We try to let A chose his own clothes now; ... he has to come back and tell us how much and we give him the money to go and buy it ... usually.* - *It seems to be his choice, because he's saying, "No, I don't want to do this", you know*
- **Self-determination and decision-making**	- *He'd like to make his own decisions ... but there aren't the options for him to do that.* - *Letting someone else help him make his decisions is too much of a worry.* - *There will always be people somehow in charge, making decisions for him and around him.*
- **Reasoning/ understanding**	- *She doesn't have the insight to see what needs to be done.* - *She doesn't have any understanding of that sexual stuff.* - *I don't think he'd understand what he was voting for.*
- **Responsibility**	- *He loses his money, and he has had so many phones, and we are just not prepared to let him have lots of money or a phone any more. They just fall out of his pocket; he can't look after his things.* - *She doesn't look after her money, cause she doesn't understand, and she'd probably give the card away if I got her one.* - *They're sometimes being a bit naughty and irresponsible, and all that stuff.*
- **Employment/working**	- *He says with pride, "I'm working now". He thinks he's a gardener now.* - *The kinds of jobs that you look at are often so inappropriate for some of the kids.* - *... doesn't understand the ethic of work, so there's no way we can persuade him to do a job if he doesn't understand that it's about money.*
- **Meaningful activities/meaningful life**	- *... going to a pub where normal people go, you know, going places and that kind of thing is fantastic, that was really, really good.* - *Does she really have to turn up to that centre three times a week to make her life meaningful?* - *Most people engineer meaning in their lives.*

Category	**Examples of quotes**
• **Vulnerability**	• *He is still profoundly vulnerable.* • *He would just be bullied and wouldn't cope, and that's a real fear.* • *They know full well that he'll just hand over anything he's got.* • *There has to be somebody making sure that what makes you happy is not being ripped offed, or being taken advantage of, or hurt or anything.*
• **Acceptance by others**	• *[There are] so few people in J's life who've really made an effort to want to be with him.* • *The folks down there just don't want him near their kids.* • *He didn't have anyone to go out with ... if he didn't have his brothers, he wouldn't have anyone.*
• **Socially acceptable behaviour**	• *He wouldn't do basic things like clean his teeth, or have a shower.* • *Being an adult means having to consider other people, and I don't see a time when J will be able to do that.* • *He doesn't have any idea of what to do when he goes out with his brother. He doesn't know how to have a conversation with someone in a nightclub, for example.*
• **Not a child**	• *She's an adult in years, but not in maturity.* • *I guess physically he's an adult, and has been for some time. ... He has adult sexual needs.* • *She is much more mature and responsible ... but sometimes reverts to childish behaviours when she is tired.*
• **Appearance/presentation as an adult**	• *Her [friend] said she felt really happy to see H being independent and "adult", just walking down the street.* • *[His brother] rants at him and says, "You're not a kid S, you've got to watch adult things!"* • *Not so much things that he does that are child-like, more a lack of things that are like you'd expect of an adult.*
• **Initiative/lack of initiative ("parental engineering")**	• *We engineer our disabled children's lives. It is quite different to a normal child.* • *... what I would hope, and what I'm trying to engineer ...* • *If I didn't get him up and off to training every day, he would spend the whole time in his room with his computer games.*
• **Difference**	• *It's quite different to a normal child.* • *It's that sort of stuff (drinking and nightclubbing) that I'll never have with M—It just won't happen.* • *She does this little pacing ... I think it's quite apparent ... that she has a disability because she has that look about her.*

Category	Examples of quotes
• **Reality**	• *He can't see things from other people's point of view.* • *There is this kind of normality curve, but where does a child like H fit on that curve?* • *You have to modify your aims in light of the reality, and once you realise what the realities are, then it takes a weight off your shoulders.* • *The ableist assumption is that the young person, even with a highly limited capacity, is going to engineer meaning in the same way. But this won't be the case for R.*

5.1.3 Development of themes

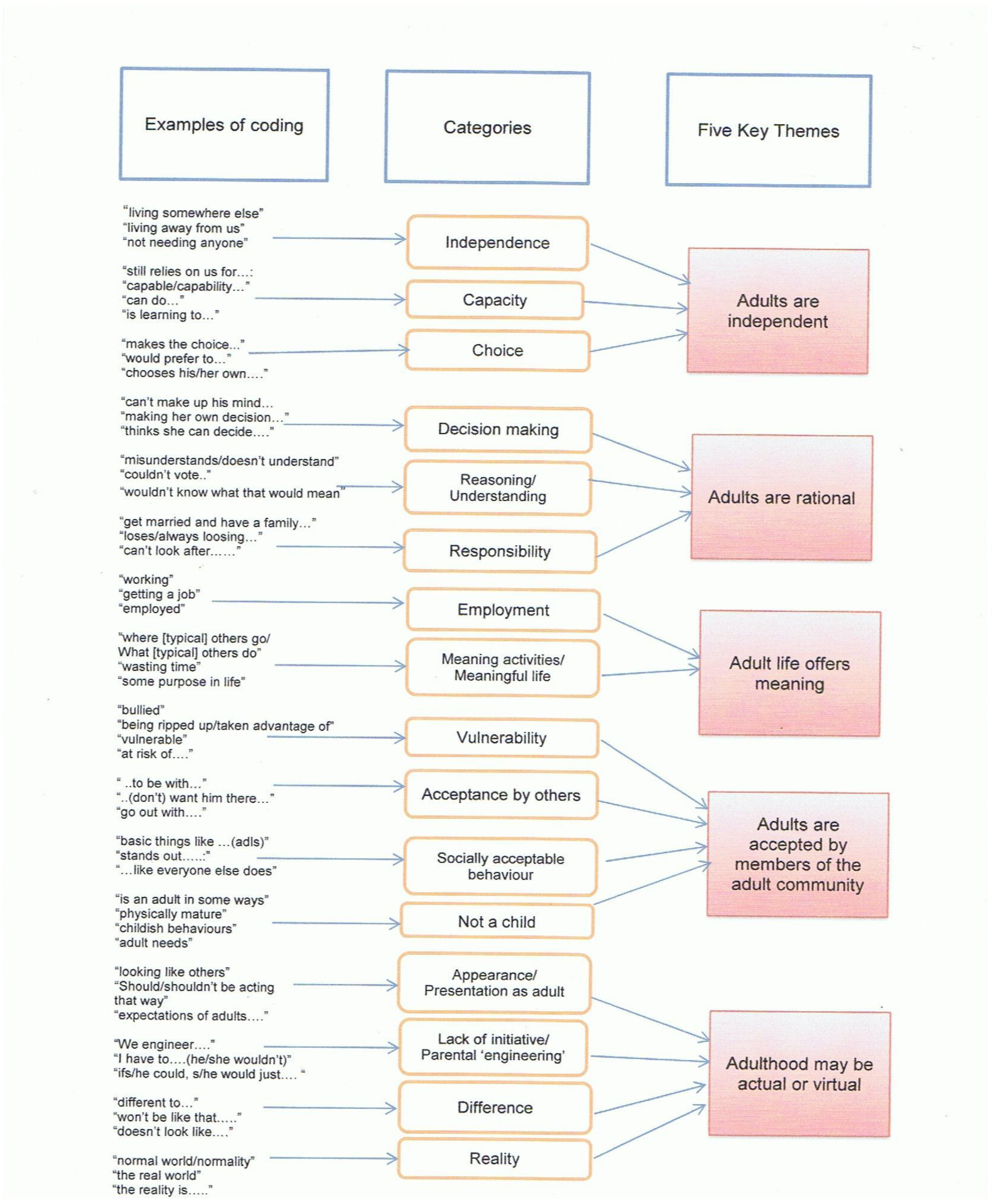
Further inductive analysis of these categories and immersion in the data allowed continued contemplation of the content, and a clearer understanding of "what was going on" within the data (Morse & Field, 1995). This deeper immersion highlighted similarities between areas. Eventually five key themes were identified that underpinned the focus group participants' conceptualisation of adulthood, and their consideration of their sons and daughters as adults in line with this conceptualisation. The earlier categories could be reduced to five major themes by recognising and acknowledging similarities within the original categories. These major themes aligned with five criteria that were assumed to be benchmarks for adulthood.

Table 5.2 Identification of key themes

Themes	Categories
Adults are independent	Choice, Capacity Independence.
Adults are rational	Self-determination and decision-making, Reasoning/understanding, Responsibility.
Adult life offers meaning	Employment, Meaningful activities/meaningful life
Adults are accepted members of the adult community	Vulnerability, Acceptance by others, Socially acceptable behaviour, Not a child.
Adulthood may be actual or virtual	Appearance/presentation of an adult, Difference, Initiative/engineering, Reality.

The process of moving from open coding to axial coding (categories) and subsequently to the five core categories, titled key themes, is further illustrated in Figure 5.2.

Figure 5.2 From open coding to key themes



5.1.4 Further reflection on key themes

Prior to the focus group meetings, participants had been provided with a letter of introduction that included an outline of the proposed study, explaining the intention to explore the concept of adulthood as it applies to young people with intellectual disability. Facilitation of the focus group focussed the concept of adulthood as the primary centre of discussion, but it is significant to acknowledge that a singular focus on this conceptualisation proved to be a difficult to achieve. Instead the transcription contains more narrative discussion of issues that exemplified challenges within the transitional phase than attempts to define adulthood. Participants chose to describe recent experiences, as they moved from a system with which they were very familiar into the world of adult services. Much of the discussion centred on descriptions of interactions that reflected the issues that have been described in the literature review, such as stress, fear for, and vulnerability of their sons and daughters, the burden of care, concerns for the future, service systems not attuned to their needs, etc. The discussion offered participants an opportunity to voice their experience of the transitional process from the world of children’s services to the world of adult services.

The actual conceptualisation of adulthood or the offering of a framework within which to consider people as adult or otherwise was not easily forthcoming. Neither was it always a comfortable topic for deliberation, and was recognised as a challenging concept to reconcile with others whose children did not have disabilities. Many comments reflected the difficulty of the parents’ personal journeys through this period of their sons’ and daughters’ lives. Comments included reference to “parents and their sensitivities”, or requests not to be treated differently. One mother commented that she had seen people “recoil in horror” when she had tried to access generic adult services, and spoke of years of “battling to be accepted” by the general population. Another mother commented that “it is difficult to know where we fit in”. It was the facilitator’s challenge to re-focus the group on the adult status of their sons and daughters, rather than the plight of the parents.

The idea of adulthood as a measure of acceptance of diversity was a strong undercurrent throughout the focus group meeting, aligning with the idea of a “hood” being a “body of persons of a particular character or class” to which young people with intellectual disability may, or may not belong. This question of the acceptability or rejection of their sons and daughters, with subsequent impacts on the parents through courtesy stigma drew a level of camaraderie amongst participants which contributed to the liveliness of the discussion. Parents expressed concerns over differences they perceived as individualist traits of each young person with an intellectual disability, and how these varied from the way DSWs saw their sons and daughters. This was seen to be exacerbated during the transition from schools and paediatric health services, where DSWs had worked with and known their children for many years, to new adult services where DSWs were perceived to “jump to conclusions”, or “follow protocols”, without taking time to get to know these young people and their unique traits. The idea that these young people are automatically considered as adults was considered disrespectful to the parents, and showed scant regard for those characteristics that parents saw as defining adults, such as social maturity and acceptance, independence and personal identity.

5.1.4.1 Adults are independent

Parents in the focus group discussion agreed that people with intellectual disability lack independence and individuation from family or other support services. One of the agreed key features of adulthood was independence, and as the group could not conceive of a time in the future when their sons and daughters would not need the assistance of others in their lives, they did not consider them to yet be adults, and questioned whether this status would ever be achieved. At best it was recognised that all young people with intellectual disability would continue to require some level of support for; personal hygiene; financial affairs; transport; and reading or written tasks, and the requirement for this support impacted their adult status. The idea of independence was characterised through phraseology such as “not living with others”, “not needing others”, “being able to look after yourself”, and “doing thing by themselves”, and was considered to encapsulate issues of choice and capacity that contribute to the perception of independence.

5.1.4.2 Adults are rational

Similar to the idea of independence and choice, the focus group offered that being able to take responsibility for decisions made in a way that was considered rational was another criterion for one to be offered adult status. The focus group participants spoke of the inability to understand important concepts, such as the value of money, or social rules, as common amongst their sons and daughters with intellectual disability. This led to a perception of personal vulnerability, and a heightened level of risk for which supervision will always be required. This then negatively affects their conceptualisation as adults, as the protection provided is likened to parental supervision of children.

5.1.4.3 Adult life offers meaning

Focus group responses indicated the importance of adult life being constructed to provide meaningful activities, whether through participation in training or employment or through contributing to the community in voluntary capacities. Parents noted very limited choices of training or employment opportunities for their sons and daughters, which were often restricted to disability-specific services. Combined with this, the recreational pursuits on offer for those who do not enter training or employment are not seen as meaningful by parents and are often not considered to be the choice of the young person, but are simply what is on offer through the youth services. Adults are identified as people who engineer meaning in their life through actively pursuing skills and knowledge and positioning themselves with others in the community in meaningful ways. Young people with intellectual disability are seen to not be undertaking self-driven, meaningful pursuits either in work-related or recreational domains, so this impedes their consideration as adults. The parents believe that, rather than being recognised as offering value to the community, young people with disability are too often considered to be burdens to the community.

5.1.4.4 Adults are accepted by members of the adult community

The idea that young people are vulnerable to harm and abuse within their community leads parents to assume they are disliked, unpopular and unwelcome by other members of the community. This failure of some members of the community to accept and protect these young people stands them aside from the community of adults by their parents. It is also recognised that adults understand the social requirements, and have the capacity to meet these requirements, displaying self-awareness along with mindfulness of the alternate perceptions held by others in the community. This awareness of self and others supports socially acceptable behaviour in the community, which leads then to acceptance in the community of adults who exist interdependently, relying on one another, and offering mutual support and cooperation with one another. Within such a community, members are not rejected, excluded, abused or mistreated in the ways parents see their sons and daughters could be when they are not openly accepted into the broad adult community.

5.1.4.5 Adulthood may be virtual or actual

This category draws on Goffman's (1976) concept of virtual versus actual social identity in his seminal writings on stigma. Goffman talks of demands that are made on people based on assumptions of "what the individual before us ought to be" (p. 12). Those demands placed on individuals to be what is expected of them offers to the world a "virtual" social identity. By contrast, Goffman explains that despite the presentation of a virtual identity, a stranger may present evidence of attributes that identify him as different to others, which he refers to as his "actual" social identity.

The idea that young people can be seen on presentation as offering an appearance of being an adult (a virtual identity), may be considered an outward response to the demands made upon them. Parents acknowledge that they are aware of the need to present their son or daughter "age-appropriately", and they take great pride in the events that showcase their son or daughter's maturity or good fit with others. However, the parents in this focus group also questioned reality of this identity, noting that what lay behind the outward appearance of socially appropriate behaviours may not always be consistent with the actual identity, which may be more aligned with non-adulthood and which does not fully meet the demands for acceptance as an adult.

This theme combines four categories:

1) Appearance/presentation as an adult: Young people are guided and supported to appear and present with adult characteristics, and to behave in ways synonymous with community expectations.

2) Lack of initiative/parental engineering: Young people should exhibit initiative in the quest for identity formation. However, this is not the case for young people with intellectual disability. Their lives are "engineered", or arranged for them by others, with young people participating often in activities arranged by others.

3) Difference/Normality: Parents recognise similarities to others in biological and chronological domains but realise significant differences in social and cultural domains that place sons and daughters apart from "typical" or "normal" development

4) Reality: the reality for people with intellectual disability is significantly different to the reality for those living without intellectual disability, and while lip service may be offered to the categorisation of a young person with intellectual disability as an adult, the social rites and rituals

> such as first loves, first cars, first alcoholic drinks, marriages, employment etc., are often missing from the reality of their lives. The totality of their actual lives may not match their virtual identity, and may in fact fall well short of what is assumed as a "real" or "actual" adult life for those without disability.

An example of this theme can be seen from one parent's belief that there is incongruence between the idealistic expectations that some agencies may have for young people with intellectual disability to be acknowledged as "adults" and what may be referred to as a more "realistic" expectation that parents have of their sons and daughters, based on their longer and closer association with them. Hilda noted that one professional had once suggested that she was "full of shit" for suggesting her son was not able to hold a conversation with the service provider. Hilda claimed her son simply mimicked the service provider, giving her (the service provider) the impression that he understood what the topic was about. However, as they walked away from this professional, her son was asked what they talked about. He replied, "I dunno!" She questioned how long this professional would need to spend with her son before she realised that he had little understanding of the subject matter, and before the "reality" took the place of the false perception of competence or the assumption of capacity.

5.1.5 Are young people with intellectual disability seen as adults by parents?

The parents spoke of their sons and daughters as no longer being children, but considered that the term "adult" was only used due to no more appropriate term being available. One mother spoke about the quandary of being able to comfortably refer to her friend's adult offspring as her "kid" or her "child", but noticed a discomfort in others when asking about her own adult son, and their avoidance of the term "child" or "kid". To the question of when, or whether their sons and daughters should be recognised as "adults", Rodney, the father of a 22-year-old daughter with Rhett syndrome replied:

> *If the definition is legally of age, sexually mature, and socially mature, if these things become a definition of adulthood, it requires the person in question to be aware of those, not just laid upon them. They have to actually be aware of what sexually mature means, or what socially mature means, … by that definition, she can't ever actually be an adult—that's impossible. But that doesn't bother us.*

Rodney did not consider his daughter to be a child, and rejected the appropriateness of the notion of the eternal child as has been portrayed in historical accounts of people with intellectual disability. However, he was comfortable with the idea that despite not being a child, she still did not meet the requirements to be acknowledged as an adult. Hilda agreed that she also was unlikely to consider her son to be an adult, stating defensively: "The answer about when [he] will be an adult is that he's not, and he never will be. If that makes me a bad parent, beat me up with it!", to which Charles added:

> *I suppose the idealist in me would like to say it will happen, but the reality is, like Hilda, that [son] is not going to be able to take on the full range of maturities, or possibilities, because he*

> *probably won't be capable, and that is mixed in with that fear issue. You know that sort of picture of what that realistic situation is.*

The focus group participants agreed that the principles of normalisation perpetuate the need to present their sons and daughters as living by societal expectations that included participation at some type of workplace, or an alternative to employment (ATE) offered by recreational services, training institutes, or day options. Rodney considered all of these options to be a waste of time for his daughter, and likened them to child minding centres. He explained his choice to plan an individualised program for his daughter, as the expectation to attend a centre each day "started to pull the family apart—nobody could do anything properly". The idea that treating everyone "normally" required everyone to be treated the same as others was refuted.

> *[My wife and I] had concerned ourselves with that issue about when she becomes an adult, but I had to go back and look at the definition of adult in terms of legal definition, a social definition and a biological definition. You can Google that, and look it up, but it's pretty straightforward. … Rather than us desperately trying to do things normally, we've taken the tack that normality can be doing things differently.*

The group appreciated the need for society to be structured in such a way that necessitates groups to be divided into different categories for ease and simplicity of administration and bureaucracy. Charles talked about "systems, supports and mechanisms" for organising the general community, and offered that whether or not this was logical, it applied equally to those with disability, noting:

> *It's exactly the issue of that in respite: the "Oh 18s—they're different". Under 18s and over 18s are put in separately—but crikey, 18 doesn't mean a brass razoo. But again it's that traditionalist structured view that that is the way society is, so people with a disability are treated the same as everyone else.*

In summary, this group of parents acknowledged that their sons and daughters were no longer children once they had left secondary schools, turned 18, and were receiving adult services, but the term "adult" is only used in the absence of a more acceptable term to describe their status as other than a child. These parents agreed that their sons and daughters were in "no man's land"; not children and not adults. They are recognised as adults in some respects, but not across the full range of domains in which the term may be used. They respected the need to refer to young people as adults when they require "labelling" for the convenience of services that provide for "adult" clients, or "adult participants", but are more cognisant of the differences between their sons and daughters and others who present as mature, autonomous, independent and responsible adults who are accepted into the community unquestioningly.

5.2 Findings from parent interviews

5.2.1. Parents' individual interview questions

The findings from the focus group meeting guided the development of interview questions for the semi-structured individual interviews with parents. The following questions aimed to elicit responses that expanded on the characteristics already identified from the focus groups but also to invite discussion of other criteria parents may consider impact on the determination of adult status.

Table 5.3 Interview Guide Participant Group 1: Parents

1)	When you think about your son/daughter now that they have reached the age of 18 or over, how do you measure their adult status? Do you now, or will you at some point, see your son/daughter as an adult?
2)	What does the term "adult" mean to you, and how does it apply to your son or daughter with intellectual disability?
3)	How do you manage situations if/when your son/daughter wants to do things that may be considered "child-like" such as listen to children's songs, or watch children's TV programs or wear clothes that depict child-associated images?
4)	What sorts of things is your son/daughter doing now they are over 18 that differ from what he/she was doing before he was 18? How have your lives changed over this time?
5)	What do you want most for your son/daughter to get from their lives? How do you measure their quality of life and how does this compare to how you measure your own quality of life or that of your other children without intellectual disability?
6)	How important is it to encourage your son/daughter to take risks, to go out of his/her comfort zone? What factors have led you to think this way?
7)	(a) What guides your thinking when you are either making decisions for, or helping your son/daughter make decisions about things in his/her life (Probes: If your son/daughter has to make an important decision and asks for your support in the process, are you influenced by what he/she wants to do, of by what you believe is in his/her best interest? What other factors may you take into consideration when supporting him/her to make a decision?) (b) If your son/daughter wanted to try something new, such as travelling to training/work on their own, but you thought it was too risky, in that they could be bullied, or get lost, or someone could steal items from them, what would you do? (c) What about other activities generally associated with adulthood, such as adult movies, going to pubs with friends, attending nightclubs, or casinos, and gambling on horses, accessing sex workers, or voting. How do you feel about your son/daughter engaging in these types of activities? Does this apply to all people with intellectual disability?
8)	The transitional phase when sons and daughters are moving beyond the school years is regarded as stressful for all families, regardless of whether the young people have intellectual disability or not. How do you think your experience compares with that of other families of children without intellectual disability, or your own experiences with your children without disabilities? Are their similarities or differences that you can identify?

5.2.2 Preamble to data analysis

> *Oh my! Am I an adult yet? Have I grown up yet? Yeah—I don't know. Looking back on my life I think I was so young and naive when I got married, but we all thought at the time we were so*

> *grown up. But we're still developing. I'm 50 now and I'm still developing, and changing and growing up. Gee—that's such a hard question.* (Doreen)

Fourteen parents were interviewed in this research. Each parent was offered an individual interview, either in their own home, or at a quiet coffee shop of their choosing. Each interview was audio recorded, transcribed, coded and categorised as for the focus group transcription, and while the interviews introduced new re-occurring words and phrases, such as self-esteem, over-expectations, and relationships with significant others, no new key themes emerged from the interview data. The new codes merged into existing categories. The idea of significant relationships with others, for example, was generally found to fall within the categories of capability and responsibility when the topic of parenthood was raised. The idea of wanting to be a married woman, though, was seen as offering a meaningful purpose in life, so was considered within the "meaningful life" category. The term "over-expectation" was aligned to ideas of capacity. The question of who judges adulthood was raised a number of times. Parents posed this question to highlight the subjective nature of this concept, and to focus the discussion on the issue of alternative perspectives. However, on reflection, this was considered to be part of the discussion of why differences exist, rather than contributing to the conceptualisation of adulthood, so will be discussed in more length in Chapter Nine – Discussion. The categories arising from the interviews, the number of participants who offered comments on this category, and examples of typical comments are presented in Table 5.4

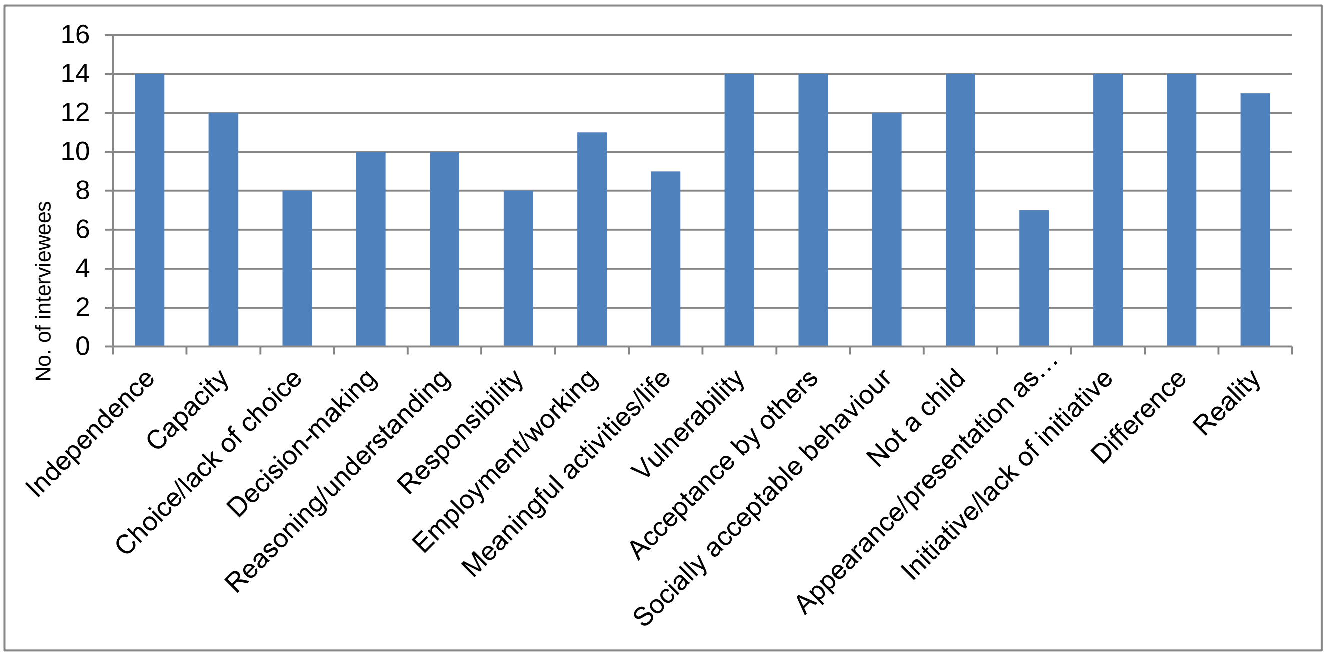
Table 5.4 Categories emerging from parent interviews

Category	Number	Examples of comments
Independence	14	• *The minute you move into high school, your independence kicks in, you're supposed to grow up.* • *... a degree of independence, to simply negotiate the community safely.* • *Even though he is supposed to be able to vote, he can't independently wash, shave, shower, and even needs help with dressing. Someone always needs to be there with him.*
Capacity	12	• *She is much more mature, much more responsible.* • *She blew the jug up the other day, can't use electricity, can't use the gas, all that sort of stuff.* • *Their performance, their ... everything about them is delayed.* • *They're way behind their years ... their development will plateau.*
Choice/lack of choice	8	• *If I gave him a choice, he'd just sit at home playing computer games.* • *If they can chose, if they know what they want to do, then let them do it.* • *There's a range of things he can make choices about ... within limits, but he can't choose to do things where he might get damaged, or abused.*

Category	Number	Examples of comments
Decision-making	6	• *They are supposed to decide on their menus for the week, but I don't think he thinks about it, or cares, frankly.* • *He could decide to put all his money on one horse, and wouldn't understand that he couldn't eat for the rest of the week!* • *... he's supposed to have the right to make his own decisions ... Yeah, right!! (laughs)*
Reasoning/ understanding	10	• *She didn't know which way to walk back to where she had to be.* • *That's a reasonable answer, but as a mother you know she doesn't mean what she says.* • *Age is not a factor chronologically, but their intellectual ability to understand where they are is more important.*
Responsibility	8	• *You're supposed to grow up and become a little bit more responsible. My kids aren't.* • *He just walks around and everything falls out of his bag, his pockets ... and he doesn't see it.* • *I say to him, you've got to let us know where you are if you're not at home when we get here.*
Employment/ Working	11	• *She doesn't like work.* • *Our daughter might at best never work more than a couple of hours occasionally.* • *I'd love her to have an independent job where she was supporting herself financially.* • *He doesn't have that idea of the whole concept of work, then we can't get him to work.*
Meaningful activities/ meaningful life	9	• *... wasn't a burden on the community ...* • *I have had real disagreements with some carers' views of wanting to make everything age-appropriate, you know. The activities have to be age-appropriate ... but it's not as meaningful to him.* • *What are the benefits of a program that starts at 9.00 in the morning and finishes at 2.30 in the afternoon, and three hours of this are spent on a bus?* • *All she wants is to get married, and have someone love her.*
Vulnerability	14	• *I try not to let her have too much money in case she loses her wallet or someone takes it off her.* • *It's a real worry. She is vulnerable, and that's one of the things ...* • *I'm fearful that she might be overestimated.*
Acceptance by others	14	• *... others causing a problem for her as well.* • *How do you make people who don't want to give people a fair go or feel threatened or uncomfortable around people who have extra needs?* • *I can see kids tolerating them but not accepting them, and that again, is a real social kick.*
Socially acceptable behaviour	12	• *They don't have particular social skills.* • *... in an accepted way, not people just tolerate them.* • *Being an adult means having to consider other people, and I don't see a time when J will be able to do that.*

Category	**Number**	**Examples of comments**
Not a child	14	- *you're still in charge of everything, but they've got these rights as an adult.* - *Because you're an adult now, you should be doing this …* - *They're not kids anymore in their bodies, but she's in love with a cartoon character at the moment!*
Appearance/ Presentation as an adult	7	- *I can see that they take away all his wrestler figures before he goes out anywhere.* - *I wish the bus they go out in didn't have signs all over it, saying, "Look at the loonies". It is better if they just go out on the regular buses.* - *I give her the money so she can be seen to be buying her own coffees or whatever.*
Initiative/lack of initiative ("parental engineering")	14	- *If we weren't driving him constantly, he'd happily stay in bed all day.* - *His range of interests are so limited, and I can't get him to try anything new.* - *The common and garden variety of kids, has the intelligence, or the street smarts, or whatever you want to call it, to negotiate their life's passage. Our kids don't.*
Difference	14	- *There is this kind of normality curve, but where does a child like [son] fit on that curve?* - *She will never go through these periods of so-called normality where she gets her first boyfriend, you know.* - *Inexperienced people might force issues of adulthood on people for whom it may not be prudent to do so.*
Reality	13	- *But realistically she's not going to want to do any of them.* - *I just feel it's a feel-good gesture.* - *Once you realise what the realities are, then it takes a weight off your shoulders.* - *The reality is …* - *She dreams of being a mother one day, but I won't let that happen.*

Figure 5.3 Frequency of coding – parent interviews



5.2.3 Discussion of key themes

5.2.3.1 Adults are independent

(Categories: Independence, Capacity, Choice)

Independence was recognised by all interviewees as a criterion for adult status. Michael spoke of the “independent” streaks that appear with puberty. Many parents celebrated achievements towards independence, such as becoming independent travellers, shopping independently, living more independently, or assuming independence in matters of personal hygiene. Independence was recognised as a goal or target, with all parents speaking of their son or daughter continuing to work towards this. In the absence of achievement of independence, and with continued reliance on family or DSWs for supervision and support, this was considered a criterion that was unlikely to be met by their sons and daughters. Parents were very focussed on their son/daughter’s inabilities. They were quick to point out areas of deficit, things they could not do that were expected of children much younger, such as reading, washing independently, and accessing the community. Eight parents made particular comments about different levels of independence shown by siblings or close relatives in their family. Their relative’s development of independence through markers such as gaining their driver’s license, or finding their first job, highlighted the dissimilar experience for their son/daughter with intellectual disability who they believed would never drive, or own a car, become financially independent, or attend nightclubs without support to assist and supervise.

For others, independence remained a dream, with Doreen expressing that, “My hope and dream, I suppose, is that he would live independently”. Her son at age 24 resided in a group home with support for all activities of daily living, and had little independence in any aspect of his life, other than being able to use his CD player. The connection between independence and freedom of choice was highlighted in his story. Despite being able to independently operate his CD player, his choice of music was stifled by support staff who would not allow him to play his preferred music (Peter Combe, the Australian children's entertainer), deeming it to be inappropriate to play in an adult group home, even in his own room.

Priscilla spoke about her efforts to establish a home for her son to share with some of his friends (also with intellectual disability or similar support needs), but without involving paid support staff. She had a vision of supported accommodation using a circle of family and friends, and believed this would offer more independence for her son in his local area than he would achieve by moving into a group home in another part of the city without the natural community supports that had sustained him in recent years. It was very important to Priscilla and her son that he could freely access his community where he was known by neighbours and local council workers, and could independently walk to local services that knew and understood him.

The capacity to be an independent worker was also mentioned by Wendy, the mother of a 23-year-old son who had commenced work two days per week at a local training college in the administration section, after proving to be a valuable worker while on work experience. Unfortunately changes to technology, and modernisation of equipment in the workplace impeded her son's capacity to work independently, as his new tasks required regular supervision. This had upset her son to the point where he had refused to continue to go to work. His self-esteem had fallen and he said he didn't like being told what to do all the time.

Summary

- Parents tended to be focussed on deficit areas, being clearly conscious of those things that their sons/daughters were not able to do independently, and this impacted their perception of their sons and daughters as independent adults.

- Parents recognised their son/daughters' wish to make independent choices but were not confident that this can be done safely.

- Rather than stifling growth of independence, parents promoted and celebrated as much independence as possible for their sons/daughters, and saw their sons and daughters as progressing, growing and learning rather than having completed their development.

- Parents reflected on the differences in self-determination and autonomy between those with intellectual disability and those close to them without intellectual disability and used this comparison to assess adult status of their sons/daughters with intellectual disability.

5.2.3.2 Adults are rational

(Categories: Decision-making, Reasoning/understanding, Responsibility)

Throughout the data were found references to decision-making, self-determination, and problem-solving. Aligned to the criteria of independence and choice, but recognised as another discrete theme was the notion that adults make decisions in accordance with reason or logic. The concern that young people with intellectual disability were not always cognisant of the consequences of their actions for themselves was prominent, as was the notion that to make rational decisions required an understanding of the impact of that decision on others. This was exemplified by Peter:

> *[Our son] doesn't know how to look after himself, and he doesn't understand the sorts of consequences of what might happen if he does things. Like, he can't understand why he can't go back to the park. He can't see things from the parents' point of view.*

Every interviewee made reference to their son/daughter's impairment of rational thought, lack of understanding of issues, impaired reasoning, and/or their inability to make decisions in their own best interest. In many cases such comments were linked to issues of vulnerability, and also to opportunities to grow and learn from understanding of the consequences of actions.

Heather expressed the view of the majority of parents, noting that risk taking, within reason, should be supported, as it allows young people to learn and grow, but explained that repercussions of any negative outcomes were more likely to be detrimental to her daughter:

> *You've got to kick your toe to know it hurts so you don't kick it again, and you've got to have life lessons for sure, but again, the ramifications for her are far greater because for her it's three steps forward and two steps back. She takes three steps forward and gets knocked three steps back. It's so much harder to recover from that.*

The lack of understanding of politics and the concept of voting was mentioned by eight of the interviewees as the reason for removing their son/daughter from the electoral roll. When asked about whether her daughter would vote in the forthcoming election, Cassie noted:

> *She wouldn't understand about the people. I took her off the roll. Maybe when she gets older I could put her back on but, until she can fully understand, there's not much point. I could go in with her and tick the box but I'd be voting twice, and that's illegal.*

This failure of services to recognise the young person's disability as permanently impacting on the their capacity to rationalise, to offer reasoned responses to questions, or to make good judgements, was noted by parents who spoke of their frustration at being stood aside or silenced in interview situations with their son or daughter.

> *Support workers take it into their heads that even if parents tell them that this is something [the young person with intellectual disability] can't do, it's like, well, they might not do it for* **you***, but we'll soon get them doing it! Like, I know he can't understand money, so it is not right to just let him have an EFTPOS card and let him go off shopping—he would have no money left for the things he needs money for. That won't ever change! But when I say this, I feel like they don't believe me; that they know better.* (Barry)

Summary

The parents interviewed tended to believe:

- Adults are able to weigh up the consequences of their actions and acknowledge the impact of their decisions on other people

- Adults can logically and rationally consider options and make choices that are considered reasonable by the majority of their community

- Adults can problem solve and keep themselves relatively safe through logical reasoning. Young people with intellectual disability struggle to solve problems using rational thought, and thus require support in ways that typical adults do not.

5.2.3.3 Adult life offers meaning

(Categories: Employment, Meaningful activities/meaningful life)

The idea that activities and occupations should offer meaning to participants was prevalent in the data from the interviews, but it was clearly and frequently articulated that meaning for young people may not necessarily be found in the same activities where adults without disability may find it. All but one parent interviewed noted concerns about their son/daughter's daily activities, and what offered them enjoyment and pleasure each day. The interviewees acknowledged the principle of offering age-appropriate activities for those with intellectual disability that allowed their lives to mirror their peers in structure and schedule, but their concerns centred on how this aligned with the quality of life of their sons/daughters. Doreen noted:

> *I have had real disagreements with some carers' views of wanting to make everything age-appropriate, you know. The activities have to be age-appropriate, but S wants to go back constantly to what he knows and what he understands. It is so hard to move him onto things like adult music where he might not get that visual kind of reinforcement like through videos and stuff like that. And it's not as meaningful to him –*

Parents discussed their hope that their son/daughter would find meaningful employment in the community for at least part of their week. However, few parents could identify workplace options beyond Disability Employment Agencies, or low-status positions such as recycle centres, or volunteering positions in charity shops. Such options were generally not seen to offer real meaning from the type of work offered, but were seen as "a better option than sitting at home doing nothing" (Tanya). Wendy's son worked voluntarily at his local library returning books to shelves, and while other parents talked of their son or daughter's work experience in some open employment situations, only Heather's son had successfully entered paid open employment on a part-time basis. One tip shop was identified as "work, but it's a fun environment, they have good modern music playing. … It's a funky sort of environment" (Heather). All parents except Rupert believed that the status of "worker" was worth pursuing, but at times the identity of the young person as a worker took some parental intervention. Peter provides his son with a $20 "pay packet" each Friday "so that he thinks he is working for real money, and that makes him feel good". Peter rationalised that this "bit of bribery" supports him to "fulfil a commitment, which is a good thing". Rodney, on the other hand, saw no value in spending time travelling to a day option, stating that "time sitting with family, or walking in the bush, or lying in the grass watching the clouds" was more meaningful for his daughter than day options, or repetitive "time-filling" tasks in supported employment services. In Margie's opinion, the types of positions on offer were unlikely to be suitable for her son, or offer any great incentive to attend each day:

> *The kinds of jobs that you look at are often so inappropriate for some of the kids. He's never going to be happy in an environment like that, it's that sort of, you know: "Let's have a big place where we can put all of the disabled people, and they'll all fit in and this is their lot in life", rather than sitting down and saying, "What spectrum of disability?" You know?*

The difference between the experience of open employment that was self-motivated, rather than arranged by parents or support staff was exemplified by Priscilla who spoke of her 15-year-old daughter and how her development towards independence was a painful reminder of her son's improbable development towards these goals:

> *My daughter has just got her first two part time jobs, and I locked myself in the bedroom and sobbed. My son is probably not ever going to do that.*

Rupert on the other hand, had no such aspirations or regrets for his daughter with Prader-Willi syndrome. He articulated his focus on helping his 21-year-old daughter to have valuable, meaningful experiences that were outside the typical system of services:

> *I know I hope this child will be happy and healthy, and well, and vivacious, and bright and engaging, and social and pleasant, and understand what joy is, and if she understands all those things, then she is ahead of people who can't value those things. So you look at the child, and say, "What is valuable for the child?" ... Then those values develop or sharpen the aims that you have for your child.*

Summary

In summary, the parents interviewed tended to believe:

- Adults have the capacity to find meaning in their daily activities.
- A "good life", does not necessarily include the routines found in spending time each day in supported employment, or day option programs
- Day options, supported employment options, and opportunities in open employment are all better options than sitting at home all day doing nothing.

- Programs need to be created around the needs of each young person to help them engage in activities that enrich their lives

- The normal rewards system of financial gains does not provide the same incentive for young people with intellectual disability, as they have little understanding of the value or money, or the capacity to exchange this for goods at another point in time.

5.2.3.4 Adults are accepted by members of the adult community

All but two parent interviewees spoke of the challenges for their sons/daughters to moderate their behaviours in line with social norms. Eight parent interviewees recognised reciprocal understanding and consideration of others in the community as a social norm, commenting on the self-focus of their son/daughter which obstructs the more socially appropriate mutuality in social interactions:

> *I can't see him ever being able to consider others. He is always not going to reciprocate, because he doesn't have that empathy to understand how we feel towards something. Yes, being an adult means having to consider other people, and I don't see a time when he will be able to do that.* (Doreen)

The non-typical behaviour stood their sons/daughters apart from others, and jeopardised their acceptance by others. The requirement to assimilate into community life in an acceptable manner was highlighted by Barbara, who talked about wanting things to "work out for the best" for her daughter. She was asked whether she was referring to her daughter's best interest, or issues of safety, or whether these were the same thing, to which she responded:

> *They're probably the same thing. So that she doesn't alienate other people, so that she's fitting within social norms. She needs to work out what other people will accept, because she really hasn't had (pause) ... that sibling "knockabout"; having to share, share relationships with people at close quarters, other than her parents, so I suppose I see it that she has to work out for herself how is the best way, the most acceptable way, the most comfortable way to be with other people in the community.* (Barbara)

Barbara added: "There is a worry in our local community that people are not very accepting, and she is seen as a, 'deficit', kind of person". The idea of true acceptance was identified as very different to the concept of tolerance. Colin spoke of his daughter's, and others' experiences at secondary college, where it was assumed inclusive practices have contributed to greater acceptance of young people with intellectual disability within their peer groups. He suggested that this expectation is unrealistic, commenting: "I can see kids tolerating them but not accepting them, and that again, is a real social kick". Colin's primary wish for his daughter was that she would grow up to be able to contribute constructively in some way so that she "wasn't a burden on the community".

The idea of acceptance versus tolerance was raised by seven parents. The typical comments are exemplified by this response from Margie, who explained that to be considered an adult required:

> *… a degree of independence, to simply negotiate the community safely, and in a friendly way, and in an accepted way, not [have] people just tolerate them, …*

There was a strong association drawn by parents between the idea of acceptance in the community and high vulnerability to manipulation and abuse by both support staff and general members of the public. The term "vulnerability", or "vulnerable", was the most commonly occurring coding throughout the parent interview data. In some cases this was aligned to the idea of impeded decision-making and capacity, but there were many examples of the vulnerability being depicted as the direct result of community attitudes that excluded, failed to protect, or directly harmed those with disability as a shunned and spurned minority. There was particular concern about sexual vulnerability of both sons and daughters:

> *If someone was to show her favour, in a particular way, she might take it the wrong way. I don't think she's ready for a sexual encounter that might be imposed on her.* (Barbara)

> *He would agree to all sorts of things that wouldn't necessarily be what he wants. He'd give in to anyone's demands rather than fight or run away.* (Peter)

The idea of vulnerability was acknowledged by Cassie, a deeply religion woman, who placed her faith in Jesus to keep her daughter with Down syndrome safe, believing an angel had lifted her daughter from the middle of traffic when she was very young. While recognising her daughter's need to be protected from harm that she believe existed in adult community venues, she trusted Him to continue to keep her safe. When asked about her daughter's adult rights to access adult venues, such as hotel bars, or adult shops, or casinos and betting agencies, Cassie was equally reliant on her Lord to ensure her daughter was safe, stating:

> *… but the Lord wouldn't let her do that; he'd put up a barrier so she couldn't do that. When you know Jesus, you know how he will stop it. He will protect her.*

Summary

In summary, the parents interviewed tended to believe:

- Adults consider other people, and are compatible with other adults in the community, with members treating each other with respect, and upholding the safety of members.

- People with intellectual disability often remain more self-focussed than others without intellectual disability, and therefore are not as well accepted by others in the community as a result of the lack of reciprocity in interactions.

- People with intellectual disability are *tolerated* in the community, rather than fully accepted and welcomed

- People with intellectual disability are often viewed as a burden for the community to carry.

5.2.3.5 Adulthood may be actual or virtual

The idea that parents identify two types of adulthood, one that is considered to be the presentation of the outer characteristics or behaviours associated with adulthood, and one that is the more “true” reality, or the actual adult status, was identified in the focus group data, and realised also in the interview data. The data from the interviews suggest that the idea of virtual adulthood may be the perception of the projection of adulthood, or the artificial structuring of the environment in order to make the young person appear to be acting autonomously, and behaving in ways that are socially acceptable by others who are recognised as adults. Parents work to present young people with intellectual disability as functioning independently and according to social norms within the community, recognising that without intervention, acts of independence may not simply emerge as they do in most cases of adolescent/youth development. The use of the terms such as “structuring”, “constructing”, and “engineering’, was common amongst the interview data, used by parents to describe their actions to help their sons and daughters achieve acceptance in the community, or to present their son/daughter as an active community member. There was an assumption by parents that without some level of personal intervention in planning and arrangement of the environment to allow for opportunities for work, engagement or shows of relative independence, these would not occur. Three examples of the types of comments referring to the planning and arranging of their children’s lives are offered below:

> *It is a matter of setting things up so that people will accept her.* (Colin)
>
> *That’s what I would hope, and what I’m trying to engineer. ... What I’m focusing on now is work.* (Heather)
>
> *There isn’t any unfolding; it’s more like structuring; we have to create the framework for our kid’s lives, [which] I think, is the fundamental difference.* (Margie)

Coupled with this theme of structuring the environment as a means of projecting an image of their children as “adult” was the sense that aims and ambitions needed to be framed within realistic expectations. While goals and aspirations were recognised as worthwhile, and necessary to ensure that young people with intellectual disability were constantly challenged to advance their skills and understanding, parents’ comments reflected concerns that the “politically correct” push for invisibility of the disability (Quibell, 2004) had taken some expectations to an unrealistic and overly optimistic level. For example, Michael noted:

> *Equal opportunity is wonderful, if you have equal ability, but you can only apply what you’ve got.*

Three parents, whose sons/daughters had all attended the same training institute, each mentioned a common phrase that they and other parents used about the training offered. They believed that the training essentially consisted of "training for unemployment", as very few graduates of the training courses successfully gained employment after completion. They all commented that the one or two years at this institute offered other opportunities to develop greater independence and provided social opportunities, but that efforts to prepare their sons/daughters for open employment were not "realistic", and that training simply paid "lip service" to providing equal opportunities for people with disability.

Parents were particularly concerned about bureaucratic agencies such as Centrelink, whose staff did not appreciate the permanence of intellectual disability, and questioned the severity of the disability using forms that requested guarantees that the young person was still disabled. The failure to recognise the reality of the life-long nature and impact of the disability angered parents who were asked questions such as, "Does your son still have a disability?", even when the diagnosis was of a genetic nature, such as Down syndrome, or permanent brain dysfunction, such as cerebral palsy. Rupert described the frustrating nature of such interviews for his daughter with Prader-Willi syndrome:

> *We were on this roller-coaster where you're constantly being asked, "Did your child's disability go away last night?" We keep having to say, "It's not going away—ever! It's here—we live with it!"*

The word "realistically" was prevalent during the course of the interviews. Parents spoke of their dreams or aspirations, but countered these with reference to a "realistic" approach that lessened these dreams to something more achievable by their sons or daughters. Expectations were expressed within a framework that acknowledged other key themes, such as limited capacity, impaired independence, challenges with meaningful employment, or other measures of social adulthood such as marriage, families or incremental improvement in problem-solving. The comments below are typical of parents who spoke of lowering their expectations, or their different "reality", for their sons and daughters:

> *What I would hope for him realistically would be very different, I don't expect that he would work full time; I don't expect that he would marry and have a family and children, those sorts of things, I don't expect those things.* (Heather)
>
> *That would be a good thing for me, I think, if he could achieve that. But realistically, I am not hopeful—I am not expecting that.* (Michael)
>
> *There have been times when it's been really tough, you know. It's still really tough, ... but realistically, opportunities only come along every now and then for this to happen.* (Doreen)

Coming to terms with his "reality" was of great solace to Rupert, who noted that planning for his daughter was less stressful once the reality of the situation was accepted. Rupert consistently referred to his 21-year-old daughter as his "child" expressing his knowledge that this "child" will be happy and healthy and value such attributes.

> *You have to modify your aims in light of the reality, and once you realise what the realities are, then it takes a weight off your shoulders. It becomes living on a month-to-month basis, or a year-to-year basis. Now people with normal children may find it deeply distressing that she will never go through these periods of so-called normality where she gets her first boyfriend, you know, she gets her first partner, buys her first house. They might find that deeply distressing, but believe it or not, it's not deeply distressing for us anymore.*

Summary

In summary, the parents interviewed tended to believe:

- Adults initiate and construct their own journeys through life, with adulthood emerging naturally from the intrinsically motivated activities that offer growth and maturity

- People with intellectual disability fail to initiate their own pathways through life, and require support to construct their life pathways

- While the aims and goals for people with intellectual disability might resemble those for people without disabilities, sometimes these fail to be sought by young people themselves, and require intervention and coercion to occur.

5.3 Summary

This chapter has presented the findings from the focus group of parents of young people with intellectual disability, as well as the individual interviews with parent participants. Five key themes emerged from the data that encapsulated the criteria parents see as necessary for identification as an adult. In essence, parents of young people with intellectual disability see adults as people who are effectively independent, able to make choices, and able to live considering the consequences of the decisions they make. They believe these decisions are based on reasoned, rational consideration that appreciates various perspectives of other members of the adult community. Adults make choices about their lifestyle, understanding the concept of reciprocity to justify time spent in work situations in return for buying power of money. Adults make choices about employment options based on personal interests and the deriving of satisfaction and meaning from their status and role in the community. Adults also derive meaning from personal non-employment pursuits, through recreational activities, the pursuit of the arts, travel, and voluntary commitment to community events. Meaning is also found in personal relationships and parenting roles. As a result of the activities and interactions in the community, adults are acknowledged within the broad "hood" of adults and accepted as "one of them"; a member of the adult community.

Finally, the parent participants in this research identified that there are two frameworks by which adulthood may be perceived. Adulthood can be recognised by what people do: how they behave, how they dress, the types of music they listen to, and so forth. For the purpose of this thesis, this perception of adulthood is referred to as "virtual adulthood", taking the definition from the Merriam Webster dictionary that offers "virtual" as "being such in essence of effect though not formally recognised or admitted". Parents then see that their sons and daughters can present with some of the essence of adulthood, but they do not formally recognise them as such, nor do they believe that they are seen by the community of adults as fellow adults. They do not see that membership of adulthood is offered to young people with intellectual disability by other adults. To parents, the measure of a true or "actual", adulthood is more affected by what people are than by what they do. So adults are rational, independent, autonomous, capable people who initiate their pathway through life and accept the consequences of their decision-making. Their sons/daughters generally do not meet these criteria, and are thus not recognised as "actual" adults. Rather, parents consider their sons/daughters are "virtual" adults in as much as they offer the essence of adulthood in their bodily presentation, their chronological age, and their legal status for adult human rights. In other domains recognised for determination of adult status, the young people are still striving towards achievement.

Chapter Six
Findings from Disability Support Worker Focus Group and Individual Interviews

6.1 Introduction

This chapter presents the findings from the Disability Support Worker (DSW) focus group and individual interviews undertaken with DSWs employed to work with young people aged between 18 and 30 in adult services. It will outline the data collected, the analysis process which lead to the categorisation of the data, and the five key themes that emerged from the data. While five themes emerged from the initial data from the focus group, more in-depth exploration of the data from individual interviews allowed greater clarity to emerge in relation to these themes, resulting in a final exposé of five moderated themes that position DSWs on the conceptualisation of adulthood.

6.2 Disability Support Worker focus group

The DSW focus group consisted of five members of the group who were all known to each other professionally. Two participants were social friends, but worked for different organisations. All five participants had over seven years' experience each in disability services, and were currently responsible for young people aged over 18 either in accommodation, recreation, training, or community access services. The focus group meeting lasted 75 minutes and was audio recorded for subsequent transcription, analysis, and identification of key themes, as described for the parents' focus group meeting.

6.2.1 Disability Support Worker focus group issues, themes and coding

The 75-minute focus group with the five DSWs was transcribed and analysed in the same manner as the data from the parent focus group and interviews, with inductive content analysis supported by NVivo software. The coding from the data analysis identified 14 categories, some of which were similar to those identified by parents, but others that were significantly different. The categories reduced to five themes. In those categories that were identified by both DSWs and parents, the context of the phrases or word usage altered their meaning or the significance and implications of their use. Independence, for example, referred not to undertaking tasks alone, or with no support as it did for parents. Rather, DSWs referred to relative independence, or levels of independence, such as "being supported to make choices independently", or the idea of doing tasks, such as walking through the city "more independently". This might involve being shadowed for example, as in the process of being transport trained, but offers a more independent achievement of a task than being fully supported.

The focus group facilitator was mindful to focus the discussion on the participants' conceptualisation of adulthood, and not to allow the conversation to become centred on perceptions of parenting, particularly when there were examples of conflict offered. For example, Herman spoke of an occasion when he was "scruffed by the throat … and pushed up against a wall", by the father of a woman who was being supported to travel independently to her workplace. The father's concern for her safety was blatant, as he threatened

Herman with: “If she gets raped in the bus mall, you’re dead”, adding, “You’ve given my baby too much freedom, and this is what you want, not what she wants, and not what we want”. In response to such statements, the facilitator re-focused the discussion on freedom and its place for clients who are offered adult status, and discontinued personal stories of clashes.

The categories identified from the DSW focus group data, and examples of typical comments from within the data are found in Table 6.1.

Table 6.1 Data analysis: Disability Support Worker focus group – Emerging categories

Category	Examples of coding words/phrases
Age/chronology	• *Age 18; that’s the point where we start.* • *I believe they have the right to be treated as participating adults ... from the time they are 16!* • *They stop being children when they turn 18.*
Independence	• *They are in the community more independently ... making more independent choices at a certain level, so I guess our philosophy ... is to be able to make some independent choices.* • *That has been a nice, neat, safe balance, where he can get that “by myself” [feeling] but I am still following my brief.* • *I judged him to be capable of getting home independently, but I was wrong.*
Capacity	• *I don’t know if he has the capacity ... to deal with that frustration.* • *I don’t think they always have the capacity to make an informed choice.* • *I think they are often more capable than their parents believe they are.*
Choice	• *That might take 10 years till they are 30 before they understand they can make independent choices.* • *It is one of the outcomes of this course to be able to make some independent choices.* • *We will always have a conversation with that person, you know; “Are there better choices?”, “Is there a healthier choice?”*
Freedom	• *For adults without disability, freedom is living without boundaries.* • *We are working with a lot of people who are experiencing new things, freedoms that they have never experienced before.* • *You presume that when you get to a certain age you are entitled to certain freedoms.*

Category	Examples of coding words/phrases
Decision-making	• *It is doing what you want to do, making decisions about what you want to do, and if you fall on your backside, you fall on your backside.* • *I am working with people who haven't had opportunities to make decisions, or maybe they don't understand what making decisions is.* • *Sometimes it is in their decisions about the meals, or what music they want to listen to, or what they want to wear. It is their home, so they should be able to make their own decisions wherever possible.*
Reasoning/understanding	• *They don't understand what making decisions is, what that actually means.* • *It depends on what scale their disability is, I think. Because that affects their understanding.* • *... if that person is "reasonable" enough to know the consequences of actions that they do ...*
Employment	• *We're looking at it from a perspective of the world of work, and employment, which they haven't experienced before.* • *When she went to work, we suggested again she only take the smallest [toy].* • *I have people whose outcome is not work; who identify that they are going to exit into day options.*
Vulnerability/safety	• *If they are safe, they can wear clothes that are outrageous. I don't care.* • *I think what if you've got a person at risk, a person being abused, who may or may not be aware of it, but is being coerced because they can't say no.* • *Are they going to stand out? Are they going to be bullied?*
Dignity of risk	• *There quite often is a dignity of risk in most things, experiences that people haven't experienced before.* • *The dignity is that he still makes that decision.* • *One of the things you have to weigh up as a service provider is your duty of care versus dignity of risk.*
Not a child	• *They are still kids, still children, in many respects, but ... everything around them is saying, "You're adult, adult, adult".* • *I don't want to see the world full of eternal children.* • *... often not trusted by other family and friends ... to move through the world as young adults.*
Guidance/support/ education	• *We shape and mould ...* • *People haven't been told or taught that capacity, or knowledge to show initiative, or to be the first one to get up and do something.* • *They come here to learn more about what is expected.*

Category	Examples of coding words/phrases
Rights	• *They have a right … say smoking, then it's not for me to say. "You can't smoke".* • *I believe whole-heartedly in people's rights to do whatever I am able to do in society.* • *It's dangerous; it's obvious, and in a lot of cases they have the right to experience that.*
Reality and difference	• *… can't deny that someone has a difference … but it's how you reframe that difference.* • *You can't deny that there is a difference.* • *… in theory, but in reality … it is the cognitive functioning that pulls that up.*

6.2.2 Development of themes

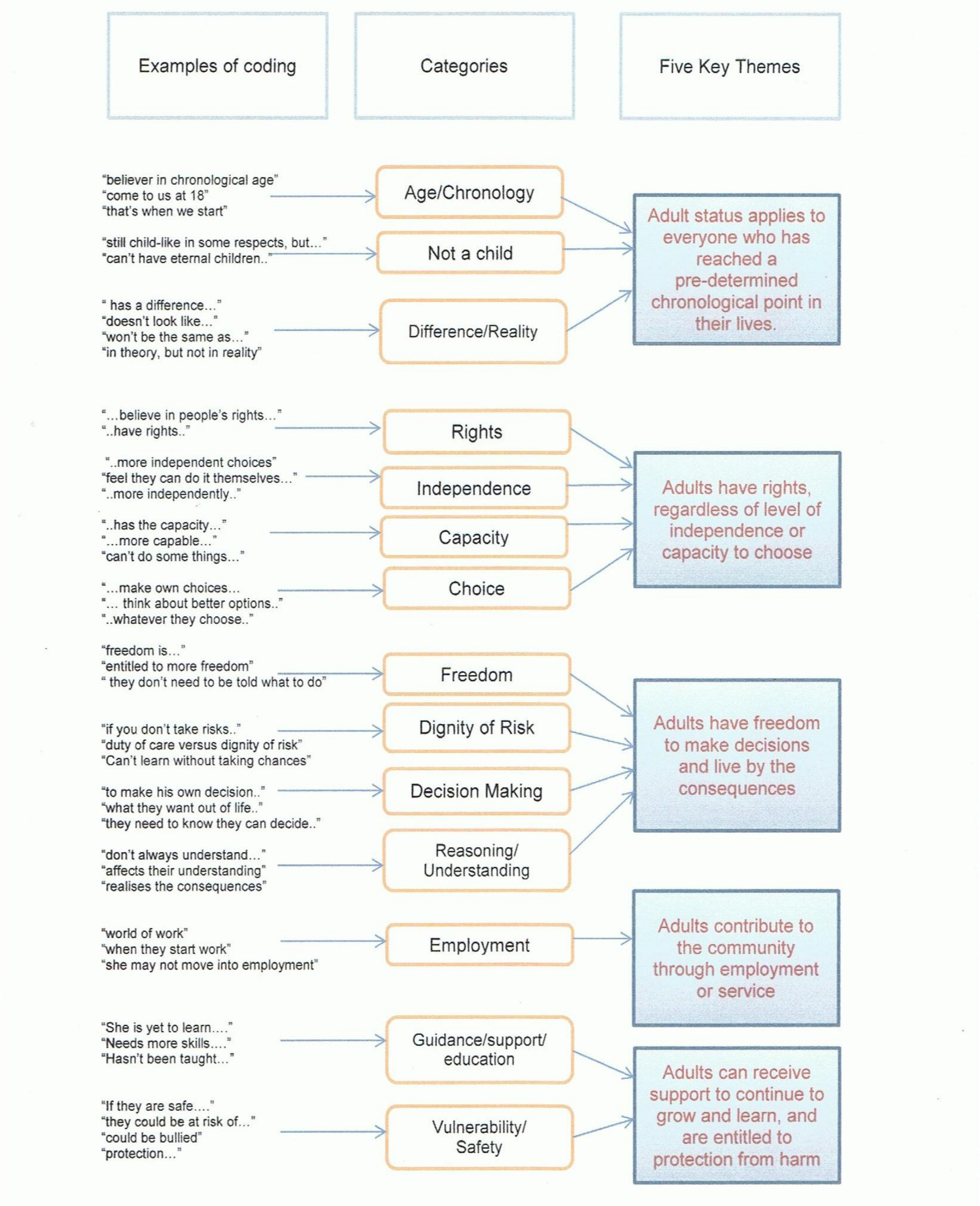
Additional reflection and inductive analysis of the 14 categories and their contexts identified five key themes, or recognised characteristics of adulthood, that emerged from the focus group meeting. The overarching principle, and first key theme that arose from the meeting is that DSWs working with young people with intellectual disability see adult status as an entitlement, a classification for all people once they reach an age that is seen to preclude them from childhood, and that offers legal recognition of their adult status. This status is granted regardless of any perceived difference of intellect or capacity, or any other potential area of discrimination. The additional four themes worked in part to justify this stance.

Table 6.2 Identification of key themes (Disability Support Worker focus group)

Themes	Categories
Adults status applies to everyone who has reached a predetermined chronological point in their lives	Age/chronology Not a child Difference/reality
Adults have rights, regardless of level of independence or capacity to choose	Rights Independence Capacity Choice
Adults have freedom to make decisions and live by the consequences	Freedom Dignity of risk Decision-making Reasoning/understanding
Adults connect to the community through employment or service	Employment (also codes within Rights, Freedom and Guidance/support/education)
Adults continue to grow and learn, and are entitled to protection from harm	Guidance/support/education Vulnerability/safety

The process of moving from open coding, through the categories, and finally to the five key themes is illustrated in Figure 6.1 below.

Figure 6.1 From open coding to key themes – Disability Support Worker focus group



6.2.3 Further reflection on key themes

Further explanation of the process of analysing the data is offered below under the five key themes. The explanations offer more detailed descriptions of how the codings were categorised and found to link together within five clear themes.

6.2.3.1 Adults have reached a pre-determined chronological point in their lives

Unlike the parents' focus group, during which it was difficult to focus parents on the defining characteristics of adulthood, the five participants in the Disability Support Workers focus group were more clearly prepared and ready to focus on the topic of adulthood. The response to the first question of "When are your clients identified as adults?" was simply: "When they turn 18" from all but one participant. Debbie believed that adulthood started earlier than 18, with an initial response:

> *I'm a strong believer in the chronological age. I believe they have the right to be treated as participating adults within both the home and the community from the time they are 16.*

When asked why she saw adulthood starting at age 16, her response was:

> *16! Trying to ensure they have the same … what we like to think about is that people have the same life experiences if they are receiving support from us, as they would if they were at home with their parents, or if they were living without a disability. One of the issues you have is that parents want the eternal child. It's not unusual to have someone come into the service as late as their 40s and they are still very childlike in a lot of things.*

Regardless of which particular chronological point in time was identified, all DSWs initially agreed that adulthood is reached at a pre-determined point in the life of a young person with intellectual disability. At some point the young person with intellectual disability ceases to be a child, and subsequently turns into a person recognised as an adult. There was an undercurrent throughout the focus group meeting that this recognition of their clients as adults was essential to counter what were perceived as negative or harmful attitudes and approaches by parents. This was coupled with the concern for the perception of people with intellectual disability as "eternal children". Matt offered:

> *Yes I do [see them as adults], because I don't want to see the world full of eternal children. There is no other category, there is no happy medium.*

This led the focus of the group onto problems associated with this categorisation, and the development of the other key themes noted below. During the course of the meeting, however, the attention often returned to the concern that young people with intellectual disability must not be considered children, and emphasis on the need for DSWs to ensure their status as adults.

Faced with points of difference that had been identified between the populations of young people with and those without intellectual disabilities, Carmen, the manager of a recreational service for 18 to 25-year-olds offered that "adulthood is a legal framework, and that's all it really is". The other members of the group agreed, citing adulthood as a very simple concept that is applicable to all members of the community regardless of any circumstance or characteristics that might make one person different to another. The group's argument formed a response to the perception that simply questioning the adulthood of people with intellectual disability somehow suggested that they were not entitled to this status. Part of the role of support agencies and their DSWs was to refute such a suggestion. There was one vulnerable element within their defence of this position. Debbie referred to the difference between theory and reality when discussing whether having the same life experiences meant that all people were “equally adult”. To this she responded:

> *I think so, in theory, but in reality I suppose it is the cognitive functioning that pulls that up. We can provide the experience, but did the person appreciate the experience? Did they recognise the experience? Did they participate in everything that typical adults participate in? Or in life generally? I’m not always sure.*

For the most part though, the discussion by the group was framed by the position of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its intention to ensure that the rights of people with disability to independence, autonomy, dignity and self-determination are respected and protected despite the level of functioning or capacity of the young people with intellectual disability.

6.2.3.2 Adults have rights, regardless of their level of independence or capacity to choose

A coding that arose frequently within the focus group data was that of client rights. This was mentioned by all DSWs, often accompanied with reference to the UNCRPD, and Article 3 that promotes “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”. All participants were conversant with this document, noting that the study of this, and other similar principles, had been a primary focus of much of their training within the disability sector, as well as the subject of professional training within their organisation. This guiding document underpinned their policies and practices. The coding of “rights” was associated with a number of categories within the analysis of the data including the ideas of independence, choice, freedom, dignity and decision-making. The UNCRPD was recognised as protecting the rights of clients to experience dignity in all things, to have their choices respected and upheld, and to be seen as independent. However, DSWs also recognised that oftentimes clients were not capable of acting independently. Debbie offered one example that almost proved catastrophic, when she assessed a client as capable of travelling by public transport to his group home independently, and supported his request to do so with near dire consequences. The role of the DSW involves a level of care to prevent harm to clients, with serious consequences to both DSWs and client if this is not maintained. A client’s capacity for independence is measured within a duty of care framework, with DSWs protecting their own position through putting into place safety measures to allow “more independence”, but not total independence. Herman offered the example of shadowing a client who had requested the opportunity to walk through the city on his own. Herman allowed him to walk on one side of the street, while he walked parallel to his client on the other side, offering the appearance of independent negotiation of the city, but with support from a distance. The idea of *greater* independence, or *more* choice, was seen to uphold the principle under the UNCRPD when young clients with intellectual disability were not capable of full independence. Any support offered did not preclude the young person from recognition as an adult, but was seen to offer greater independence *because* they were adults with a right to independence.

6.2.3.3 Adults have freedom to make decisions and live by the consequences

Freedom was a new category identified within the DSW data that was not raised in the parents' data. The DSW focus group participants believed that they worked with adults who should have the opportunity to experience freedom from constraints in their pursuit of independence. Freedom was coded within the category of independence at times, but was also noted to contribute to the idea of decision-making. This idea of freedom to take risks in a "freer" environment was aligned with the code "dignity of risk", that worked as an opposing force to the DSW duty of care. In accord with the UNCRPD document upholding the rights of young people with intellectual disability to independence and choice was the recognition of their right to freedom, self-determination and decision-making. The intellectual capacity of clients was acknowledged as a limiting factor, but not one that was either necessarily permanent or insurmountable. DSWs considered it their duty to promote freedom and decision-making by the client, within the limitations of their duty of care. This was recognised as a difficult dichotomy to balance, and group members were challenged to know the extent of freedom that could be offered. Matt, a manager of a residential service, related the idea of adulthood to the ability and capacity to make decisions, responding to the question of whether all his clients were adults with the response:

> *Well that depends; there are some that have guardianship orders, but there are some that don't. They might not have parents, and can make decisions about a lot of things, and we might only intervene with their decisions if they are at risk to themselves or to others.*

The concept of in loco parentis was raised, with the group acknowledging that their role was to "shape and mould", their clients through offering broader opportunities. Despite wanting to extend their clients, recognition of their duty of care was clear, with Matt noting:

> *Even though there is that thing, "[in]* loco parentis*": acting in the role of parents, even though we want to advocate for more things, we also are quick to put the brakes on should someone become "at risk". You know you have that duty.*

The idea that young clients needed to be given "new" freedom to become self-determining as a result of their adult status and the end of a time where decisions were overseen by parents was raised by Herman, who commented that "[t]here are a lot of parents who take that [decision-making] away [from their children] as well". There was general agreement amongst focus group participants that part of their responsibility was to ensure that young people with intellectual disabilities be given opportunities that would otherwise not be offered if they were to remain solely in the care of their families. This reduction, or severing, of the protective links was considered appropriate because the young person had become an adult; it was no longer appropriate to live under what DSWs saw as stifling parental protection. The degree of risk involved in any undertaking needs to be measured, but allowing young people to learn from the consequences of their actions whenever possible was seen as more appropriate, and a higher priority within a rights framework, than denying them the opportunities to try new things under the guise of duty of care.

> *For adults without disability, freedom is living without boundaries, it is doing what you want to do, making decisions about what you want to do, and if you fall on your backside, you fall on your backside. However we put up lots of boundaries for these people—we are like the gutter guards at the bowling alley, but we don't stop them going bowling!* (Jackson)

6.2.3.4 Adults contribute to their community through employment or service

The DSWs present at the focus group meeting were not directly employed in disability employment or training services. All were working with young people who were attending work-focussed training, or had started working in either supported or open employment, but were working in accommodation, recreation or personal support services. The connection between adult status and being a worker was evident with DSWs recognising the pursuit of employment as a normalising pathway and one that is considered for all young people with intellectual disability with often unpredictable success. DSWs talked about the value of work experiences for their clients, often in a voluntary capacity, such as in charity opportunity shops, or in school canteens. These were seen as opportunities for young people to be accepted into their community, as well as offering them an identity as a worker who contributes to their community. There was discussion regarding various enterprises, such as a pet supply shop run on behalf of a local dog rescue service that had been staffed by young people with intellectual disability. This was seen to offer the clients the opportunity to be recognised as offering a valued service to the community. This shop offered an opportunity for members of the community to identify the young people with intellectual disability as staff, in line with SRV (Social Role Valorisation) principles.

It was acknowledged that there were many young people with intellectual disability for whom employment, or voluntary service would not become an option. However, Matt offered that simply being a consumer in the new world of the National Disability Insurance Scheme (NDIS) provided for their perception as adults with buying power that subsidised their community's economy. It made them valued contributors to the community's development. Seeing clients as valued consumers was also evident in Carmen's comment:

> *When the NDIS is fully operational, people will have to rely on our guys for their jobs in theory. So staff and clients will need each other, which I suppose they do now!*

Recognising that people with disabilities will be viewed as consumers under the new insurance scheme adds to their possible acceptance within the economic community by offering an opportunity to strengthen their desirability within the retail, tourism, hospitality and service industries.

6.2.3.5 Adults can receive support to continue to grow and learn, and are entitled to protection from harm

This theme was founded on the principle that young people with intellectual disability are adults by virtue of their age, and that they are receiving adult services, but still required training or guidance in the development of new skills. This was recognised as no different to any other young person who was undertaking an apprenticeship, or further training, or learning new home skills such as cooking either from their parents, or from community training opportunities. Herman drew the analogy to adult education classes that have existed for generations to support the learning of domestic and recreational skills. The DSW focus group acknowledged that in many ways young people with intellectual disability are not as skilled as those without disability, but this variance in skill levels did not negatively impact their right to adult status. The concept of life-long learning is recognised as a noble pursuit, and applies equally to those with intellectual disability. To the DSW focus group members, impairments in understanding or reasoning, or gaps in knowledge or skills, do not exclude young people from adulthood. The role of DSWs is to support learning and skill development of these young people who are recognised as adults regardless of their knowledge, understanding, skills or experience in worldly events.

Similarly, vulnerability to harm or abuse entitled any young person, regardless of intellectual capacity, to protection within the community. Opportunities to learn to protect oneself are commonplace in the community. Vulnerability was recognised as applying to everyone, but more particularly to other marginalised groups who were known as adults, but who had limited capacity to defend themselves. This vulnerability, or limited ability to respond safely to threats or taunts, does not alter the adult status of people who are aged over 18. Jackson summed this up by commenting about his own journey through karate classes that he had started at age 16, and noted that he was still learning at age 30. He explained:

> *I guess they are more vulnerable than most. Sure, you know there are guys that will give them a hard time, but people have given me a hard time often enough! That doesn't relegate me to being a child again does it?*

6.3 Disability Support Worker interviews

6.3.1 Disability Support Workers' interview questions

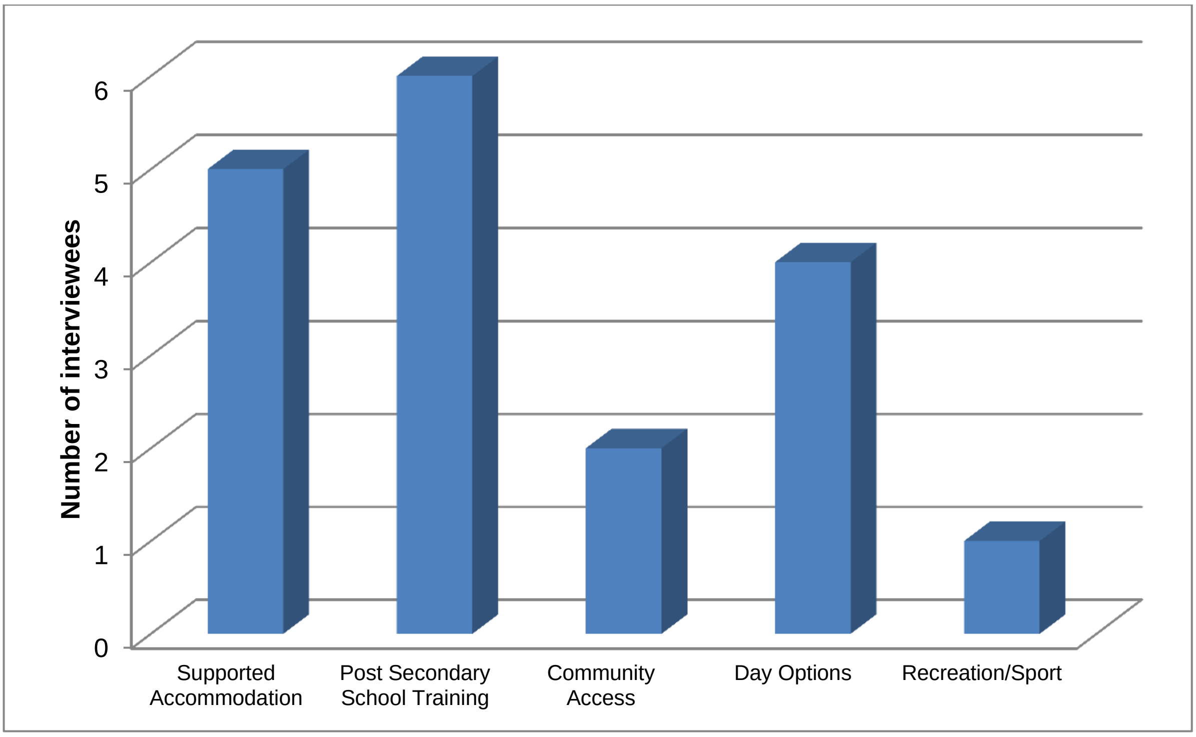
The DSW focus group analysis guided the development of questions for the semi-structured individual interviews with DSWs working with young people with intellectual disability aged 18-25. The guiding questions aimed to elicit data that would further expand on the themes identified from the focus group discussion, as well as allow narrative to further illuminate interviewees' conceptualisation of adulthood, and their idea of young people with intellectual disability as adults or non-adults. The interview questions can be found in Chapter Four – Research Design and Methodology.

6.3.2 Preamble to emerging categories

> *I could have slapped her [shop assistant]. They just take the liberty to deal with people as if they weren't adult.* (Myf)

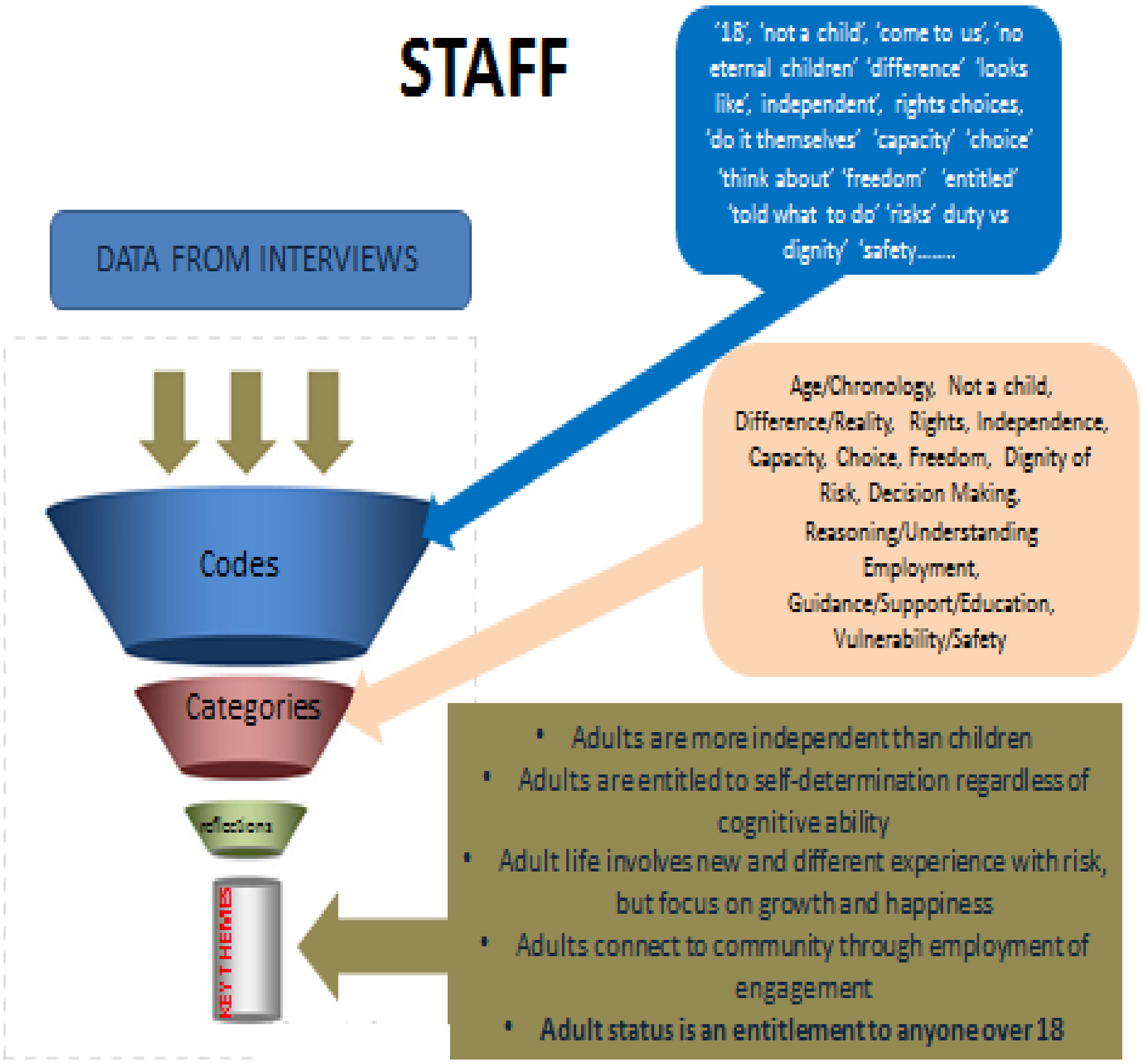
Individual interviews were conducted with 12 DSWs from a range of disability agencies, including recreational services, training colleges and other training agencies, accommodation services, services offering activities other than employment (ATE) or day options, community access, and supported employment. Six of the interviewees worked casually across more than one service, combining support within residential services in the mornings and evenings with additional work in day services, such as recreation, or training agencies. The cohort of interviewees represented 12 different agencies specialising in support for people with disabilities. While they did not all work exclusively with young people between the ages of 18-25, they all worked in at least one service that specifically targeted this age group. Five interviewees worked in group homes that accommodated young people in this age range, six work for organisations that delivered post-school training services, either as direct trainers, or as DSWs within the program, two worked in the field of community access skill development (transport training), four worked in day option programs that catered for young people, and one worked in a recreational program.

Figure 6.2 Disability Support Worker employment types



Interviews were held outside working hours either in the DSW's home or a local coffee shop that offered private space for interviews. Interviews were transcribed, analysed, coded, and categorised. As with the parent interviews, the process of analysis of the data can be demonstrated through illustration (see Figure 6.3)

Figure 6.3 Process of analysis: Data from Disability Support Worker interviews



The resultant categories and examples of coded phrases are presented in Table 6.3.

Table 6.3 Data analysis: Disability Support Worker interviews – Emerging categories

Category	Examples of coding words/phrases
Age/chronology	• *There is a general idea about adulthood when you reach a certain age, you start to become an adult.* • *I know that just because they're 18 doesn't mean that they are adults, but it applies to everyone, you know.* • *Suddenly they come to this model, which is an adult model—very non-directive, and "You're an adult now", and they keep hearing this.*

Category	Examples of coding words/phrases
Not a child	• *They may have been treated as children and they are told predominantly what they can and cannot do. They are often not trusted … to move through the world as young adults.* • *"She is 21, but she has the mind of a 14-year-old. We can't treat her like a 21-year-old." I've heard that a lot from parents; it's difficult.* • *We hear ourselves saying a lot to the parents, "Your children are not children any more".*
Reality and difference	• *If they take one step, or put one foot outside society's adult expectations—our "adult goalposts"—that is how we expect people should behave, and there's trouble.* • *If you wear that, you might get people staring at you. And you might be fine with that, and that's fine with me if you are fine with it.* • *This is the real world. There has to be a winner and a loser. Part of his learning has to be that he will lose. That's life.*
Rights	• *What right do I have to refuse him a cream bun and offer him an apple?!* • *I believe whole-heartedly in people's rights to do whatever I am able to do in society.* • *She felt we were taking her rights away from her, to decide what she does with her money.*
Independence	• *… what they do in that independence.* • *… doesn't mean they are automatically able to live independently in an adult world, because they haven't experienced an adult world in an independent way.* • *… helping him to grow towards independence.*
Choice	• *But it is still people's free choice to smoke if they want to, if they are of age.* • *If there is no health, diet requirements for that person, no serious medical considerations, then I think that freedom of choice should be there.* • *If you do mind people staring at you, you might like to reconsider your choice.*
Capacity	• *What is the likelihood that they would do it again. So, if they lost their money, are they likely to do that again.* • *I don't know whether that is due to what they can or cannot do, or their status as an adult.* • *I would need to assess him as being capable first*
Freedom	• *To live with certain freedoms, you have to have grown up with certain experiences,* • *Could they say, "I really feel like one of those this morning", and just have one? Or will someone say, "No, they are for later, or they are for tomorrow."?* • *Here the people feel a lot freer.*

Category	Examples of coding words/phrases
Decision-making	• *They might have been given opportunities to make decisions, but that scares them.* • *…have to do with my direct experience of that person, and whether I feel that person is able to make that decision.* • *Letting them make their own decisions? Well you could be there for a whole day, because people haven't been told or taught that capacity, or knowledge to show initiative …*
Understanding/reasoning	• *Some of them don't have the understanding of when they might be at risk* • *I think I am more associating experience and knowledge with adulthood.* • *…a few are still a way back, because they haven't had experiences, or they haven't understood those experiences.*
Vulnerability/safety	• *We know these people tend to be vulnerable, which complicates the dilemma.* • *Safety first, even above dignity … I have to bring them back safe. Everything else is a bonus.* • *Everybody over the age of 18 can potentially do all things that adults do, but we need to rally around them to keep them safe.*
Dignity of risk	• *… pursuing whatever they want to pursue. And then you consider the dignity of risk, duty of care.* • *…so then you have to support that person in making other choices, because the risk is too great.* • *One of my values in terms of support is to allow people to take risks*
Duty of care	• *…that risk might be too great, because he's in danger. I have the duty to step in then* • *There are two conflicts with what the person themselves wants to do, whether they have informed choice or not, whether they have the information they need around them to make an informed choice, and then what our brief is.* • *If they want to do something that others don't want them to do well I guess I'd try to work with the organisation,*
Guidance/support/ education	• *They are introduced to things that are a lot bigger than what they have experienced with their family.* • *At the end of the day, all you can do is provide information or education for him to make informed choices.* • *We, in this program, try to mould people so they fit into society, and to a degree we have to!*
Community connection	• *If I have people, and every year I do, who don't want to, or can't get a job, and so they end up in day options, then I probably relax … because then it doesn't matter so much.* • *I have to trust somewhere … that other people within the community would look out for that person* • *I would think that is awesome, that people can make contact with others and make connections within the community.* • *… society at large should approach these people in that way [as adults].*

The number of participants who offered commentary that could be coded into the 15 categories is illustrated in Figure 6.4. Seven categories were common to all interviewees. These categories included: age/chronology, “not a child”, rights, choice, decision-making, vulnerability/safety, and duty of care. At least three-quarters of all participants (number ranging from 9-11) noted the remaining eight categories, namely: independence, freedom, understanding/reasoning, guidance/support/education, reality/difference, community connection, and capacity. Examples of the types of coding used to deduce categories are offered in Figure 6.5. As illustrated in this diagram, these categories were subject to further reflection, and the identification of five final key themes that exemplified the conceptualisation of adulthood by DSWs who worked with young people aged 18-25 who are living with intellectual disability. These are discussed further in the following section.

Figure 6.4 Frequency of coding – Disability Support Worker interviews

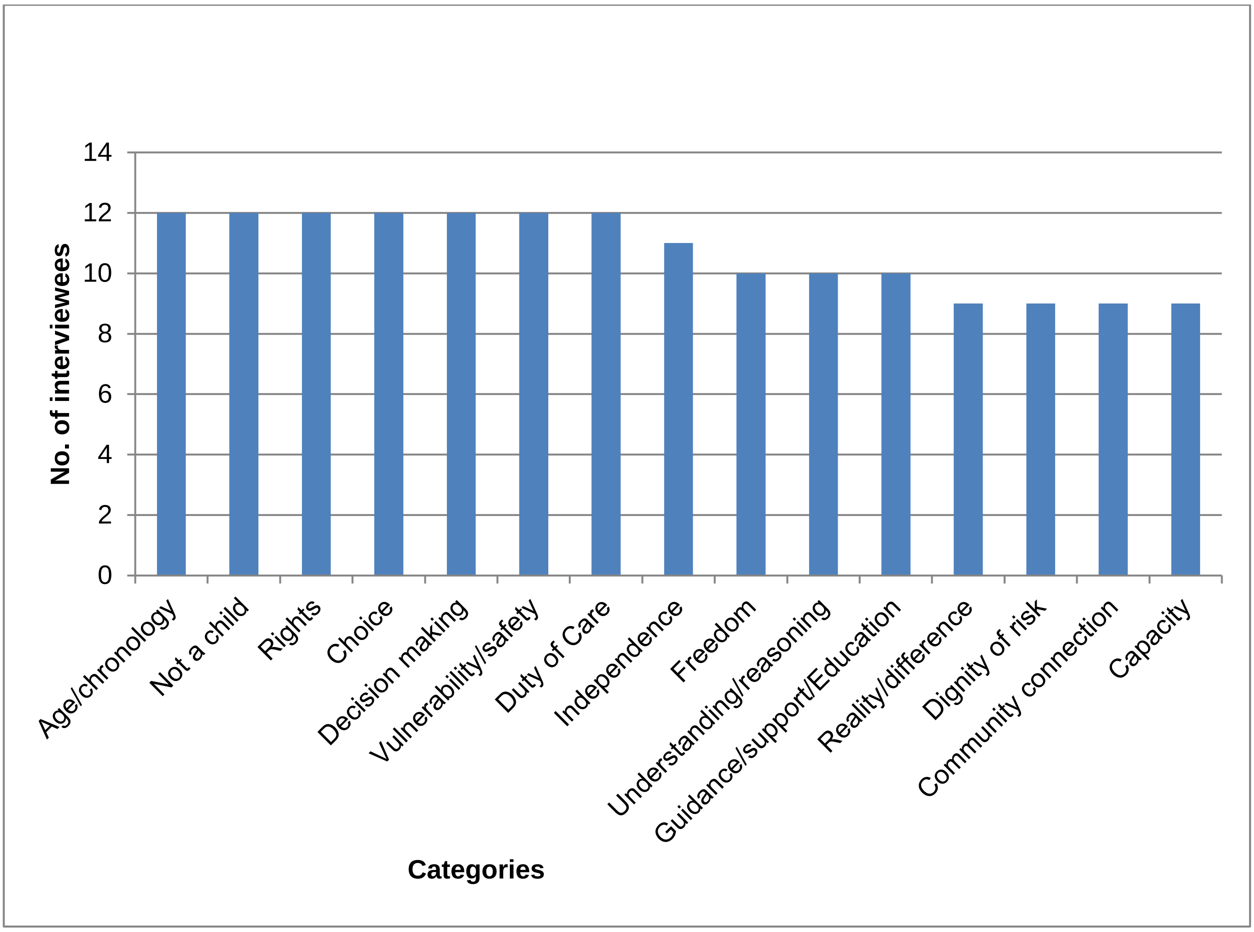
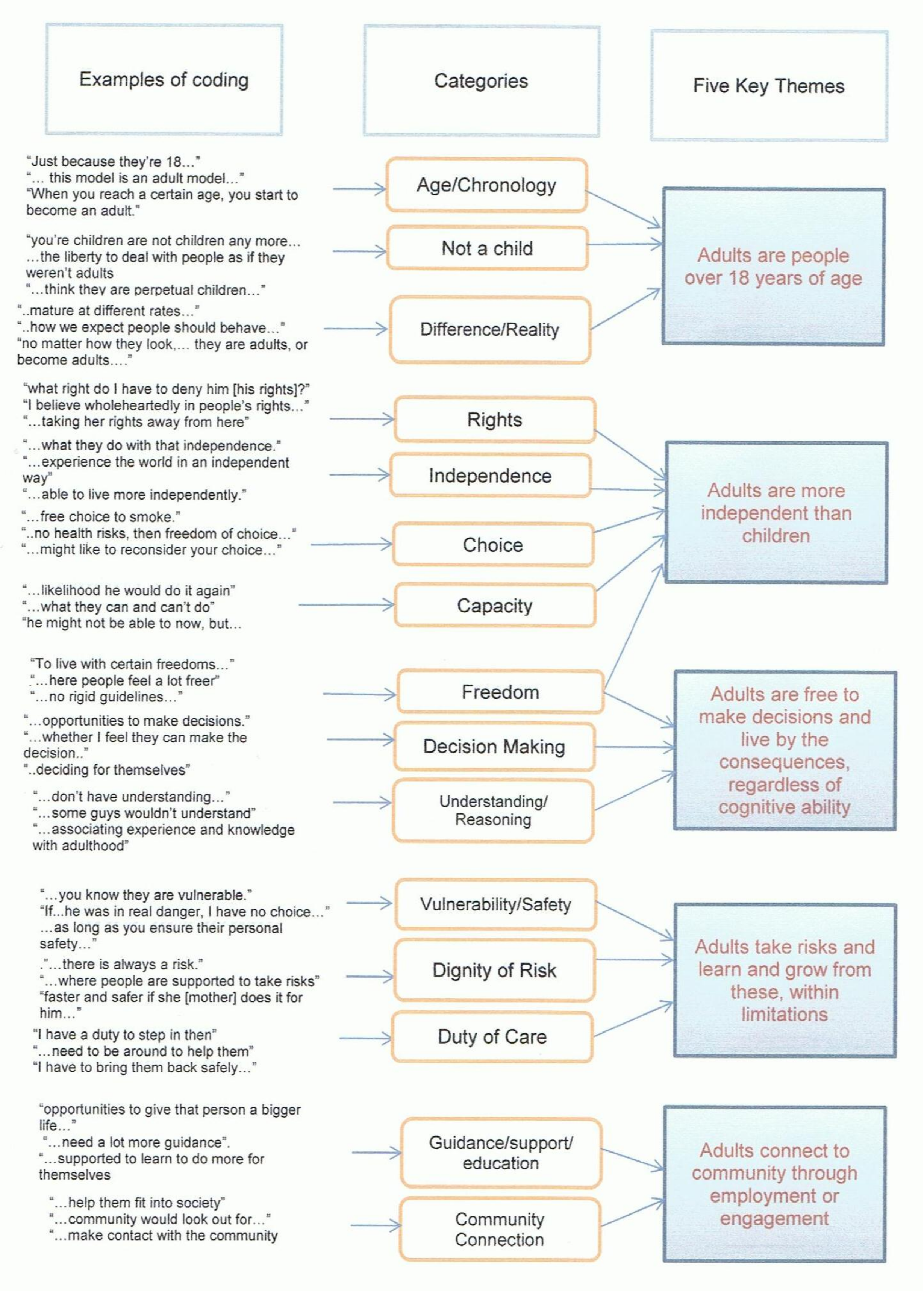


Figure 6.5: From open coding to key themes – Disability Support Worker interviews



"Just because they're 18…"
"… this model is an adult model…"
"When you reach a certain age, you start to become an adult."

"you're children are not children any more…
…the liberty to deal with people as if they weren't adults
"…think they are perpetual children…"

"..mature at different rates…"
"..how we expect people should behave…"
"no matter how they look,… they are adults, or become adults.…"

"what right do I have to deny him [his rights]?"
"I believe wholeheartedly in people's rights…"
"…taking her rights away from here"

"…what they do with that independence."
"…experience the world in an independent way"
"…able to live more independently."

"…free choice to smoke."
"..no health risks, then freedom of choice…"
"…might like to reconsider your choice…"

"…likelihood he would do it again"
"…what they can and can't do"
"he might not be able to now, but…

"To live with certain freedoms…"
"…here people feel a lot freer"
"…no rigid guidelines…"

"…opportunities to make decisions."
"…whether I feel they can make the decision.."
"..deciding for themselves"

"…don't have understanding…"
"…some guys wouldn't understand"
"…associating experience and knowledge with adulthood"

"…you know they are vulnerable."
"If…he was in real danger, I have no choice…"
…as long as you ensure their personal safety…"
."…there is always a risk."
"…where people are supported to take risks"
"faster and safer if she [mother] does it for him…"

"I have a duty to step in then"
"…need to be around to help them"
"I have to bring them back safely…"

"opportunities to give that person a bigger life…"
"…need a lot more guidance".
"…supported to learn to do more for themselves

"…help them fit into society"
"…community would look out for…"
"…make contact with the community

6.3.3 Key themes

The five key themes that were derived from the data from DSW interviews were essentially similar to those identified from the DSW focus group, with minor, but notable differences in some categorisations. The data from the DSW interviews linked the idea of freedom to both the idea of greater independence and to decision-making, and a new category was found in the interview data. Stronger emphasis was found placed on support staff duty of care, which connected with the categories of vulnerability/safety and dignity of risk within the theme of: "Adults take risks and learn and grow from these". There was no significant mention of the idea of employment as a requisite for adult status within the interview data, but very strong mention of guidance, support and education as a part of adult life. Unlike the focus group, which linked training and support to the idea of ensuring client safety, DSWs interviewed in individual interviews linked training and support to community engagement, either through developing work skills to support employment in the community, or more often to allow greater community participation. After analysing the data from the interviews and comparing this with the findings from the focus group meeting, five final themes were inductively identified:

1) Adult status applies to all people over 18 years of age

2) Adults are more independent than children

3) Adults make decisions for themselves regardless of cognitive/rational ability

4) Adult life involves new and different experiences that may involve risk, but promotes happiness

5) Adults connect to community through employment or engagement

6.3.3.1 Adult status applies to all people over 18 years of age

(Categories: Age/Chronology, Not a Child and Difference/Reality)

There was general acceptance amongst interviewees that age 18 marks a significant point in adult development as either the point at which the transition to adulthood begins, adulthood itself arrives, or as the point when childhood ends. In the 19th year it is assumed young people, regardless of intellectual capacity, maturity levels, behaviour, or appearance, cease to be children and those with intellectual disability transfer to adult health or disability-specific services. Interviews commonly included comments such as: "We are working with people who are young adults", or "When you reach a certain age, you start to become an adult", and services were considered to follow an "adult model" of service in which clients were treated as "potentially adults". This alignment of adulthood with age 18 acknowledged the legal recognition of adulthood and adult rights at that chronological point in life. However, while DSWs could articulate the linkage between age 18 and non-child status, it was also acknowledged that this point marked the start of a process, rather than the attainment of full adult status through their use of phraseology such as "potential adults", "you start to become …", or by suggesting that they are required to treat clients as adults "as much as I can”. The notion of adulthood beginning at age 18 decreed how services should alter the way they respond to clients as adults, and present them to the community as adults, demanding appropriate adult interchanges from both the client themselves and members of the community. One interviewee spoke with hostility about retailers who called her clients “darling”, believing the shop staff took liberties when they dealt with people “as if they weren’t adults”. As well as having a role to play in educating the general public about young people with intellectual disability having achieved adult status, there was also mention by 11 of the 12 interviewees of the need to “shift” parents’ thinking about their sons and daughters as “children”. Interviewees referred to parents seeing their sons and daughters as “perpetual children” who would never “grow up” or were protected as children, “told what they can and can’t do”, and prevented from travelling through their world “as young adults”. The need to recognise age 18 as the point at which adulthood begins was predicated on that chronological point being a clear defining marker of the end of childhood.

DSWs realise that maturity levels differ amongst young people of the same chronological age, and that this applies broadly across all 18-year-olds with or without disability, but with a need to differentiate between recipients of children or adult services, the 18th birthday is the logical point at which to use language to denote different categorisation of those no longer children. It is not an option to remain a child. The best that can be offered is the demarcation of adults into young adults and other adults. Yet 10 of the12 interviewees also recognised that this need to differentiate between “children” and “young adults” offers a conundrum. Rick, for example, was adamant that his clients not be referred to as children, yet offered:

> *With young “adults” I work with on a daily basis; they are still kids, still children, in many respects. I know when I was 18/19, I was very much a child—I wanted to be a child. I wanted to live out, and maximise that childhood. The irony is that at this age they have everything around them—TV, internet, other people, educators, family—all saying, “You’re adult, adult, adult.” They must find this very confusing, like, “Hey, what does that mean?”*

Referring to their attendance at services catering for other young people with intellectual disabilities, Rick added:

> *The only role models I have are other children or others who are doing childish things. That’s the only modelling I’ve got, and you’re all saying to me, “*adult, adult, adult*”. So what does that actually mean?”*

On a similar theme, Tina reflected on the need for experiences to contribute to the development of independence and capacity to make choices:

> *Just because a person is 18 or 19 doesn’t mean they are automatically able to live independently in an adult world, because they haven’t experienced an adult world in an independent way. They need a lot of support in doing that and that might take 10 years till they’re 30 before they understand they can make independent choices.*

Yet despite misgivings and identification of challenges to the principle, DSWs see that contemporary social structures require social groupings of over-18s and under-18s regardless of skill level, cognitive ability, mental capacity, emotional dependency, maturity and so forth. This requirement provides the overarching framework on which all interviewees identified 18 as the end of childhood and the beginning of adulthood, despite any differences between their clients with intellectual disability and the general population of others of the same chronological age. So for Tina, being dependent on others did not preclude her clients from being adults. Young adults simply need the support and opportunities to develop more adult characteristics, such as independence, or to become “more adult”.

Summary

1) Disability Support Workers who work with young people with intellectual disability acknowledge them as adults once they turn 18 years of age.

2) The attainment of adult status aligns with the end of childhood, but growth and learning continue during young adulthood.

3) Disability Support Workers see it as essential to refer to young people as adults to counter their perception as eternal children

4) Even though young people with intellectual disability are recognised as adults at age 18, this does not suggest that all people aged 18 have attained emotional maturity, or cognitive capacity for independence. These are not pre-requisites for adult status.

6.3.3.2 Adults are more independent than children

(Categories: Rights, Independence, Choice, and Capacity)

The idea that part of the DSWs’ role was to support growth towards independence was intrinsically linked to their employment within “adult services” whose guidelines included a philosophy of empowering clients, and supporting independence wherever possible. Abbey, a DSW with a post-secondary training institution for young people with intellectual disability, spoke about the focus of training to develop the ability to make one’s choices, seeing this as a sign of increased independence:

> *They are in the community more independently, so they are making more independent choices at a certain level, so I guess our philosophy, our course supports that; it is one of the outcomes of this course to be able to make some independent choices.*

Similarly, Patrick, who supports young people in group-homes, recognised that he and his colleagues considered ways they could support independence for residents, citing only health and safety concerns that would prevent his clients from making their own choices:

> *If there is no health, diet requirement for that person, no serious medical considerations, then I think that freedom of choice should be there. Whatever they can do independently, they should be encouraged to do, and we should butt out.*

DSWs recognise that the young people with whom they work are not independent in many aspects of their lives, and note that full independence for many of these clients is often unlikely, despite training and support provided over many years. However, by providing young adults with intellectual disability further training, experiences and conversations that support and encourage them to understand the implications of their choices, DSWs believe their clients will become more independent than children whose primary unpaid carers are more likely to be focussed on protection than the promotion of independence. DSWs also recognise that few people live totally independent lives, acknowledging that communities rely on interdependency for survival. Linda likened her support work in a training institute to the crew on an aircraft who flew her to different Australian states, and who she hoped would fly her safely and manage any emergency on board. She offered:

> *There are simply some things that I have to rely on others to do for me, some things I will never learn to do for myself, or be allowed to even try! It doesn't stop me being an adult.*

Eight of the interviewees drew attention to the UNCRPD and its protection of the rights of people with intellectual disability to freedom of choice and independence. Four of these interviewees also noted that while their clients had been protected under the United Nations Convention on the Rights of the Child until the age of 18, this convention recognised the role of families in their children's care and protection, while the UNCRPD supported autonomy and greater freedom to be self-determining without the need to include parents in the process. Ellen, who was a social trainer/teacher of vocational education, believed that the rights of young people with whom she worked matched her own, stating: "I believe whole-heartedly in people's rights to do whatever I am able to do in society". This applied to making choices, but these needed to be informed choices so that clients make choices that support their best interest. Ellen, and all but one other DSW interviewee, acknowledged that limitations should be placed on a client's right to choose if poor choices impact their health or safety, or the safety of others around them. The general sense from interviews was that clients with intellectual disability should be free to make their own choices, "within reason". Where the boundaries of reason actually lay, though, was not always clear. For example, while some DSWs believed in the right of clients to choose to smoke, stating that, "It is still people's free choice to smoke if they want to", others felt it their duty to "enter a conversation with the person about health, and the implications about that choice for them". Similarly, in respect to choosing their own clothes, half the interviewees (6) supported their client's right to wear whatever they wanted, believing they would learn from consequences if they did not wear appropriate wet weather, or winter clothing, and "would do better next time". The other half thought more along the lines of Sacha who noted that if her client did not want people staring at her, she would counsel the client, suggesting that "she might like to reconsider her choice". These six interviewees said they would offer conversations about "options" and "contingencies" in order to ensure choices were based on information that was clearly understood by clients. However, all agreed that provided clients were offered all information, it was their right to make choices, as this right was an adult right supported by policies and principles that framed professional practices. In this way, clients of adult services, recognised for their adult rights, are more independent than children. Levels of independence are offered and supported on a continuum commensurate with perceived capacity and safety considerations. While some level of support and protection may be offered paternalistically, it is at a lower level than would be offered for children, and regarded as a lower level than would be offered by parents of young people with intellectual disability. This then aligns with the third key theme that identifies adults as free to make their own decisions within limitations of rational capacity.

Summary

1) Disability Support Workers do not believe independence is a necessary criterion for adult status.
2) Disability Support Workers recognise interdependency between adults does not preclude adult status.
3) Disability Support Workers allow young people with intellectual disability to make choices, but accept that this freedom has some boundaries/limitations.
4) Adults should be free to make choices, provided they have sufficient capacity and understanding to make informed choices.
5) Adults are more independent than children who are under the care and protection of parents or guardians.

6.3.3.3 Adults make decisions for themselves regardless of cognitive/rational ability

(Categories: Freedom, Decision-making, Understanding/reasoning)

Support worker interviewees believe adults are people who are free to make their own decisions and that part of the DSW role is to guide those with limitations towards decision-making that indicates rational intention. The category of “freedom” contributed to the key theme of decision-making in similar, but discretely different ways to the theme of independence. The concepts of choice and decision-making require differentiation here. The idea of a choice in the previous key theme is confined to people being given the right, or the opportunity to choose, often between items such as food, clothing, or destinations. A decision is recognised as the same as a choice when it is simply “deciding between” pre-existing alternatives. However, within this third theme, the idea of decision-making is aligned with the concept of self-rule or autonomy, and the capacity of a person to take charge of his own life through realising his objectives, and being his own agent. Decision-making within this concept involves more than a choice between two options.

The willingness of support workers to allow this type of decision-making is hindered by the judgement of lack of capacity to understand the consequences of actions. Examples include a comment by Shane that, “Some of them don't have the understanding of when they might be at risk”, or Neville's observation that, “Given half a chance, he would race off into the middle of the road after the footy without any awareness of the cars”. The capacity to reason, or understand is seen as central to the notion of making one's own decisions, and Linda explained, “most of the guys would listen to that, but we've had some guys who don't understand”. It was noted that understanding that is typically derived from human experiences can be limited when the person has an intellectual disability. DSWs noted the need to offer experiences, despite recognising that “they haven't understood those experiences”. This was not a reason for discontinuing experiences however; DSWs believed that their clients simply required additional opportunities and life-experiences to become more capable of making better decisions. Opportunities for self-determination and decision-making were identified by all DSW interviewees as fundamental components of adulthood, and these were seen to be missing from the experiences of many of their clients. Mark commented:

> *I have come to a gradual understanding that I am working with people who haven't had opportunities to make decisions, or maybe they don't understand what making decisions is.*

Despite recognising that their clients should be supported in their decision-making and offered more opportunities to make decisions, DSWs identified compromised cognitive capacity as impinging on the autonomy of this aspect of adulthood. Sacha noted:

> *It is really decision-making that is most restricted in a person with intellectual disability. Quite often there is a guardian involved, or an order in place, because someone is unable to make an informed choice or decisions in a safe and appropriate way and understand the consequences.*

Summary

1) Disability Support Workers believe adults make their own decisions about life issues.
2) Disability Support Workers believe that challenges in rational decision-making arise from lack of life experiences or opportunities to make decisions, and this capacity can increase.
3) Disability Support Workers uphold the principles of supported decision-making to the greatest degree possible
4) Disability Support Workers recognise that some people with intellectual disability may make decisions that they (the support staff) cannot support under their duty of care as the decisions are not perceived to be in the client's best interest or may be outside the boundaries of safety.
5) Disability Support Workers believe limitations on freedom or compromised capacity in decision-making have no impact on a person's right to adult status.

6.3.3.4 Adult life involves new and different experiences that may involve risk, but promotes happiness

(Categories: Vulnerability/safety, Dignity of risk, Duty of care)

While DSWs recognised that their position involved responsibility for the safety of their clients, the "rights model" of support required them to consider duty of care only when it involved a risk of death or permanent serious injury to their client or another person. Neville summarised the responsibility of DSWs through their duty of care to their clients with intellectual disability when he commented that above every other consideration in his work he had to consider:

> *[I consider safety] first – even above dignity … I have to bring them back safe. Everything else is a bonus!*

Many similar comments were found in the data alluding to the importance of keeping clients safe as a fundamental consideration of the work undertaken by DSWs. All interviewees made mention of this in their narratives. DSWs spoke of their duty to "step in" to prevent danger or resolve potential areas of conflict that could result in serious injury or harm for their client or others. However, it was also noted that the measure of safety needed to be weighed up against the potential for growth through taking risks, and trying new things. The concept of supporting clients to "step outside their comfort zone" was mentioned by four of the interviewees, with similar comments by the other eight, all believing that young people needed to be encouraged to "have a go" and try new things, or to venture into new places, thereby opening themselves up to opportunities to grow. Linda explained that as a DSW she encouraged her clients to try many new things, and believed that if she held her expectations high, the clients would rise to meet these expectations;

> *They might be expected to do things that their family has never expected them to do, or at college, they've never been expected to do. Or things to talk about—they've never spoken about certain things before, and it's quite new and frightening.*

Such "things to talk about" included sex. Access to internet sites, pornography and sex workers were considered by some DSWs as the right of the client due to their legally acquired adult status. Yet for other DSWs, some limitations were identified within this assumption of rights. Linda went on to explain:

> *I guess I am thinking mostly about young men who are curious, sexual—just horny, but they don't have avenues to explore that. I guess the internet is a dangerous place. I wouldn't encourage looking at pornography on the internet. If they wanted to buy a porn magazine—full informed—I'd sit that person down, and have a really good talk with them about the realities of porn magazines, and porn in general. Porn is different to a real experience.*

The assessment of risk was an area of concern for some DSWs, but the guiding principle was recognised as allowing people to take risks to the extent where they were not putting themselves or others at risk of death of permanent serious injury, or that may have a negative psychological impact on their client. This was seen to be often a matter of professional judgement, and did raise concerns for some DSWs, particularly around sexual issues.

Summary

1) Disability Support Workers recognise that they have a primary responsibility (duty of care) for the safety of their clients.
2) Disability Support Workers believe this duty of care must be measured against the dignity of risk, so that young people with intellectual disability are supported to take risks and extend their experiences beyond their "comfort zone".
3) Disability Support Workers believe that even when some negative outcomes arise, these offer opportunities for young people to grow and develop new skills which better equips them to handle similar situations in the future.
4) Disability Support Workers are guided by the principle of dignity of risk, but are sometimes not confident in their ability to assess risks, most notably in relation to sexual freedom.

6.3.3.5 Adults connect to community through employment or engagement

(Categories: Guidance/support/education; Community Connection)

After analysing the data from the DSW individual interviews, it became clearer that they considered adulthood to involve more connection with their community than actual contribution to the community. The idea espoused in the focus group that clients with intellectual disability actually contribute was moderated by the comments by individual DSWs. DSW interview data revealed that adulthood involves being part of a community, and having "a sense of citizenship", or "rights to access the community, and use the community", along with opportunities to "make connections with the community". Mark talked about the rights of his young clients to enjoy the pub life on Fridays after work, adding, "that is awesome, that people can make contact with others and make connections within the community". There was also a belief that under the right circumstances, the community would also connect to young people with intellectual disability, with Neville hoping that "other people in the community would look out for this person". A specific example of this "looking out" for people was explained by Mark as a wish that he could "rely on the guy behind the bar not to let this guy drink himself to oblivion". There was also mention of community organisations such as church youth groups that catered for people aged from the early teens until the early 20s, but those with experiences of such groups had not found them to be particularly accommodating and clients had not attended more than two or three times.

DSW interviewees acknowledged that with employment opportunities hard to find for many young people with intellectual disability, there can be limitations on the way people can be engaged in paid positions within their community. However, as participants in community events such as art shows, music festivals, fund-raising events, or through volunteering in various ways in the community, young people with intellectual disability were seen to be contributing to community life in meaningful ways. Examples offered by interviewees included clients helping out in conferences, being part of community events in dance troupes, and participating in sporting events. Volunteer activities included distribution of pamphlets through letter drops, and handing out commemorative ribbons in the streets of the CBD. Patrick pointed out that the ANZAC Day parade in his community would not be the same if his 25-year-old client did not attend, having been attending with his family since his very early childhood. Being in paid employment was not considered an essential consideration for recognition as an adult member of a community.

Participation in recreational activities was seen to be a good means to support inclusion within the community. For some interviewees, this participation entailed involvement in mainstream activities, such as being part of a local darts team, or part of a swimming club. One client was also a volunteer with his local rural fire brigade. For other interviewees, participation in disability-specific activities such as Special Olympics sports, or dancing troupes, or disability arts groups was recognised as belonging to a community, as these often involved competing alongside non-disabled athletes, or putting on performances at community events. “Giving back”, was recognised as a goal for some clients, with one group home encouraging the residents to volunteer their time at the local Riding for the Disabled stables where they had ridden in the past. As Abbey explained:

> *It doesn’t hurt for them to realise that they had the chance to ride horses because someone else had put themselves out for them. There are some easy tasks that they can do, and I think it helps them feel good about themselves. It also helps them keep in touch with people they knew since school.*

Summary

1) Disability Support Workers believe adults connect with other adults in their community through either employment or community engagement.

2) Disability Support Workers do not believe that paid employment is a pre-requisite for recognition of adult status

3) Adults can contribute to their community through participation in community events and activities

4) Being an active member of an adult community should raise the acceptance of people with intellectual disability, so that other adults look out for those with intellectual disability.

6.3.4 Summary

The analysis of data obtained through the DSW focus group meeting and individual interviews with DSWs highlights the clear-cut acknowledgement of an age as a determinant for one's adult status. As the legal age of majority in Australia is 18, this is considered to be the point at which adulthood is generally assumed to be conferred on young people with intellectual disability. This then supports the DSWs' perception of their clients as people whose rights are guided by the UNCRPD rather than the United Nations Convention on the Rights of the Child. These rights include the right to be self-determining, with freedom to make their own choices, and to grow and learn from the consequences of their decisions and choices. As part of this recognition of the opportunity to learn through both negative and positive consequences, DSWs support their clients to live, work, socialise and recreate with adults without disabilities in the broad community. DSWs recognise that accessing the community offers risks to the emotional and physical wellbeing of their clients. They argue that within a dignity of risk framework, unless the clients (or other members of the community) are at risk of serious harm or death, they should be allowed and encouraged to take risks that promote learning and personal growth opportunities. This is considered to be their right. Intellectual disability is not regarded as an impediment to recognition as an adult once a young person has reached the age of 18 and has left the secondary school system. Despite the potential for negative consequences, the potential for development and learning which can subsequently lead to greater self-determination and independence is a greater prospect, or higher ideal. It is understood that negative consequences should be minimised where possible, but not used to deny clients community access or employment opportunities, which are their human rights as they have reached the legal age of majority.

Chapter Seven

Findings from Young People with Intellectual Disability Focus Group

7.1 Introduction

This chapter will present the findings from the 75-minute focus group meeting conducted in April 2016 with 13 young people aged between 18 and 21, with varying degrees of intellectual disability. It will present the key themes identified from the focus group data. It is apposite to revisit the definition of intellectual disability before reflecting on the findings from this focus group of young adults. The DSM-5 notes that for a diagnosis of intellectual disability, a person must have deficits in general mental ability that will affect their "reasoning, abstract thinking, judgement, academic learning and learning from experience". These deficits will subsequently impact one or more aspects of daily life activities, resulting in the need for on-going support at school, work or independent life. Each member of this focus group had a level of diagnosed intellectual disability, ranging from mild to moderate, with two students using communication devices to communicate with the facilitator. As noted in Chapter Four, there were accompanying diagnoses of autism, Down syndrome, speech disorders, and other rare genetic conditions. The facilitator has over 20 years' experience working with young people with intellectual disability, and was well skilled to facilitate this group, supporting and encouraging the young people's participation while not guiding their answers.

The focus group discussion was recorded and transcribed. The facilitator recorded in writing any communication offered via the communication devices for inclusion into the transcript. The transcript of the focus group was re-read to the participants one week after it was conducted, to allow participants to add to or amend any comments made. Only minimal amendments were suggested, none which changed the meaning of the comments from the original meeting. The data from the meeting was analysed through an iterative process in which the transcript of the focus group discussion was analysed, coded and categorised. The software package, NVivo was again used to organise data, with words and phrases found in the transcript used in the development of codes and categories. From this analysis a number of themes/ideas arose:

1) Adulthood results from biological changes.

2) Adulthood involves a level of responsibility, (including marriage and parenthood).

3) Adulthood is linked to freedom and independent living.

4) Adulthood can be measured as a chronological milestone.

5) Adulthood is not an "all or nothing" concept.

6) Adulthood offers changes in what you can do and how you are treated

Examples of the comments that contributed to the construction of these key themes are presented in Table 7.1 below:

Table 7.1 Key themes – Young people with intellectual disability focus group

Key Themes	Examples of comments
Adulthood results from biological changes	• *The only way to know you're an adult is if you've got hairs on your private parts. ... When you start turning adult, you get hairs".* • *... you get pimples, and you get hair under here (indicating armpits) and here (indicating groin).* • *When men grow up their voice changes. That happens when you are 19 I think. My voice is starting to break I think.*
Adulthood involves a level of responsibility (including marriage and parenthood.)	• *You get more responsibilities.* • *You become more independent and you take on more responsibility.* • *You have to look after some people, and you have to get a job, and if you are the boss, you have to look after some people. [Facilitator: Who might you have to look after?] Little kids, or people about the same age, or sometimes old people; people as they get old.* • *You have to look after your own kids like your parents look after you.* • *You are an adult when you are married and have a family. I will have five children. You are a young adult when you are 21 and then you can get married. When you have half-a-million dollars you can get married.* • *When I am an adult I will live at Richmond and have two babies and two dogs and two cats.*
Adulthood is linked to choice, freedom and independent living	• *Boyfriends and girlfriends move out of their family home when they are 18.* • *You get more confidence and people let you be free when you're an adult.* • *I could move out if I wanted to. I don't want to live with anyone else. I want to stay in my bedroom with my computer. I don't want to move out but maybe one day I will move in with [my sister].* • *When I won't have to live at [service name] any more I can move out of [service home] and live by myself, and I want to live by myself, and go on holidays to see my real mum.* • *Your parents help you with the toilet and all that when you are a kid, when you become 18 or 19, or 15 or 16, your parents stop, and you have to do it yourself. They can help you a little bit, but when you are an adult you can ask them for help sometimes, but a lot of it, we've got to do for ourselves.*
Adulthood can be measured as a chronological milestone	• *Around 17 ... you're becoming a teenager.* • *You can't be an adult when you are a teenager. You are not an adult when you are eight-***teen** or *nine-***teen.** *You can't be an adult until you are 20.* • *These years—15-19—are still teen years, but when you are 18 you are a legal adult.* • *I'm going to be an adult when I am 20.* • *It's when you're out of your teens—so you have to be 20 to be an adult.* • *I'll be an adult when I'm 64.*

Key Themes	**Examples of comments**
Adulthood is not an "all or nothing" concept	• *A bit like being an adult on P-plates. You know; like you can drive and that, but you are still learning while you have your P-plates up; you're not a fully licensed driver and you have to go slow!* • *It doesn't really matter what age you are; it's just part of growing up I guess! You don't have to worry about what illegal is when you're 21, because you know you're in your 20s, so if I was 20, I wouldn't worry about how old I was, I'd just worry that I'm becoming an adult.* • *When you're turning 21, which is classed as an adult, it's when you turn 21 you are more mature, means you learn a bit more about the world, like you learn to read and write, learn to drive, learning is part of you as a human being—being yourself.* • *I guess they have some opportunities like an adult. They are living some aspects of being an adult, but not all of it.* • *… immature adults; swearing and all that.* • *You become more mature, more advanced, more socialised.* • *It is when you start becoming a young adult, but not a full adult.* • *Some people become adults at different paces.* • *It happens over time. It doesn't happen on one day.*
Adulthood offers changes in what you can do and how you are treated	• *You are an adult when people treat you like an adult.* • *Drinking; you can drink alcohol at 18 in Australia, but in America you can't drink beer till you are 21.* • *You can go to the movies without anyone with you.* • *You can go to MA movies.* • *You can go and have a beer at the pub.* • *They can have sex. And casual sex.* • *Adults can have children.* • *… go to clubs, like bikie gangs, and to the clubs like the Casino.* • *When I first thought I was becoming an adult was when I was 16 because I started putting make-up on. So when I was 15 I didn't know how to put any make up on; never did my nails, or didn't have jewellery, but as I've got older, I just feel more adult.*

7.2 Key Themes: Young people with intellectual disability focus group

7.2.1 Adulthood results from biological changes

The recognition of physical changes as indicators of development toward adulthood was clear from the outset of the focus group meeting. The first question: "*What do you think makes someone an adult?*", elicited an initial response that reflected an understanding of the biological changes that occur. Noah quickly jumped in to state that:

> *The only way to know you're an adult is if you've got hairs on your private parts. … When you start turning adult, you get hairs.*

To which Jacquie added:

> *And you get pimples, and you get hair under here (indicating armpits) and here (indicating groin)".*

Other physiological changes that occurred through puberty were identified by other participants, including periods and breast development for women, and voice changes for men.

7.2.2 Adulthood involves a level of responsibility (including marriage and parenthood)

Participants were able to identify an increased level of responsibility as being associated with the idea of being an adult. Audrey commented that when someone was an adult, “you get more responsibilities”, adding that:

> *You have to look after some people, and you have to get a job, and if you are the boss, you have to look after some people [such as] little kids, or people about the same age, or sometimes old people; people as they get old.*

Cyril was able to associate the idea of responsibility with an increase in independence. Other comments showed recognition that parenting would require a level of responsibility for any children produced, with Richard also appreciating the need to be financially able to support a family before making this commitment, noting that: “When you have half a million dollars, you can get married”. Adults are generally seen to be people who are married with children, although Audrey was able to question this idea when she noted that: “There are some people who are still living with their parents when they are 30, and some live there for their entire lives”. Audrey’s responses throughout the focus group meeting indicated higher level thinking than many of the other participants. Her responses were more broadly focussed than those of others. She believed that these people were adults, and therefore rationalised that not all adults married and reproduced. Marriage and parenthood were not essential criteria for adult status. However, Audrey agreed with the group consensus that if people were married, or did have the responsibility of children, they were definitely adult.

7.2.3 Adulthood is linked to freedom and independent living

The concept that there was more to “adulthood” than simple physical/biological changes was acknowledged by Jacquie: “You get more confidence and people let you be free when you’re an adult”. When asked what was meant by the idea of being free, she explained that she could not currently spend time alone with her boyfriend unless she went for a coffee, and then her father would sit in the car outside to give the couple some “private time” in the coffee shop. Jacquie associates adulthood with a reduction in constant supervision. She explained that it had been “really good” in the previous week when her father went for a walk instead of sitting in the car supervising them, and that he had recently started talking about trusting her to walk to the local shops by herself.

The notion that moving away from the family home is a sign of having reached adulthood was commented on by three participants. Cyril, who is 20 and still living at home with his parents, explained that one does not have to wait until one is 21 to move out of the family home. Cyril believes he has the option to move out whenever he wants, but acknowledges that he does not want to move out of his family home. Cyril commented that he had a choice about where he lived:

> *I could move out if I wanted to. I don't want to live with anyone else. I want to stay in my bedroom with my computer. I don't want to move out but maybe one day I will move in with [my sister].*

When pressed about whether he thought of himself as an adult while he was living at home with his parents, Cyril appeared to not understand the question, and became a little agitated, responding: "I don't know, ask someone else".

Noah also associated adulthood with freedom. As a teenager who was placed into the care of services in his early teens, Noah sees the age 21 as being:

> *When I won't have to live at [service name] any more. I can move out of [service home] and live by myself, and I want to live by myself, and go on holidays to see my real mum.*

He sees the imposition of a court order to remain in supervised accommodation until the age of 21 as a limitation on his freedom which he assumes will be lifted, allowing him freedom to make more choices and have less supervision, thereby being an "adult".

One participant, Jacquie, referred to the idea of the need for personal care impacting her recognition of herself as an adult, noting that:

> *Your parents help you with the toilet and all that when you are a kid, when you become 18 or 19, or 15 or 16, your parents stop, and you have to do it yourself. They can help you a little bit, but when you are an adult you can ask them for help sometimes, but a lot of it, we've got to do for ourselves.*

7.2.4 Adulthood can be measured as a chronological milestone

When asked about the age people might be when adulthood is reached, Noah started counting: "18, 20, 21, 22 …", and looked at the facilitator as if expecting to be met with a response of affirmation when he said the "correct answer". There was a general sense that the students believe there to be a chronological point at which people assume to enter adulthood, but when that chronological point occurred was unclear. Only Jacquie could link the age 16 to an actual behavioural change in her life, noting that:

> *When I first thought I was becoming an adult was when I was 16 because I started putting make-up on. So when I was 15 I didn't know how to put any make up on, never did my nails, or didn't have jewellery.*

The connection of "age" or "number" and adulthood was generally vague. There were many responses to questions of whether participants saw themselves as adults, and when they believed this had, or would happen. When this question was put to Lauren, she answered that she was an adult and became an adult when she turned 19. The next two respondents (Richard and Sally) then also responded with "19", despite

Richard noting earlier that he would be a young adult and marry when he was 21. Other ages suggested as the markers of adulthood included ages 64, and 30, with Thomas adding 55 to the list of possible ages of adulthood, adding: "'cause that's my favourite number". The development of number concepts in people with moderate intellectual disability has been shown to pass through the same stages as it does for people without disability, but with many years' delay (Bashash, Outhred, & Bochner, 2003). This would suggest that while these young people can cite legal ages for voting, entering bars, accessing differently rated movies etc., there is little real understanding of any of these numbers as measures of adult status.

7.2.5 Adulthood is not an "all or nothing" concept.

Another key theme that was deduced from the focus group data is that adulthood is not definitive or absolute. People can be "a bit of an adult" without being fully adult. When the facilitator asked the group whether they thought people who remained living at home until they were 30 or older are adults, and whether they are living adult lives, Thomas, a participant with mild level intellectual disability and autism responded by saying: "I guess they have some opportunities like an adult. They are living some aspects of being an adult, but not all of it!" The facilitator reflected this commented back to Thomas, saying: "So they have some features of being adult, but they are not fully adult? Is that what you are saying?" To which Thomas replied: "Yes I think so. They are a bit of an adult, maybe". To this, Lesley (aged 20 with mild intellectual disability and autism) added:

> *"A bit like being an adult on P-plates. You know—like you can drive and that, but you are still learning while you have your P-plates up—you're not a fully licensed driver and you have to go slow!"*

Along with Lesley's example of the "P-plate adults", participants recognised that there are other "watered-down" types of adults. Lauren talked of "immature adults". When asked what she meant by this term, she responded with "swearing and all that". This was taken to mean that people can be "adults, but not mature", to which Lauren agreed, but did not expand.

Some members of the group recognised that there was no one point at which people became fully adult, noting that "some people become adults at different paces", and "it happens over time. It doesn't happen on one day". The idea of transitioning to adulthood over a period was also noted by Audrey who reflected: "[Puberty] is when you start becoming a young adult, but not a full adult". Despite this discussion, when asked, all participants offered an age at which they believed they had, or would become an adult, as noted in point 7.2.4 above.

7.2.6 Adulthood offers changes in what you can do and how you are treated

At the end of the focus group session, when each participant was asked about what changed when people became adults, Cyril responded: "… in my opinion, but it's not just about age. You're an adult when people treat you like an adult." This was a solitary idealist conceptualisation of what constitutes change within relationships that marks the onset of adulthood. Other participants offered a more materialist list of opportunities on offer to people once they turned 18. These opportunities included voting, drinking, attending cinemas without supervision, being able to access MA- or R-rated movies, drinking alcohol, driving cars, gambling at the Casino, or going to bikie gang clubs. It also included options to leave home or move in with boyfriends, although these were options the participants were not keen to pursue with any sense of immediacy, with the majority of participants believing they were not ready for such moves at this point.

7.3 Summary

In summary, young people with intellectual disability in this focus group identified the following points that contribute to their conceptualisations of adulthood:

1) Adulthood can be associated with a chronological point in time, yet it is recognised as a process that happens over time, starting at puberty with biological changes. Adult bodies differ to children's bodies.

2) People do not have to be fully adult; within the process of becoming adults people can be immature adults, a “bit of an adult”, or “adults with P-plates”, still learning to be adults.

3) Adult status offers greater freedom of choice, and the option to move into independent or shared living arrangements, but this does not have to happen until the young person wants it to happen. Living at home with parents does not preclude one from being an adult.

4) People who are married or who have babies are adults, but one does not have to be married or have children to be an adult. Again, choosing to live at home with parents, or not having a partner, does not stop one from being an adult.

5) With adulthood comes increased responsibility for self and others, along with permission to access venues and opportunities not offered to children. Adults have the choice to attend clubs, or drink alcohol, gamble, have casual sex or watch R-rated movies, amongst other “adult” activities. These are choices, and not compulsory criteria for being an adult.

6) The young people with intellectual disability in this research do not consider themselves as children. Nor do they identify as fully adult. While some see themselves as just “a bit adult”, they recognise that they are “more”, adult than they were when they were children. However, some who are still 18 or 19 years old prefer to consider themselves as still teenagers—somewhere between childhood and adulthood.

Chapter Eight
Mapping of Findings

8.1 Introduction

The previous three chapters, Chapter Five, Chapter Six, and Chapter Seven, have presented findings from data analysis of focus groups and interviews with parents, Disability Support Workers (DSWs) and young people with intellectual disability. This chapter will compare and contrast these findings to identify common themes and common features identified within conceptualisations of adulthood. It will initially present the similarities and difference between conceptualisations held by the key stakeholders in their lives of young people with intellectual disability. It will then outline the compatibility or incompatibility of the perspectives of parents and DSWs within the five key themes that were revealed in the data analysis. The conceptualisation of adulthood offered by young people with intellectual disability will then be compared to ideas identified by parents and support staff. The chapter will conclude with a review of the overall mapping of perspectives using the theoretical framework to compare biological, identity, social and cultural measures of adulthood offered by the research participants. This mapping reveals that while similarities exist in beliefs about biological and social measures, the cultural and identity domains offer areas of potential conflict which are discussed in detail in Chapter Nine.

8.2 Mapping conceptualisations: Parents versus Disability Support Workers

In Chapter Five, the data analysis showed parents identified the following factors as central and fundamental to a perception of people as adults:

- Independence in personal care and self-help skills
- A level of problem-solving skills commensurate with independent activities of daily living, such as independent transport or community access
- Understanding money concepts and responsibility for money/budgets and buying own items
- Capacity for decision-making in a way that promotes safety for self and others
- Initiative and self-motivation/self-determination
- Freedom of choice/autonomy/independence in decision-making
- Rational intelligence and cognitive functioning that offers one:
  - The capacity to safely assume adult rights
  - The ability to cognitively and physically defend oneself
- Physical development/sexual maturity
- Recognition as “other than child”

- Appearance in regular community activities/acceptance by other adults
- Capacity for safe relationships with other adults
- Initiative to explore identities
- Finished secondary schooling
- Chronological age (over 18 years)

In Chapter Six, the DSWs' list of central features necessary for identifying one as an adult was somewhat shorter. The defining characteristics for consideration as an adult by DSWs included:

- A measure of independence and freedom of choice
- The right to, and capacity for self-determination
- Freedom of choice/independence in decision-making
- Physical/Sexual Maturity
- Recognition as "other than a child"
- Interest in relationships and sexuality
- Recognition and entitlement to equal treatment within legal framework for adult consideration
- Acceptance as having a rightful place in the community
- Finished secondary schooling
- Chronological age (over 18 years)

The similarities and differences in factors considered to be determinants for adulthood are set out in Table 8.1 below. Each characteristic is also identified as corresponding to a conceptual lens through which adulthood may be considered.

Table 8.1 Comparison of coding: Parents versus Disability Support Workers

Factors that contribute to recognition as an adult	**Parents**	**Disability Support Workers**	**Conceptual lens**
Independence in personal care and self-help skills	✓	✓	Biology
Physical development/sexual maturity	✓	✓	Biology
Initiative to explore identities	✓	×	Identity
Initiative and/or self-motivation/ self-determination	✓	×	Identity
Recognition as "other than a child"	✓	✓	Social
Appearance in regular community activities	✓	✓	Social

Factors that contribute to recognition as an adult	Parents	Disability Support Workers	Conceptual lens
Finished secondary schooling	✓	✓	Social
Over 18 years—legal rights	✓	✓	Social
Entitlement to adult rights within a legal framework	×	✓	Social
Freedom of choice/autonomy/independence in decision-making	✓	✓	Culture
Problem-solving skills for independent activities of daily living, (e.g. transport/community access)	✓	×	Culture
Understanding and responsibility for money/budgets and buying own items	✓	×	Culture
Capacity for decision-making in a way that promotes safety for self and others	✓	×	Culture
Rational intelligence and cognitive functioning that offers one: (a) capacity to safely assume adult rights (b) ability to cognitively and physically defend oneself	✓	×	Cultural
Capacity for safe relationships with other adults	✓	×	Culture

This comparison shows that there is general consensus with points that identify young people with intellectual disability as having adult physical characteristics; there is little dispute over the physical and biological changes indicating that young people with intellectual disability are physically mature and capable of reproduction. General consensus between DSWs and parents also lies in the idea that adults meet social guidelines as set out by social structures, establishments and institutions. Social structures provide adult services for those over 18, who have completed secondary schooling, and who are no longer definable as children. Adults are expected within our society to engage in social activities with others in the community, and not to live in isolation. Legal and social institutions support arrangements for adults to receive services with other adults, and to be recognised as non-children. Services for children and adults are separated for issues of convenience, supervision and safety, and for financial management. This then accounts for the recognition of appearance in the community as a determinant for adulthood that is agreed on by both parents and DSWs, while acceptance in the community is seen as necessary by parents, but not by DSWs. DSWs believe young people with intellectual disability have a rightful place in the community with their rights protected by discrimination laws, recognising social eligibility established by social rules. Parents talk more of actual acceptance in the sense of being warmly welcomed into a community, and embraced by others around them, not simply eligible to be present.

The differences lie in the domains of cultural determinants and identity development. Cultural expectations align with the concept of culture as a set of learned behaviours and beliefs that are internalised, and characterise groups of people. These are socially transmitted, and can change over time. Parents do not see their sons and daughters assuming many of the learned behaviours of the mainstream culture, culminating in what are considered irrational or unsafe practices. Parents believe this impedes the recognition of their sons and daughters as adults. DSWs do not see these behaviours are necessary determinants of adult status. Nor do they consider issues of identity development to influence their perception of young people as adults. DSW interviewees did not assume any requirements for cognitive development or personal initiative before people can be considered adults. The requirements identified by parents, but not supported by DSWs included:

- A level of problem-solving skills commensurate with independent activities of daily living, such as independent transport or community access
- Understanding and responsibility for money/budgets and buying own items
- Capacity for decision-making in a way that promotes safety for self and others
- Rational intelligence and cognitive functioning commensurate with other adults that offers one:

  a) the capacity to safely assume adult rights

  b) the ability to cognitively and physically defend oneself

- Capacity for safe relationships with other adults

DSWs do not believe adult status is dependent on such factors, and young people can be considered adults regardless of levels of intelligence or cognitive functioning that contribute to problem-solving, safety, or understanding of rights. Instead, biological, and legal and societal measures take precedence in determination of adult status.

Conversely, parents did not consider recognition and entitlement to equal treatment within a legal framework as a determinant for adult status for their sons and daughters with intellectual disability. However, in other respects there were areas of agreement between both cohorts that adulthood involves:

- Some level of independence
- Some level of self-determination and freedom to make own choices
- Physical maturation
- Biological/Sexual maturity
- Recognition as being “other than a child”
- Having a rightful place in their community
- Finishing high school and being over the age of 18

The agreement of these factors as characteristics of adulthood, however, did not mean there was consensus on the construction of adulthood by parents and DSWs. How these factors were perceived to either support or negate one’s recognition as an adult contrasted between the two groups. While the themes were similar, in some areas the actual translation of these themes showed up the variances in perceptions by stakeholders. These similarities and variances are presented in further detail below.

8.2.1 Being adult involves a level of independence

Parents link adult independence to personal care and activities of daily living, along with independent control of money. DSWs do not link this independence in the same way, believing that people can be interdependent, or even totally dependent on others for support, without this precluding their consideration as being an adult. DSWs link independence to freedom of choice, believing that adults are entitled to make their own choices, and with some limitations, are entitled to live, learn and grow through experiencing the consequences of their decisions.

8.2.2 Adults are self-determining, have a measure of freedom to make choices in their life

The parents responding to this study believed that adults are people who have some capacity for freedom of choice, and the rational capacity to be self-determining and to understand the consequences of choices they make. They expressed the belief that adults make rational choices, and one measure of adulthood is the capacity to make decisions and choices that would be considered reasonable by other “adults”. When young people with intellectual disability make decisions that are considered “unreasonable”, parents see these as discordant with adulthood status.

The DSWs who were interviewed also saw adults as people with freedom of choice, but believed that this included making bad decisions. DSWs saw negative consequences of decision-making as opportunities that allow people to grow and learn. While recognising limitations that ensue as a result of their duty of care to their clients, they expressed a desire to support the decisions made by clients, upholding their self-determination to the greatest degree possible.

8.2.3 Adults are physically mature

There was agreement between parents and DSWs over the concurrence of physical development with biological adult status. Both sets of interviewees agreed that biological adulthood can be aligned to physical maturity regardless of any cognitive or sexual capacity.

8.2.4 Adults have a level of sexual (biological) maturity and capacity for safe relationships

While parents and DSWs agree that biological maturity is a marker of adult status, the need for a level of cognitive capacity for sexual engagement was a significant point of difference. Aligned with the idea of rationality, parents expressed that without judicious capacity to understand and problem solve issues associated with safety in sexual relationships, young people should not be awarded the adult right to sexual freedom, or sexual expression with others. This is not to say that parents did not wish for their sons and daughters to have sexual relationships, quite the contrary. The majority of parents expressed a desire for their son/daughter with intellectual disability to find a partner, and even to marry, but one codicil that was dominant was that no offspring should result from such a union. Parenthood is seen as a domain synonymous with adulthood, and this was not seen as an appropriate option for their sons/daughters. DSWs on the other hand believed that interest in sexuality and the development of relationships is a right for people who are biologically mature, and this is not reliant on mental capacity; rather, it is a right for all people who want such relationships. The concern for the welfare of offspring was expressed by DSWs, with guidance from Family Planning or doctors recognised as a right for clients. Only two DSWs were prepared to say categorically that they would support their clients if they wished to have children, with others saying they understood the family concerns, but divested themselves of responsibility in this matter by offering to refer their clients to other services.

8.2.5 Adults are accepted in the community of adults

Parents are cognisant of community responses and reactions to their sons and daughters, and do not see them as welcomed into the general community by those who are not in their lives through familial or paid connections. Parents believe that adults are welcome amongst other adults, and that true acceptance by others in the broad community of adults is a requirement for recognition of adult status. They do not believe their sons and daughters with intellectual disability are welcomed into the “hood” of other adults without disability. DSWs express a belief that being with others in the community will build acceptance and break down barriers to inclusion, and thus promote the rights of their clients to be present in the community, attending community events and living within the community.

8.2.6 Adults should be contributing members of the community – not a burden

Aligned with the previous point regarding acceptance into the community of other adults is the concept expressed by both parents and DSWs that adults contribute to community. This was another point of general agreement. Parents talked commonly about wanting their children to be other than a “burden” on the community, and both parents and DSWs spoke of people with intellectual disability having a “rightful” place, which was explained as having a valued role within the community, either through paid employment, or through voluntary activities.

8.2.7 Adults are recognised as “other than a child”

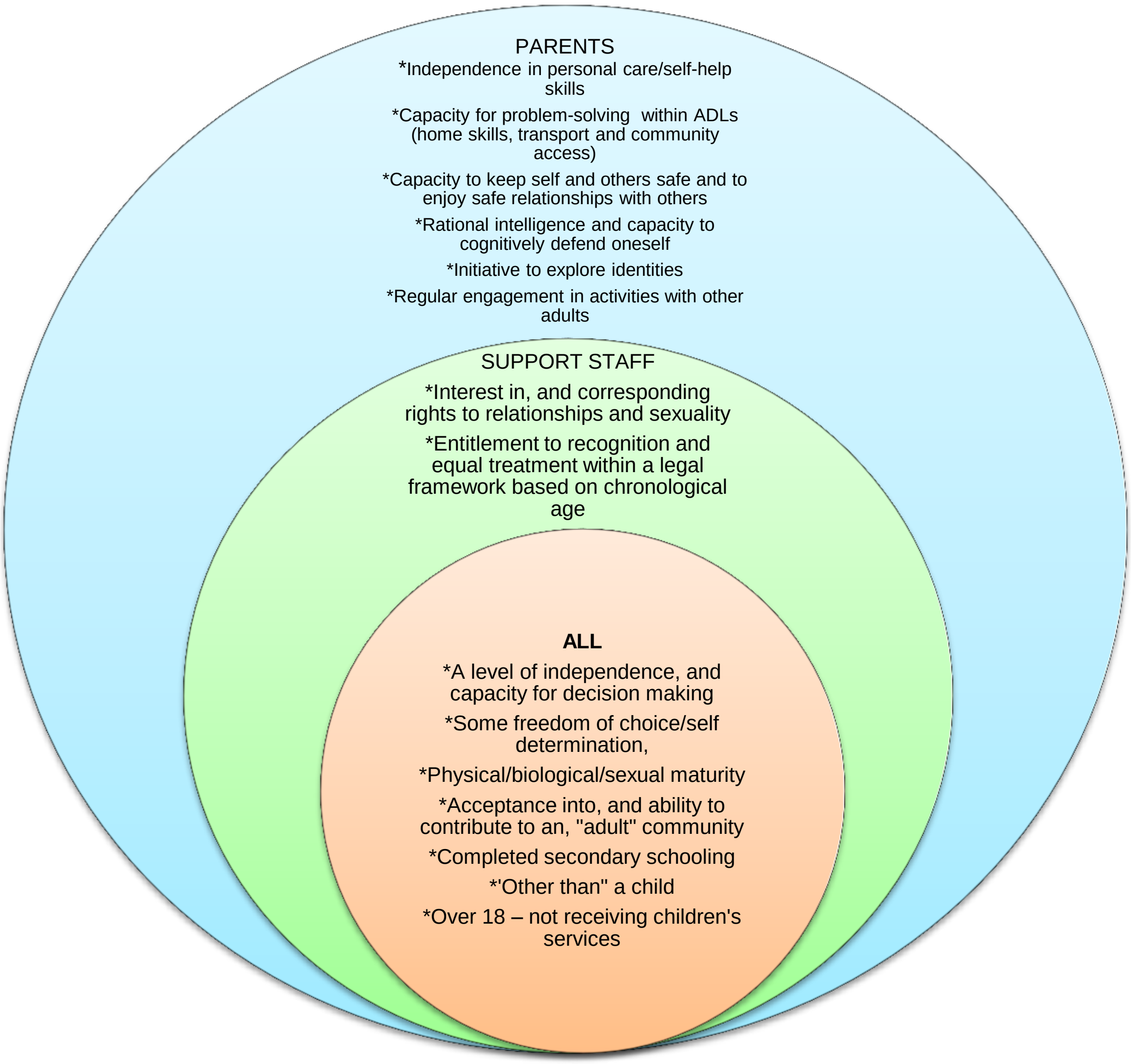
This was a point of both agreement and disagreement between parents and DSWs. Neither group of interviewees considered young people with intellectual disability as children once they had reached age 18, had left school and were attending adult services. This was clearly enunciated by parents who struggled with the lack of an appropriate term by which to refer to their sons and daughters, recognising that while they were indeed still their “children”, they did not want to give others the impression that they considered them to be children by using the word publicly. One parent explained it was easier for him to refer to his “sons”, which did not suggest an age or stage of development, recognising that this problem of classification of “other than children” was made more difficult when families had both sons and daughters and wanted to refer to them collectively. Identifying young people with intellectual disability as “other than children” though, did not mean that parents agreed with the DSW perspective that the young people were therefore adult, but considered than neither adult nor child, but somewhere in between.

8.2.8 Adults have finished secondary schooling/adults are over 18 and ineligible for children’s services

Another two areas of agreement between interviewees was that adulthood can be aligned to the completion of secondary school (end of year 12) which generally correlates with turning 18 and transferring from paediatric to adult services. These factors were considered clear delineations between being a child and no longer being a child, and thus corresponded to a new life stage as a recipient of adult services, attending adult facilities, having adult rights and so forth; a stage distinctly different to that of the school child, the minor, or the recipient of children’s services.

The common and discrete characteristics outlined above are depicted in the Figure 8.1. The inner circle outlines the common features recognised by parents and DSWs offering areas of consensus on determinants of adult status. The next level circle shows those factors that support staff believe support a young person’s recognition as an adult, which involve their rights to relationships, and their entitlements based on their chronological age. The outermost circle notes those requirements that parents believe must be met for one to be considered an adult, but that support staff do not see as essential for adult status. The factors in the outer two circles offer potential for conflict between parents and support staff.

Figure 8.1 Characteristics of adulthood: areas of difference



8.3 Five key themes

Five key themes were initially identified from the data analysis of the parents' interviews. These themes were also identified within the data gathered from DSWs. Within these themes were similarities, but also differences from which conflict between stakeholders could arise. Significant points of difference could be distinguished under the headings of these five themes. These five major themes are discussed in detail below, under the headings:

1) Adults are independent
2) Adults are rational beings
3) Adult life offers meaning
4) Adults find acceptance in the community
5) Adulthood may be actual or virtual

Each of these five themes offer questions that relate to the data analysed. These questions are presented in Table 8.2

Table 8.2: Key themes and associated questions

Key themes	Associated questions
Adults are independent	Can young people with intellectual disability function on their own? Does this matter? Does this impact their adult status?
Adults are rational beings	Do young people with intellectual disability understand the consequences of their actions? Are their decisions/choices “reasonable”? Does this impact their adult status?
Adult life offers meaning	Will young people with intellectual disability gain anything from participating in planned or unplanned activities? Does it matter if they do not? Are these activities that others gain meaning from in their life? Do they offer value to their life? Does this impact their adult status?
Adults find acceptance in the community	Will young people with intellectual disability be welcomed by others who are considered adults by the broad community? Will others acknowledge and treat them equally as fellow adults? Will they be safe in the community? Does this impact their adult status?
Adulthood may be actual or virtual	Will this happen in the real world? Is this true, or representative of those without intellectual disability, or is it an imputed status projected onto someone by some, but not all stakeholders? Is this naturally occurring, or has it been engineered? Does this impact their adult status?

It is within the answers to these questions drawn from the data analysis that the differences and potential conflict between parents and DSWs can be found. The alternate answers to these questions have been synthesised, and précised in the following tables, which highlight the significant points of difference in the perspectives of parents and DSWs within these five key themes.

Table 8.3 Key themes: parents’ beliefs compared with Disability Support Workers’ beliefs

Theme 1: Adults are independent	
Parents believe	*Disability Support Workers believe*
• Adults **are independent** in personal hygiene, self-help and activities of daily living skills	• Adulthood is **not synonymous with independence**. Adults are interdependent. Reliance on support from others does not preclude one from adulthood
Theme 2: Adults are rational beings	
Parents believe	*Disability Support Workers believe*

• Adults have **rational cognitive functioning** which allows them to assume responsibility for their actions	• Adulthood is an entitlement for all people over 18 **regardless of cognitive functioning**
Theme 3: Adult life offers meaning	
Parents believe • Adults have the capacity to **locate meaning** in their daily activities	*Disability Support Workers believe* • Adults **do not necessarily gain meaning** from their activities, but should gain acceptance in the community through their activities
Theme 4: Adults find acceptance in the community	
Parents believe • Adults are **accepted into a community** of like-adults, and are treated with respect and in a way that ensures their safety and is free from harm	*Disability Support Workers believe* • Adulthood entitles one to partake in a degree of **risk taking** from which it is assumed **learning** will occur. This can arise from **placement in the community**.
Theme 5: Adulthood may be actual or virtual	
Parents believe • Adulthood for people with intellectual disability is **more virtual** (contrived or engineered) **than actual**	*Disability Support Workers believe* • **Adulthood for people with intellectual disability is** more actual than virtual

8.4 Potential for conflict

Having identified these five areas in which significant differences can be identified between parents and DSWs, the following tables set out how the conflict between the two groups of stakeholders may arise from their different beliefs and perspectives on what constitutes adulthood and how this impacts young people with intellectual disability.

8.4.1 Theme 1: Adults are independent

The first of these is the idea that to be awarded adult status, one needs to have a level of independence. For parents, this involves independence in basic personal care and simple activities of daily living, such as cooking, cleaning, and independent travel, for example. DSWs do not agree that this is a requirement for recognition as an adult, and object to the suggestion that their clients are children or child-like as a result of deficits in areas where they require support.

Table 8.4 Potential for Parent-Disability Support Worker conflict – Theme 1: Adults are independent

Observation	Potential for conflict
Parents believe adults are independent in personal hygiene, self-help and activities of daily living skills	Parents object to the perception of their son/daughter as adult when they are reliant on others for personal support: Exemplar quote: *We know he is an adult in some ways, in that he has an adult body, and probably adult sexual needs, but he can't stay at home without someone to look after him—cook his meals, we still even need to run his bath. I mean, he is partly adult, we know that, but he's not independent.*
Disability Support Workers believe adulthood is not synonymous with independence, but can involve interdependence and reliance on support from others	Disability Support Workers object to the perception of clients as children regardless of levels of dependency or presentation. Exemplar quote: *Society at large needs to be more aware of the fact that anyone, no matter how they look—whether they have small stature, or look "cutish", like those with Down syndrome, and no matter what they can and can't do for themselves, are adults, or become adults, and have adult rights.*

8.4.2 Theme 2: Adults are rational beings

The second area that offers the potential for conflict is the idea that adult status is dependent on a level of rational capacity. Parents identify deficits in their son's or daughter's problem-solving skills that necessitates the need for supervision and protection. Contrasting with this idea, DSWs consider their job is to prioritise support for young people to take risks, engage in new experiences, to be self-determining and have freedom to make their own choices. While recognising that duty of care requires safety to be considered while undertaking their supervision of clients, this should not compromise the autonomy of the client.

Table 8.5 Potential for Parent- Disability Support Worker conflict – Theme 2: Adults are rational beings

Observation	Potential for conflict
Parents believe adults have rational cognitive functioning which allows them to assume responsibility for their actions	Parents want young people with intellectual disability to be supervised and protected as they are unable to make rational decisions and choices Exemplar quote: *He is still profoundly vulnerable, and if we weren't keeping an eye on his things, his money, his phone all the time, he just wouldn't have anything! He misunderstands what people are trying to tell him, but other people don't know this. Letting someone else help him make his decisions is too much of a worry—he would agree to all sorts of things that wouldn't necessarily be what he needs, or even what he wants*

Disability Support Workers believe adulthood is an entitlement for all people over 18 regardless of cognitive functioning	Disability Support Workers understand their role includes a duty of care, but believe also that they are obliged to provide dignity and opportunity for growth through risk taking Exemplar quote: *We treat everyone potentially as adults, putting our safety measures all around them, and then take a step back and think: "Where can this go wrong?", rather than thinking: "Oh, these are all diminished people, and they can't make their own decisions, so we have to protect them".*

8.4.3 Theme 3: Adult life offers meaning

The third area of disagreement and potential conflict is the concept that life provides opportunities for meaningful outcomes for adult members of a community. Parents believe adults gain more than simple pleasure from many of the activities they engage in and need to be given opportunities to be other than "burdens" on their community. They seek opportunities for meaningful engagement in the community for their sons and daughters, but do not believe this comes from the normalising routines such as going to day options, or recreational programs. Activities offered by DSWs offer opportunities for their young clients to gain acceptance in the community, regardless of whether this has particular meaning to the client or not.

Table 8.6 Potential for Parent- Disability Support Worker conflict –

Theme 3: Adult life offers meaning

Observation	Potential for conflict
Parents believe that adults have the capacity to locate meaning in their daily activities	Parents want a "good life", for their sons and daughters that is not necessarily achieved through normative adult activities. Exemplar quote: *What are the benefits of a program that starts at 9.00 in the morning and finishes at 2.30 in the afternoon, and three hours of this are spent on a bus? Does she have to go to some type of institutionalised learning and activity centre to make her life fulfilled or fulfilling, or meaningful*?
Disability Support Workers believe adults do not necessarily need to gain meaning from their activities, but should gain acceptance in the community through their activities	Disability Support Workers are concerned about the presentation of clients as members of the adult community; gaining meaning from activities is not a priority. Exemplar quote: *One of the things I feel is important is promoting people with intellectual disability at any age as being meaningful participants in society, or having a part in society. I think it's about presenting an image, and also about promoting respect and, not so much understanding, but I suppose, respect for place in community*

8.4.4 Theme 4: Adults find acceptance in the community

The fourth area of potential conflict involves the concept of acceptance, rather than simple appearance within a community of other adults. Parents do not believe that the general community is accepting of people with intellectual disability. While their sons and daughters are protected, and provided with opportunities to participate in community events, parents do not believe this equates to full acceptance into the community of adults. For young people with intellectual disability, the lack of acceptance and the continuing stigma from being marginalised may have detrimental effects on them through abuse or neglect. DSWs feel responsible for supporting these young people to find a rightful place in the community. While acknowledging that some negative experiences can occur, DSWs believe these are learning opportunities that exist for all members of the community, and people should not be hidden from them as a result of their intellectual disability.

Table 8.7 Potential for Parent- Disability Support Worker conflict – Theme 4: Adults find acceptance in the community

Observation	Potential for conflict
Parents believe adults are accepted into a community of like-adults, and are treated with respect and in a way that ensures their safety and is free from harm	Parents believe the interactions with member of the general community may have potentially detrimental effects on their sons and daughters with intellectual disability. Exemplar quote 1: *Parents of little children don't like him hanging around and if he is there on his own, they have called the police. The police bring him home, and tell him he can't go down there—he hasn't done anything wrong, the parents just don't want him near their kids.* Exemplar quote 2: *I feel that [the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)] is a feel-good gesture … It's all well and good and supports egalitarianism, but how do you make someone [accept young people with intellectual disability] when they feel threatened, or uncomfortable around people who have extra needs?*
Disability Support Workers believe adulthood entitles one to partake in a degree of risk taking within the community from which it is assumed positive growth and social learning will occur	Disability Support Workers support the of right young people with intellectual disability to a place in the adult community, and believe they are more likely to have beneficial consequences from their interactions with others Exemplar quote: *… just a sense of citizenship, and a sense of rights, that all people, regardless of their circumstances, have basic rights, whether that is accessing the community, using the community, making adult decisions, one of my values in terms of support is to allow people to take risks. Because that's what everyone does. I want to do something, and I've never been there before, but I want to do that—I don't want anyone to stop me. So why should I deny that same chance for someone else*?"

8.4.5 Theme 5: Adulthood may be actual or virtual

Parents believe that young people with intellectual disability do not seek out, or initiate opportunities for growth within the community, but are guided and supported to experience opportunities that are created for them. While this may offer a parallel pathway through education, training, recreation or employment for their sons and daughters with intellectual disability, it is not a "real" situation, but one that is artificially created or engineered. DSWs see that by having the same opportunities to attend education, training, recreational or employment opportunities, these young people are have the same experiences as all other adults, and are experiencing a "real" adult life.

Table 8.8 Potential for Parent-Disability Support Worker conflict – Theme 5: Adulthood may be actual or virtual

Observation	Potential for conflict
Parents believe that adulthood emerges naturally for young people without intellectual disability but that it is engineered for those with intellectual disability in the absence of their initiative	Parents believe that the environment in which young people with intellectual disability are adults is artificial, and that their children are adults only within a context which is not authentic. Exemplar quote 1: *There isn't any unfolding, it is more like structuring, we engineer our disabled children's lives, I think, is the fundamental difference. It's quite different to a normal child.* Exemplar quote 2: *That's what I would hope, and what I'm trying to engineer. … What I'm focusing on now is work*
Disability Support Workers believe that there is some imagery involved in the presentation of people with intellectual disability as adults, but that this does not stop them being considered as real adults	Disability Support Workers believe that having the same experiences as other adults in an authentic environment equates to real adulthood Exemplar quote 1: *What we like to think about is that people have the same life experiences if they are receiving support from us, as they would if they were at home with their parents, or if they were living without a disability* Exemplar quote 2: *I have come to a gradual understanding that I am working with people who haven't had opportunities to make decisions, or maybe they don't understand what making decisions is, what that actually means, and a realisation I am actually working with adults, young adults.*

8.5 Conceptualisations of adulthood by young people with intellectual disability: comparison with parents and Disability Support Workers

Having compared and contrasted the findings from the analysis of parents' data and DSWs' data, the voice of young people with intellectual disability is now reviewed against these findings. The factors that young people identified did not clearly align with the themes identified by parents and DSWs. Young people with intellectual disability are aware of social structures that impose age restrictions, and social roles such as parenting or employment as identifiers of adult status. However, a number of factors that were identified by parents and DSWs who examined the concept of adulthood through cultural or identity lenses were not noted in the findings from the young people. This section compares firstly the factors identified by parents and DSWs and notes whether these were also identified by young people with intellectual disability themselves. It then compares and contrasts the characteristics of adulthood that were described by the young people with those described by parents and DSWs. Finally it looks at the four domains of adulthood established in the theoretical framework and explores the perspectives of the three groups of research participants based on this framework.

8.5.1 Overview of mapping

A comparison of factors identified within the data of the three groups of participants in this research is offered in Table 8.7. Young people identified 10 of the factors identified by parents, but did not mention others such as rational intelligence, capacity for decision-making, acceptance in the broad community of adults, or the idea of exploring identities. The young people identified their rights as being a component of being an adult, but recognised these more as rights to access social venues and apply for licenses, or to drink alcohol more than they associated them with rights to autonomy or freedom of choice. All of the young people in the focus group (aged 18-21) wanted to stay living with their parents for the time being, although they recognised that if they had wanted to move out, it was possible to do so once they turned 18. More complex and abstract concepts, such as the concept of being rational may not be within the capacity of young people with intellectual disability to identify and consider. The young people focussed their discussion on more observable and measurable factors, considering actions that they will be able to do, and recognising different opportunities that will present for them. Abstract ideas about capacity, and rationality of thoughts were not mentioned as contributing to access to these opportunities. For example, the factors identified by the young people focussed on the opportunities to access community facilities, rather than on involving social interactions with members of the broad community within those facilities. The intricacies of social interactions and relationships were not part of the conversation in the focus group, nor were the nuances of communication. The young people's beliefs were more similar to those of their supporting DSWs and differed from the parents in this aspect. They aligned more with materialist concepts of biology and social structures than with more idealist concepts associated with identity construction or cultural beliefs and values.

Table 8.9 Comparison of factors: parents, Disability Support Workers, young people with intellectual disability

Factors that contribute to recognition as an adult	Parents	Disability Support Workers	Young people with intellectual disability
Independence in personal care and self-help skills	identified	identified	identified
Physical development/sexual maturity	identified	identified	identified
Initiative/desire to explore identities	identified	not necessary	not mentioned
Initiative and/or self-motivation in daily tasks	identified	not necessary	not mentioned
Self-determination/Freedom of choice	identified	identified	identified
Recognition as "other than a child"	identified	identified	identified
Appearance in regular community activities with other adults	identified	identified	identified
Finished secondary schooling	identified	identified	identified
Over 18 years, legal rights	identified	identified	identified
Acceptance in the community of other adults	identified	not necessary	not mentioned
Entitlement to adult rights within a legal framework	not mentioned	identified	identified
Problem-solving skills for independent activities of daily living, (e.g., transport/community access)	identified	not necessary	identified

Factors that contribute to recognition as an adult	Parents	Disability Support Workers	Young people with intellectual disability
Understanding and responsibility for money/budgets and buying own items	identified	not necessary	identified
Capacity for decision-making in a way that promoted safety for self and others	identified	not necessary	not mentioned
Rational intelligence and cognitive functioning commensurate with other adults that offers one: a) capacity to safely assume adult rights b) ability to cognitively and physically defend oneself	identified	not necessary	not mentioned
Capacity for safe relationships with other adult	identified	not necessary	identified

From the focus group meeting young people with intellectual disability identified six features of adulthood:

1) Adulthood results from biological changes
2) Adulthood involves a level of responsibility (including marriage and parenthood)
3) Adulthood is linked to freedom and independent living
4) Adulthood can be measured as a chronological milestone
5) Adulthood is not an “all or nothing” concept
6) Adulthood offers changes in what you can do and how you are treated

When compared to the factors outlined by parents and DSWs (see Table 8.7), these ideas were found to align at times with parents’ ideas, and in some ways with the beliefs expressed by DSWs, but at times to differ from both in significant ways that are described below.

8.5.2 Adulthood results from biological changes

This adult characteristic finds general consensus between all three cohorts; there is no argument about the physical development of young people as being one contributor of recognition of adult status.

Table 8.10 Features of adulthood comparison of beliefs:
Adulthood results from biological changes

Young people identify that …	Adulthood results from changes to the body, breast development, pubertal hair, voice changes periods, etc. Exemplar quote: *You’ve got hair on private parts.*
Parents	Parents agree that young people with intellectual disability are biologically mature and have developed physically adult bodies
Disability Support Workers	Disability Support Workers agree that young people with intellectual disability are biologically mature and have physically adult bodies
Observation	No conflict

8.5.3 Adulthood involves a level of responsibility (including marriage and parenthood)

The concept of adulthood requiring a measure of responsibility is shared by parents, DSWs and young people. Differences lie in the types of responsibility that adults are expected to assume. Parents believe that fundamental skills and capacity to assume responsibility for one's basic hygiene needs is the minimal requirement for consideration as an adult, and the young people also believe that they will assume this responsibility when they become adults. They also believe they will be able to be responsible for others, including children when they are "adults", while DSWs tend to believe that the young people will learn to be more independent if provided with the right opportunities to be self-determining. DSWs see their role as encouraging independence and supporting young people to make their own decisions.

Table 8.11 Features of adulthood – comparison of beliefs:
Adulthood involves a level of responsibility

Young people identify that …	As they become adults they will be expected to assume more responsibility for themselves for personal care, and activities of daily living, such as cooking and maintaining their own home. Adulthood is associated with being married and having their own children; these are determinants of adult status. Exemplar quote 1: *When you're an adult you get more responsibilities … and you have to look after other people …* Exemplar quote 2: *You are an adult when you are married and have children.*
Parents	Parents agree that responsibility is a characteristic of adulthood and link this to responsibility for personal care, and capacity to be responsible for oneself and for others Parents agree that a cultural marker of adulthood is marriage, or responsibility for others, such as children. Given their concern over the inability of their sons and daughters with intellectual disability to assume responsibility for themselves, they do not see this measure of adulthood as an option for people with intellectual disability.
Disability Support Workers	Disability Support Workers believe that they can provide support that allows young people with intellectual disability to assume more responsibility for self-determination, which in turn allows them to be less reliant on others. DSWs acknowledge the equal rights of all people under the UNCRPD to choose with whom to live, and to be safe from discrimination in terms of marriage or personal relationships. They uphold these rights in the course of their duties, assuming the clients' rights take precedence over those of their family.

Observation	Parents believe those who are unable to assume responsibility for personal safety and safety of others are not fully adult. Parents wish to continue to provide supervision and support for their sons and daughters. Young people with intellectual disability believe they can, or will be able to at some point, care for themselves, as well as be responsible for raising children and caring for others at some point in their future. DSWs believe in supporting young people with intellectual disability to make their own informed choices, and to take responsibility for their actions in order to become more self-determining and to assume their rights. Result: Parents and young people with intellectual disability believe they are yet to be adults, as a result of lack or capacity *or* lack of desire to assume responsibility for self and others. DSWs believe that young people with intellectual disability are adults, regardless of any lack of capacity to assume such responsibility.

8.5.4 Adulthood is linked to freedom and independent living

Young people with intellectual disability believe that will be offered more freedom as they are recognised as adults and recognise that there may be a point in the future where they choose to live away from their family homes. DSWs consider young people with intellectual disability to be adults and therefore see their role as facilitating the young people's independence from their parents. Parents believe that freedom to live independently and to make one's own choices requires rational capacity that the young people are yet to acquire. Parents want to continue to work with their sons and daughters to build capacity for independent living for the future.

Table 8.12 Features of adulthood – comparison of beliefs:
Adulthood is linked to freedom and independent living

Young people identify that …	At some point in their future young people with intellectual disability expect to live either independently, or in a home with friends or a partner, and to have more autonomy over their lives. However, they see that people can still be adults even when they remain living with their parents. Exemplar quote 1: *People let you be free when you're an adult. … I can move out if I wanted to when I'm an adult.* Exemplar quote 2: *Some adults stay living with their parents till they are 30.*
Parents	Parents believe that adults are independent and autonomous beings who are free to make independent choices, and live by the consequences of their actions. They do not see this applying to their son or daughter simply because of their chronological age but work to develop independence for their son or daughter over time.
Disability Support Workers	Disability Support Workers believe that people are interdependent, and that no adults are truly independent, so this is not a determining factor for adult status. Being dependent on others does not impact adult status, but DSWs believe support should be directed by clients, not their parents

Observation	Parents are reluctant to relinquish support for their son/daughter with intellectual disability to services that may not provide adequate safeguards, and allow too much "freedom". Parents want their sons and daughters to eventually find alternate accommodation, but this is not always a high priority for today's young people. DSWs believe more freedom in decision-making promotes personal growth. They believe their role is to support independence from parents and to help young people see that moving out of home and having greater freedom is part of normal development. Young people with intellectual disability associate adulthood with freedom and moving out, but do not want to move out of the family home too soon. It is not immediately sought, but something to look forward to when the time is right.

8.5.5 Adulthood can be measured as a chronological milestone

Young people with intellectual disability are knowledgeable about regulatory ages that apply to social institutions, seeing the age of 18 as a point that they are socially and legally recognised as adults. However, simply being a particular age does not signify any real changes in the parent-son/daughter relationship for these young people, and does not effectively change their behaviour or social life. Parents do not see that chronology makes any difference to the consideration of young people as adults other than in legal terms. DSWs are committed to educating young people about their adult rights on turning 18, and to ensure they have opportunities to have experiences and opportunities that are available to other 18-year-olds.

Table 8.13 Features of adulthood – comparison of beliefs:
Adulthood can be measured as a chronological milestone

Young people identify that …	Adulthood is associated with a chronological marker, but there is little agreement as to what that marker is. To some young people it is associated with puberty, for others, it is when they can legally enter "adult", premises. For some it is when you are no longer a teenager, while others nominate random numbers with little apparent understanding of concept of chronological age. Exemplar quote 1: *This could be when one is no longer being a teenager, or the age of 18.* Exemplar quote 2: *I'll be an adult when I'm 55, 'cause that's my favourite number.*
Parents	Parents recognise that adulthood in a legal or social sense can be linked to chronological markers such 18 or 21, but don't believe that legal or social rights should apply if/when not all other measures of adulthood are met by young people.
Disability Support Workers	Disability Support Workers consider rights and entitlements that apply to the broad community as a result of reaching chronological milestones apply to those with intellectual disability, regardless of capacity
Observation	Parents believe that before adult rights can be conferred, there need to be criteria met within social, cultural, and biological domains, not through simply meeting chronological milestones. Young people also do not align adulthood to chronological ages, despite knowing that they can legally access some venues, choose to vote etc.

8.5.6 Adulthood is not an "all or nothing" concept

Young people identify that adulthood is a process that happens over time, and that during the process, people can be "a bit of an adult", or an immature adult. Parents believe the same, and talk of young people as being adults "in some ways, but not in others". DSWs tend to see adulthood as a distinct life stage that begins at the end of childhood, and is supported in legal terms. It is seen by DSWs as the stage one reaches at the end of childhood; this position conflicts with the perspective of parents and young people with intellectual disability.

Table 8.14 Features of adulthood – comparison of beliefs: Adulthood is not an "all or nothing" concept

Young people identify that …	Becoming an adult is a process—people start to become adults, and the process happens over time Exemplar quote: O*ne can be an adult in some ways, and not in others*.
Parents	Parents agree that young people can be adults in some ways and not in others. One can meet biological or physical determinants, but not be adult in a social or cultural sense.
Disability Support Workers	Disability Support Workers tend to link adulthood predominantly to biological or chronological measures, seeing young people with intellectual disability as entitled through social structures to access adult entitlements regardless of cultural characteristics. Being adult in legal or physical terms means being awarded full adult status with adult entitlements.
Observation	Young people with intellectual disability receive mixed messages about their own adult status. Their perception is more aligned to that of their parents, acknowledging some adult characteristics, but equally acknowledging areas in which they do not assume adult status. They see themselves being "a bit adult" and on the way to full adulthood. This is similar to parental perspectives, but dissimilar to the views of DSWs DSWs believe the perspective of young people with intellectual disability is influenced by parents, but this can be changed with further education, training and guidance.

8.5.7 Adulthood offers changes in what you can do and how you are treated

Young people with intellectual disability know that their age allows them entry to bars or casinos, permission to watch MA or R rated movies or have casual sex. They may choose to smoke or to drink alcohol. However, they believe these options are only possible with the permission of their parents with whom they still live, and whose rules they continue to follow. The young people believe that as they become "more adult", those around them will treat them differently, offering greater freedom and supporting their participation in adult activities. Parents agree that adults are treated differently to children, but while their sons and daughters are in the grey area between childhood and adulthood, they cannot be treated as fully adult. DSWs believe that by treating young people as adults, they will more rapidly learn to act in accordance with adult expectations.

Table 8.15 Features of adulthood – comparison of beliefs:
Adulthood offers changes in what you can do and how you are treated

Young people identify that …	People are treated differently and allowed to do more things when they are adults. Exemplar quote 1: *You are an adult when people treat you like an adult.* Exemplar quote 2: *You can go and have a beer at the pub.*
Parents	Parents look forward to treating their sons and daughters in ways more commensurate with adult expectations, aligning this with cultural expectations of adult behaviour, not chronological age
Disability Support Workers	Disability Support Workers believe young people with intellectual disability should be treated as adults once they turn 18 and are considered adult within social structures, such as adult support services. They support their social and sexual rights, and their right to be part of their “adult” community.
Observation	Young people with intellectual disability continue to seek guidance and permission from primary caregivers to access adult social venues and opportunities. They continue to follow rules established by those who continue to be seen as authority figures in their lives, but believe this will change over time. Parents are concerned about the lack of initiative shown by the young people to seek autonomous direction in these areas. Disability Support Workers actively work to encourage access to adult venues and activities and to support young people with intellectual disability to engage with the broad community safely and with mutual respect.

8.6 Summary

In summary, this chapter has compared and contrasted the factors identified by parents, Disability Support Workers and young people with intellectual disability. It has examined the data analysis of interviews and focus group meetings and mapped areas of consensus and areas of disagreement. The areas of disagreement will be discussed as potential causes of tension or conflict in Chapter Nine. To summarise the findings from this mapping of conceptualisations the four domains or lenses through which one can consider the concept of adulthood are reviewed.

8.6.1 Biological domain

There is general consensus amongst all three groups that the human body develops to a state of maturity and presents typically regardless of any intellectual disability. Physical development and associated physical skills are assumed to offer people a level of independent skills that align with the concept of adulthood. Adult bodies are also recognised as being sexually mature, and capable of reproducing. The bodies of people living with intellectual disability develop physiologically in ways that are more similar than dissimilar to typically developing bodies.

8.6.2 Identity domain

Parents believe that in the process of becoming adults, people explore various identities, seeking to become individuals with an identity of choice. They do not see this happening for their sons and daughters. Instead, they need to engineer opportunities during the transition to adulthood to find work or training options or other recreational services that can provide routines for their sons and daughters. This can result in identity foreclosure which resolves the issue of identity diffusion. That is, the young people are believed to not be prepared to explore a range of identities (diffusion), so they are encouraged and supported into roles as workers or clients of services, and this is likely to be their long-term identity (foreclosure). Conversely DSWs see young people with intellectual disability as forced into identity foreclosure through limitations placed on their exploration of alternate options by parents. DSWs believe parents restrict risk taking and exploration of opportunities for personal development, denying them a stage of identity moratorium. The concept of identity development was not raised in the young people’s focus group. Few were interested in exploring work options that might provide an alternate identity to that of “client of services”. The most significant alternate identity to their current status was that of a parent at some point in the future but the young people in this research were not contemplating this identity in the immediate future.

8.6.3 Social structural domain

As with the biological determinants of adult status, there was general agreement that people cease being children, and either become, or start to become adults when then have finished school, are over 18 years of age, attend “adult” health, education, training, and recreational services and are entitled to access social venues such as hotels, bars, casino, different genre movies, and so forth. All three groups acknowledged the structure of society into services for children and services for adults, and the support available to adults through legal entities, and international conventions such as UNCRPD. Young people with intellectual disability see that they are at an age where social rules allow them to access a broader range of services, but still assume parents have final authority over such access. Parents recognise that 18-year-olds are legally allowed to access any social venues but do not see this as an entitlement for young people simply because they are 18. Their belief is that this requires a level of maturity that may not be commensurate with chronological age. DSWs believe that the maturity to adapt to the requirements of adult experiences can be developed through actually having the experiences, and believe young people should be supported to access any service or social agency to which they are entitled.

8.6.4 Cultural domain

The focus group of young people talked minimally about issues that fall within the cultural domain relating to the learned behaviours and beliefs that characterise groups of people. These tend to be the idealist, or abstract concepts underpinning parents’ conceptualisation of adulthood. Parents see cultural beliefs about adulthood as recognising characteristics such as autonomy, self-determination, responsibility, rationality and acceptance, all of which support independence as fundamental requirements for acceptance as an adult. DSWs argue against this perspective, offering that dependence on others, or interdependence between people does not negate adult status, but rather is the natural order of a community that is fundamentally interdependent. The young people in this research believe that they will become more independent in time, and agree that this is an expectation for them as they continue to develop skills. They look forward to a time they can have greater freedom to make their own choices. Independence to young people is regarded as the development of skills that allow for people to do things alone; there was no mention of idealist traits such as problem-solving, or being able to rationalise and consider the perspective of others, for example. Many of these young people are already recipients of services that support them to safely access the community, and to use public transport more independently. They see this as helping the young people with intellectual disability to become adults, but did not explore more abstract concepts of rational thought, or cognitive defence of themselves.

Parents also believe that adulthood from a cultural perspective offers a meaningful life through an occupation or functional role in society. Studying parents' perspectives on successful transition to adulthood for their sons and daughters with intellectual disabilities, Henninger and Lounds Taylor (2014) found that having some functional role in society was the most frequent theme expressed by parents. This role in society did not have to necessarily mean either full-time or part-time paid employment, but included "general feelings of productivity and contributing to the community" that fitted the needs and abilities of the individual with the intellectual disability (p. 102). The parents in this research agreed that this is a significant measure of adult status. This in turn can contribute to true acceptance, rather than simple tolerance within the broad community that would contribute to the safely of young people with intellectual disability in the company of other adults in the community.

8.6.5 Conclusion

There is little disagreement amongst the three groups of research participants about the biological determinants of adulthood, or how society organisations and structures delineate between people as either children or adults and cater for their needs accordingly. The areas of potential conflict are within the cultural considerations of people as adults by those who work with these young people. More idealist characteristics that are harder to measure and that develop over time impact how these young people are identified as adults or non-adults by stakeholders. It is in these areas that the tensions seem to exist. These are the areas where differences are apparent. Such differences may lead to areas of disparity that parents, DSWs and young people with intellectual disability will need to negotiate during the life stage beyond the school gates. It is this area that is explored in greater detail in Chapter Nine.

Chapter Nine
Discussion

9.1 Introduction

This chapter will discuss the findings from the previous four chapters and the implications of these findings. It will explore differences in conceptualisations between parents and Disability Support Workers (DSWs) within the five key themes identified in the findings, and overlay these with the conceptualisations of adulthood expressed by young people with intellectual disability. It will explore whether differences in conceptualisations contribute to conflicts between parents and DSWs. Finally it will discuss the inadequacy of any definition of adulthood to serve young people with intellectual disability, their parents and their support staff in their negotiation of roles and responsibilities in the post-school years.

Before any discussion of the findings from this study it is germane to revisit the purpose of the research in order to keep the research question uppermost in the reader's mind. This study investigated and considered what "being an adult" means to parents, disability support workers, and young people with intellectual disability. It aimed to identify similarities and differences between conceptualisations held by these stakeholders. In doing so, it reflected on the potential for tensions to arise from the incompatibility of such discourses. Further it considered whether currently acknowledged definitions of adulthood are adequate, or serve those with intellectual disability in any constructive manner. This research looked at whether the processes involved in guiding the actions of support staff and family members of young people with intellectual disability as they are transitioning out of the school years and into post-school options and adult services are based on the same, or different conceptualisation of adulthood by stakeholders. It explored various conceptualisations and sought to identify whether differences actually contribute to the tension that was identified in the literature, causing friction between families and service providers during this transitional phase after secondary schooling. This chapter now reviews the findings with these questions in mind.

The word "adult" is a common-use term. It is not one that requires explanation in the course of general communication and everyday conversations. It is used on the assumption that its meaning is clear to the parties engaged in any written or verbal interaction. It is recognised as having synonyms such as "mature", or "grown up", and is a dichotomous position to that of "child". It is rarely subject to further lexical scrutiny. However the findings from this research show that the assumption that this term means the same thing to everyone within the context of young people with intellectual disability is not justified. The mapping of conceptualisations presented in Chapter Eight show differences in conceptualisation of adulthood by parents, support staff, and by young people with intellectual disabilities themselves in five key areas: independence, rationality, meaning, acceptance, and the "reality", of adulthood experiences. Such differences clearly hold potential to contribute to tensions experienced by stakeholders, inviting opportunities for support staff and family members to use the same language to misunderstand or miscommunicate with each other. There is not one recognised definition of adulthood that is shared by stakeholders. The term "adult" is used in various frameworks, with differing connotations and implications that are framed by the relationship between the individuals using the term and those to whom they are referring. The fluidity and variability of its meaning effectively makes it meaningless. It does not hold to one clear set of defining characteristics, and while we each hold to, and apply a concept of adulthood to people with whom we engage, this concept is our own, and not universal.

The one common thread found in the conceptualisations of young people with intellectual disability, their parents, and their support staff is that an adult is someone who is not a child. However, the relative importance of this defining characteristic fades somewhat into insignificance in the wake of other determinants that may be seen as more vital to the consideration of one as an adult. For parents who consider independence, rationality, and contribution to community amongst the identifying determinants of adult status, the fact that their sons and daughters are not children becomes irrelevant to their consideration as adults. On the other hand, to support staff, the idea that young people with intellectual disability are not children is paramount. It is the basis of disability support policies that use the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) framework and its respect for autonomy, self-direction and decision-making. It guides the practices of DSWs and sets their interactions with their clients. It also colours their interactions with their clients' families. Clients who are seen as "not-children" are positioned notionally aside from their parents, with client wishes and preferences taking precedence in decision-making due to their right to autonomy. At the same time, the ideas of autonomy and responsibility further present a theoretical position which does not always play out in practice for DSWs who face challenges applying these principles in the course of their duties. The dilemma for support staff is also discussed by Jingree and Findlay (2008) who describe their need to balance being facilitators of choice who support their client's autonomy alongside their duty of care for their wellbeing. There exists, then, a further dichotomy in the findings between the theoretical consideration of young people with intellectual disability as adults and the practical application of this theory. The question of professional ethics, and the negotiation of the space between respect for autonomy and caring for clients' wellbeing is well covered by Jewell (2010), so while this will be touched on briefly within the following discussion, the firmer focus in this chapter is on the conceptualisations held by DSWs and parents. This discussion will initially explore the five key themes which emerged from the data and concept analysis and which were identified in the previous four chapters.

9.2 Key themes

9.2.1 Independence

The question of capacity for independence perhaps lies at the heart of much of the grey area of difference between those who staunchly support the rights of all young people, including those with intellectual disability, to be recognised and treated as adults, and those who question the simplicity of this concept. While the disability support workers interviewed in this research believe it is fundamental to acknowledge and support the rights of their clients to be recognised as adults, the young people with intellectual disability and their parents found fault with this basic premise. The key difference under the theme of independence is that parents believe full adults to be independent persons who are able to attend to their personal hygiene, can maintain themselves without the need for intervention, and who manage their own activities of daily living, such as budgeting, housework, food preparation and other similar daily chores. When they observe that their sons and daughters cannot attend to simple matters of personal hygiene; adjusting the temperature in order to shower safely or run a bath; staying at home unsupervised; cooking their meals; making their own appointments etc., parents do not consider them to have attained full adult status. This can be summed up by the comment: “He is an adult in some ways, we know that, but he’s **not independent**”. Parents believe independence and autonomy are paramount considerations for one to be recognised as an adult. While young people remain dependent upon others for fundamental personal hygiene needs, or require support in activities of daily living, parents do not perceive them as having become fully adult.

The young people with intellectual disability initially identified themselves as adults, but this was generally a response to seeing themselves as “other than children”. They recognised they were not independent, but did not see independence as an immediate priority, preferring instead to talk about “living some aspects of being an adult, but not all of it”, and “being a bit like an adult on P-plates!” There was an assumption by these young people that parents would leave their supporting role at some point, with greater independence in personal hygiene and self-management issues assumed to develop in time, which would further their identity as an adult. As Jacquie explained, she felt she would still be able to ask her parents for help for some time ahead, but that there would be a growing expectation for her to be able to attend to her toileting hygiene and to her food preparation within the next few years before she planned to move interstate with her boyfriend. While these young people did identify greater independence as a characteristic of adulthood, they recognised that they were still not ready to live independently, understanding that some people still lived at home with their parents “until they are 30”. These participants with intellectual disability identified that they had more to learn and assumed there would continue to be people in their lives to support them into the future. Independence was recognised as an expectation for being an adult, but this would happen sometime in the future; this was one of the reasons they offered for not considering themselves to be fully adult.

Conversely, disability support workers do not see independence as a necessary delineator between childhood and adulthood, acknowledging that many relationships within the adult age range include facets of interdependence, involving reliance on support from others. Such a perception aligns with the idea that “no man is an island”. It accepts that we all turn to various professionals to provide us with goods and services, accepting a role within a cooperative of other adults. Being reliant on others did not preclude people with intellectual disability in their services from being considered adults. It simply recognises that some people need a broader range of services than the majority of the community. This was typified by comments such as: “No matter what they can and can’t do for themselves, [they] are adults, or become adults, and have adult rights.”

This spectrum of approaches to adult status as a product of independence highlights that the tension that arises from differences in conceptualisation of adulthood is unlikely to be resolvable. The position one holds in relation to the person under scrutiny clearly impacts their perception of that young man/woman as an adult. Parental experience, and the natural order of generational life stages, appears to influence the parents' perception of sons or daughters in terms of the care they have received and presumably will continue to receive beyond that of the typically developing population. The continued parental role, or the need to act in *loco parentis* by paid support staff beyond the typical expectation of other young people, is seen to situate the young person outside the bastion of adulthood in the parents' eyes. The challenge then arises as to how to reconcile these seemingly incompatible notions of (a) the young person as an adult who may assume adult rights to autonomy and self-determination regardless of capacity for independence, and (b) the young person as a non-adult who may be still comfortably dependent within the parent-child relationship, and who may be reluctant to relinquish this relationship. Within the deliberations on this challenge it surely must be apropos to acknowledge the position taken by the young person themselves. In the interest of person-centred planning, this would seem to be a paramount consideration. The following anecdote is presented with this in mind.

One young man with intellectual disability who was invited to participate in the research declined the invitation. His mother explained in correspondence to the researcher that he was frightened by the idea of being an adult, and his anxiety levels had risen significantly in response to the suggestion that this topic was to be discussed. While not having direct input from this young man for the purpose of this research, his was considered a highly significant response, and his mother signed over authority for her concerns to be mentioned in this study. She wrote:

> *N is overwhelmed by the idea that everyone expects more of him than he is capable of. He feels pressured to think about moving out of the home. His simple pleasure in life is to ride his bike around the streets [near his home]. He has never even thought about leaving home, and we have never talked to him about this, but this year it seems all the focus is on making him independent, and [staff] talking to him about living somewhere else and getting a job. When he came home with the letter about the study you are doing, he said he didn't want to go to TAFE any more.*

The question to be considered here is why there is an apparent urgency for those working with this young man and others like him to need to shift these young people's status from persons who wish to remain comfortably dependent on their parents to young people who are, or who can be perceived to be functioning more independently. The talk of being, or needing to become independent quickly, as a result of a chronological life-stage, rather than a developmental one, is likely to contribute to the tension between parents and DSWs. The connotation, if not the explicit expression, is that this requires severing dependence on parents, which neither the parents, nor the young people want.

9.2.2 Rational thought and understanding

The second key theme to emerge from the data sees a dichotomy of opinions over whether adults need to be rational beings who understand the consequences of their actions. Parents believe this is a necessary constituent feature of being adult, and believe the lack of rationality and reasoned understanding of actions means their sons and daughters with intellectual disability are vulnerable and in need of protection from harm that can result from their irrational actions. As noted in Chapter Two, state legal guardianship acts are founded on the premise that people with intellectual disability have a reduced ability to make rational decisions. The UNCRPD and subsequent trickled-down policies strongly defend the right of these people to be supported in their own decision-making. However, earlier research has shown that the perceived risks of physical emotional, financial and sexual abuse prevents parents and support staff from fully endorsing the decisions of these young people with intellectual disability (Jingee & Finlay, 2008; 2012). Parents spoke of their sons and daughters' misunderstanding things they hear, misreading other's non-verbal communication, and their subsequent vulnerability to abuse as a result. Colin noted:

> *It's a very high ratio of supervision and care because they're vulnerable, they don't have road sense, they don't have particular social skills. F's the best; she'll talk the leg off the table but without fear, you know, she'll talk to anybody anytime, anywhere, and she'll challenge aggressive behaviour, or naughty behaviour, and that could be a bully boy with tatts in the mall doing something wrong, she might take a cigarette, she doesn't understand the inherent dangers.*

Young people with intellectual disability were seen to fail to understand the rules of social engagement with others in the community. Some parents saw that their sons and daughters remained more self-focussed than others in the community, with little empathy for other members in the community. As Margie noted:

> *I can't see J ever being able to consider others. He is always not going to reciprocate, because he doesn't have that empathy to understand how we feel towards something. Being an adult means having to consider other people, and I don't see a time when J will be able to do that.*

Yet the need to be an "independent practical reasoner", with an ability to "evaluate our reasons for actions" (Macintyre, 2012 p.74), is not considered a requirement for adult status by staff supporting these young people. Policies flowing from the UNCRPD appear to take precedence in the minds of support staff. While DSWs agree that the capacity for critical reasoning may not coincide with the chronological arrival of adulthood, this does not deny these young people the right to self-determination. From the comments made by most of the DSWs interviewed it seems policies based on the UNCRPD's general principle that calls for "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" are considered to hold relatively greater importance than protection against their actions, regardless of the rationality or reasonableness of those choices. The right to self-determination, regardless of rational limitations is identified as a priority by some staff members. However, this is not to say that safety is not also recognised as important. Nor does it suggest this priority is the same for all support workers. Rick, for example, insisted that his first priority was:

> *Safety first; even above dignity … the situation has been undignified, and I've felt that the person has been undignified. … but they have still been safe. Safe from harm. If it is my brief to support*

> *someone on behalf of the agency, then during my shift I have to bring them back safe. Everything else is a bonus.*

However, it seems the primary guiding principle for the majority of the DSWs in this research was to empower their clients to be autonomous, self-determining young people, allowing people to take risks, with safety a secondary consideration. This was perhaps best expressed by Ellen who explained:

> *They have a right ... say smoking, then it's not for me to say, "You can't smoke". You have to consider all the risks that come with smoking, there are health risks, monetary costs, all sorts of things that come with smoking, but it is still people's free choice to smoke if they want to, if they are of age, and they want to experience that. And food—again, if there is no health, diet requirements for that person, no serious medical considerations, then I think that freedom of choice should be there.*

This is interpreted to mean that young people with intellectual disabilities need opportunities to make choices, even if the outcome has some potential negative connotations, if they are to be supported to develop their autonomy as a matter of priority. Having no opportunity to experience making choices, even those with an element of risk, denies the person the opportunity to gain new knowledge, and to develop as a result. This reasoning justifies the role of the disability support worker to allow their clients to learn through experiencing consequences of their decisions. However, herein lies a question of degree of risk that offers the prospect of conflict between the young person's parents and their DSWs. Sasha expressed her disappointment that one client's mother seemed to do everything for her son, including delivering him to his workplace every morning. Sasha believed this young man was capable of learning to use public transport to travel to and from his work, recognising that in the process of learning lay the potential for him to come to some harm, but noted: "He won't ever learn to deal with the public until he is allowed to find his own strategies to respond." The difference here appears to lie in the emotional connection between the parent and their child, as opposed to the professional connection between the DSW and the client. It is perhaps more difficult for a parent to allow the natural consequences of actions to occur when the resultant impact may be physically or emotionally painful, given the parental instinct to protect one's young from harm. This is exacerbated by the perceived vulnerability of the young person as a result of their intellectual limitations. On the other hand, the DSW is charged with the responsibility of supporting their clients to grow in skills and independence, and if this involves some pain for a greater gain, then the justification apparently falls within their professional duties.

The offering of opportunities to make one's own decisions is seen by support staff to promote autonomy. Through making decisions, one may be empowered to be more autonomous. In the absence of any level of autonomy, this becomes a paramount consideration for support staff. The fear expressed by parents is that their sons and daughters will potentially make bad choices, or bad decisions. While libertarian principles may guide support staff in supporting freedom of choice, parents fear the ramifications of their son or daughter's choices, believing that little good results from young people making bad choices as a result of their lack of understanding and capacity for rational reasoning. On the other hand, few support workers would disagree with the sentiments of Mark, who when discussing his support of young people experiencing alcohol, stated:

> *For the most part, I don't think we have a right to stop them—in some cases it's obvious that its dangerous—it's obvious, and in a lot of cases they have the right to experience that, and with support, and fully informed, they should be able to.*

9.2.3 Meaning from activities

When one explores questions on the purpose of life, there is a plethora of quotations to draw from, such as poet, philosopher and writer Ralph Waldo Emerson's:

> The purpose of life is not to be happy. It is to be useful, to be honourable, to be compassionate, to have it make some difference that you have lived and lived well.

The parents interviewed during this research agree with this sentiment that it is important for adult life to have purpose through engaging in meaningful activities. They actively seek these for their sons and daughters, allowing them to "give back" and to be useful members of their community. Walker and Rogan (2007) describe meaningful activities in terms of paid employment, volunteering, friendships, learning and growing personally and professionally, and they include leisure and spiritual activities in this description. This research shows that particularly parents of young people with more mild to moderate levels of intellectual disability believe this is an important adjunct to acceptance as an adult. Adulthood is recognised by these parents as a time and place in which people engage in activities that give their life meaning, not just pleasure. Living a life that centres on pleasurable activities alone is seen as belonging predominantly to childhood. The ability to forego short-term pleasure for paid or unpaid activities that offer possibilities of satisfaction, challenges, social engagement, and "meaning", (Schwartz, 2015) is seen as a measure of adult life. For those with less severe impairments, to be recognised as adults, pleasure should be counterbalanced by some capacity to contribute to the good of the community and give people a sense of authentic meaning and purpose amongst others. Simply attending centres for the sake of having something to do each day was not accepted as "meaningful", with parents seeking activities such as "community-based non-work" (Sulewski, Butterworth and Gilmore, 2008) that offer young people the opportunity to engage in meaningful activities in the community, rather than spend meaningless time in a disability-specific facility.

Balancing work with some concept of happiness was important for Wendy who was actively seeking a work option for her son:

> *I think the other thing is the kinds of jobs that you look at are often so inappropriate for some of the kids, He's never going to be happy in an environment like that, it's that sort of, you know; "Let's have a big place where we can put all of the disabled people, and they'll all fit in and this*

> *is their lot in life", rather than sitting down and saying, "What spectrum of disability?", you know?* (Wendy)

It appears that this perceived linkage between happiness and meaningful activities lies on a spectrum closely aligned to the severity of the intellectual disability. In this case Wendy's idea of "happiness" for young people with relatively mild levels of intellectual disability, such as her son, is linked to satisfaction derived from engagement in a working environment. This is fundamentally different to the happiness Rodney spoke of for his daughter who has a profound level of intellectual disability, and who seeks pleasure from the simple things in life, such as walking through the bush and feeling the breeze on her face, or the happiness Doreen wants for her son through simple access to his choice of music.

9.2.3.1 "The Good Life", concept

The ideas of happiness and meaningfulness are interwoven within the concept of a "good life" in disability studies. The question of what constitutes a "good life" remains the focus of much debate in the disability literature, as does the idea of what offers "meaning" in the lives of those with intellectual disability. A systematic review of studies from nine countries about the everyday lives of people with intellectual disability undertaken by Gjermestag, Luteberget, Midjo and Witso (2017, p. 223) talks of "meaningful activities at home, like watching television, listening to music and gaming alone or with others". This idea does not hold for the parents of young people with intellectual disability in this study. Such a suggestion is likely to rile parents who describe their efforts to engage their sons and daughters in anything other than computer games or watching television, seeing these as simple pastimes, or time-killers with no value to the wider community.

> *My way of thinking is you either get a job, or keep on with your schooling, or some other type of program –not just sitting at home … If I gave him a choice, he'd just sit at home playing computer games.* (Heather)

While the question of what offers their life meaning was not explicitly asked of the young people in this study, some personal preferences were clear from the data. The idea of family life was at the forefront of many young people's mind, with no mention of employment in their future life plans, despite being enrolled in a work oriented training program. Many of the parents in both the focus group and the individual interviews talked of how they have "engineered" or made decisions for their son/daughters' pathways into work, or further training. It is conceivable that the young people in this research may not have opted to attend work-focussed training if this had not been arranged by their parents and/or secondary school teachers. Johnson, Walmsley and Wolfe (2010) feature the personal narrative of one of the authors with a learning disability, Marie Wolfe, who when asked about the idea of a good life responded:

> "I like it when I don't have people telling me what to do kind of. My own life. When I am my own boss. That's how I like it. Just having my own space like you know. Sometimes it can get a bit annoying if you don't have enough to do, kind of." *(p. 17)*

The young people's idea of the good life included having more freedom, going to the Casino, driving cars, and "going to clubs, like bikie gangs!" Using more makeup was also on Jacquie's agenda. Their thoughts were not aligned with Emerson's proposal that the purpose of life is to be useful, but rather that happiness was the primary objective of any future plans. Purpose in life was linked to family life and doing pleasure-oriented activities. This perception of being predominantly pleasure oriented relegated them to non-adult status by the parents in this research.

DSWs recognised that some young people with intellectual disability wish for experiences associated with adult life, but need support to access their opportunities. Providing opportunities for pleasurable activities is seen as part of the duty of DSWs, but this is also balanced with the idea of such activities being separate to work commitments if the young person is indeed engaged in some form of paid or unpaid work:

> *They want to take that other step into the things that they couldn't do before. They look at cars [and contemplate the question]: "Could I possibly drive a car, like any other adult, you know? Could I go to a bar and have a beer like everyone else?", and we say, "Yes you can [but] not in work time."*

Even in cases where young people with intellectual disability are working, or volunteering, this often occupies less than a recognised full-time employment load, and offers more time in the week for pleasure related activities. With more time spent on recreational activities rather than meaningful ones, and parents seeing happiness as a by-product of pleasure-based activities, this further relegates young people to a world of non-adults, whose life constitutes more play than work.

9.2.3.2 Parenting

While the young people in this research similarly looked forward to greater freedom, few of them had ambitions to join the work force. They were, however, very focussed on marriage and parenthood. Lauren noted that she would have two babies when she got married, while Jay looked forward to having two babies, two dogs and two cats. When asked when this would happen, she answered: "When I am an adult I will have two babies". The goal of parenthood was not confined to the women in the group, with Richard noting that:

> *You are an adult when you are married and have a family. I will have five children. You are a young adult when you are 21 and then you can get married. When you have half a million dollars you can get married.*

While parenthood is often considered a marker of adulthood and a meaningful role in one's life course, this was not considered by parents to be an option for young people with intellectual disability. Some parents agreed that happiness through relationships was part of their vision for their son or daughter, but were generally adamant that grandchildren from such relationships were not part of this vision. Parenthood was considered an inappropriate aim for young people when they were viewed as unable to independently care for themselves, and could not be trusted to safely and successfully rear offspring.

All but two DSWs stridently argued for the rights of their clients to make their own decisions regarding parenthood, although this was coloured by the concept of informed choice. The DSWs often felt out of their depth on this matter, and generally offered that they would refer the matter on to a relationship counsellor, or to Family Planning, so that their client would be equipped with all the information they required on which to make an informed decision. The idea of clients with intellectual disability as parents was possibly the most challenging concept faced by DSWs, and one they felt ill-equipped to manage on their own;

> *It depends on what scale their disability is, I think, because that affects their understanding. If they are on the more extreme end, then I don't know ... there is an issue, it is an issue, because they don't understand, and I don't think they could make an informed choice, and they could end up in a situation where they are have to give it [the baby] up ... but still I don't know. How do you, how do you make that?*

9.2.3.3 Meaning from work

Cyril, who had a mild level of intellectual disability, was the only young person with intellectual disability who could offer that as an adult it was assumed he would take on more responsibility, and talked of joining the workforce after completing his studies. While parents expressed their wish for their son or daughter to join the workforce, finding meaning in life was considered incongruous with the opportunities on offer to their children through participation in disability-specific work or day support options. Little in the literature portrays a rosy picture of post-school outcomes for students with intellectual disabilities. Studies by Foley et al. (2014), Hogansen et al. (2008), and Stewart et al. (2012) amongst others, show that outcomes in today's workplaces fare little better than their counterparts did in previous decades. Young people with intellectual disability are still often found to be ill equipped to enter the workforce, with research findings indicating that they are often unable to generalise the learning from their school life to the world of employment and adult living. As a result, many adults with disabilities are seen as consumers of public resources rather than contributing citizens within their society, spending their days in day option programs and recreational pursuits that the parents in this research saw as comparable to baby-sitting services, or glorified respite centres. For example Barbara explained:

> *I'd love her to have an independent job where she was supporting herself financially, wasn't a burden on the community, felt comfortable with herself, self-assured, but that's not going to happen, I know it's not going to happen. I guess she'll be happy enough to spend days at [recreational service] hanging with her friends.*

9.2.3.4 Adult rites and rituals

Normal activities associated with membership of an adult community were questioned by the parent cohort. Rites, or acts associated with the passage to adulthood, such as voting, were considered meaningless for young people with intellectual disability by some parents who believed their son or daughter lacked understanding of the significance or consequences of the act itself. It was recognised that the physical act of attending a polling booth and ticking a box may be within the capacity of young people, but there was considerable doubt over their capacity to recognise the significance of this action or to achieve any sense of purpose in so doing:

> *She wouldn't understand about the people. I took her off the roll—maybe when she gets older I could put her back on, but until she can fully understand there's not much point. I could go in with her and tick the box, but I'd be voting twice, and that's illegal.* (Cassie)

> *He doesn't vote—we took him off the electoral roll. We wondered whether this was the right thing to do, but really I don't think he'd understand what he was voting for. What would be the point?* (Peter)

Conversely, support staff believe that participation in all realms of community open to adults is important, and actively support the rights of young people with intellectual disability to participate in "adult", activities, roles and rituals.

> *I believe they have the right to be treated as participating adults within both the home and the community from the time they are 16. What we like to think about is that people have the same life experiences if they are receiving support from us, as they would if they were at home with their parents, or if they were living without a disability.*

However, when asked whether he thought that having the same experiences as other adults made them the same as other adults, this DSW remarked:

> *I do, in theory, but in reality I suppose it is the cognitive functioning that pulls that up. We can provide the experience, but did the person appreciate the experience? Did they recognise the experience? Did they participate in everything that typical adults participate in? Maybe not.*

9.2.3.5 Marcia's Stages of Identity Development

The idea that support staff can "provide the experiences" for their clients aligns with parents' concerns that their sons and daughters lack initiative and that many of their experiences have to be arranged by others. Parents saw their sons and daughters as lacking self-motivation and drive to initiate and organise their own activities or interactions with others, and this extended to their failure to pursue alternative identity forms. In respect to Marcia's stages of identity development (Marcia, 1980), parents see their sons and daughters as being in a state of identity diffusion, with little idea of what they want, and few dreams for the future. As a result, these young people are less likely to try new things, to venture into the world, or make any real commitment to experimenting with new identities. This state of identity diffusion also aligns with the young person's lack of commitment to seeking real purpose, but to simply seek immediate pleasure, and to find the easy way through life (Marcia, 1980). Parents concur with Gjermestad et al. (2017) findings that meaning in their sons or daughters' lives is most often found in familial relationships, computer games, and television programs. While one young man identified as a council worker when he spent time with councilmen in his neighbourhood playground, this was an isolated case of a state of identity achievement in terms of occupational goals. Unfortunately this was a precarious identity, likely to be lost as parents of young children in his community sought his removal from the playground environment.

DSWs, on the other hand, more often position these young people in a state of identity foreclosure, assuming that they blindly accept their parents' ideologies and values and a "pseudo-identity" of a tainted person that places restrictions on their future opportunities. DSWs do not see that these young people may assume the identity of "dependent son or daughter" willingly, yet this research would suggest that this is indeed the case, with young people happily assuming to remain living in the parent-child relationship for the time being, just as many young people without cognitive impairment are these days. DSWs see their role as actively pursuing changes in this identity for their clients, creating opportunities for young people to at least experience identity moratorium, and providing chances to explore alternate life choices.

9.2.4 Acceptance in the community

Parents clearly want their sons and daughters to establish roles within the community that position them as accepted members. But this is not without challenges due to the persistence of stigma and negative attitudes within the community. The question of personhood and acceptance into the "hood" of adults underpins parental concerns that their sons and daughters do not qualify as full adults in the eyes of the community at large, and remain the subjects of prejudice and discrimination. Dichman, Kosyluk, Lee, and Jones (2016) explain that societal treatment of people with intellectual disability exposes the tension between fear of people who are different, and concern for their protection. The fear is exposed through eugenic practices, such as pre-natal screening, and optional termination of defective foetuses, or through sterilisation of young women with intellectual disability to prevent either reproduction of flawed individuals, or children who cannot remain with their natural parents. Conversely, concern for the wellbeing of people with intellectual disability has led to laws and policies that protect their right to community inclusion. This concern also plays out through parental attitudes which can lead to infantilisation of adults with intellectual disability. DSWs believe this attitude of infantilisation is perpetuated by parents who over-protect their sons and daughters. The DSWs claim that parents have failed to recognise their sons and daughters as grown members of the community: "They still see them as kids". "They refer to them a lot as, 'the kids'". Conversely the claim that the young people are, or are likely to become full members of the community is refuted by the parents: "[I wish he could] negotiate the community safely, and in a friendly way, and in an accepted way, not people just tolerate [him]". Herein lies yet another incompatibility that creates tension between parents and DSWs.

Despite the laws and policies stipulating rights and supporting self-determination, negative and stigmatising attitudes persist throughout the community. Such attitudes are known to contribute to the vulnerability of people with intellectual disability who are reported to be up to 10 times more likely to experience abuse than those without disability (Frohmader & Sands, 2014). Frohmader and Sands claim that 90 per cent of Australian women with intellectual disability have been subjected to sexual abuse, and highlight that many crimes against women with intellectual disability go either unreported, or inadequately investigated. Parents are only too aware of the vulnerability of their sons and daughters to financial, emotional, physical or sexual abuse. Vulnerability was the most commonly featured concept in the data. Parents fear that interactions with members of the public may have a detrimental impact on their sons and daughters with intellectual disability. Recognising that the rights of young people are stipulated through international conventions or service policies does little to alleviate the concerns parents express in relation to their son or daughters place in the community. Colin explained:

> *I feel that [UNCRPD] is a feel-good gesture. ... It's all well and good and supports egalitarianism, but how do you make someone [accept young people with intellectual disability] when they feel threatened, or uncomfortable around people who have extra needs?*

Conversely, DSWs note that part of their professional role is to support young people to find their rightful place in the community, believing that there are benefits to be found from engaging with the general population:

> *... just a sense of citizenship, and a sense of rights, that all people, regardless of their circumstances, have basic rights, whether that is accessing the community, using the community, making adult decisions. One of my values in terms of support is to allow people to take risks. Because that's what everyone does. I want to do something, and I've never been there before, but I want to do that—I don't want anyone to stop me. So why should I deny that same chance for someone else?*

An accepted place in a community usually requires reciprocity of interaction with other community members in a way that commands mutual respect and consideration, but as noted by Goffman (1960), those who do not adhere to the norms of a community are considered deviant, are marginalised, and stigmatised. The parent cohort in this research did not believe their sons and daughters commanded the respect of the broad community, and understood this to be associated with the young person's failure to consider others when making personal choices. Goffman, in *Fun in Games* (1961, pp. 23-24), notes that “socialization in our society can be measured by the rate at which a child foregoes frank demands to ‘look at me’ and ‘watch me do this’, just as ‘desocialization’ is felt to be measureable by an increased openness and persistence of self-reference”. Parents saw all too often that this persistence of self-reference remains a feature of the persona of their son or daughter, particularly when the intellectual disability was accompanied by some autistic traits.

> *He remains the centre of his own universe. The world has to revolve around him, his patterns, his needs. ... Just once in his lifetime, I would like him to consider us!* (Tanya)

Coupled with this failure to consider others, parents also express their concern that the community at large is not accepting of their sons and daughters who “don't fit within social norms”, or who are viewed “as a deficit kind of person”, or pitied as “the poor little thing”. Cathy wished she could:

> *Wave a magic wand, and change human nature overnight, but I think we have to realise that this won't happen, and people will always have prejudices and see differences regardless.*

DSWs again expressed their responsibility to address the negative attitudes found in the general community, upholding the rights of the young people in their care to have a place in the community. They believe that opportunities to engage and interact within the community help people with intellectual disability to assimilate, to understand community expectations, and to learn from their time with others without disability. Such opportunities are also seen to allow the community to understand, accept and be more welcoming of those with intellectual disability.

9.2.5 Actual versus virtual adulthood

Goffman in *Stigma* (1961) explains that society establishes the means of categorising persons and determines those attributes considered ordinary and natural for members of these categories. Social settings themselves determine the categories of persons expected to be encountered there. "Normal" social intercourse in established social settings offer participants a means to anticipate the actions of others, such that on meeting strangers, we can anticipate their "category" and "attributes", which Goffman suggests offers the "social identity" of the stranger. We rely on normative expectations, often going unquestioned until such time as the problem arises of whether these are being met or not. Until this time, we are unlikely to be cognisant of our demands that the stranger match our assumptions of what this individual should be. When this stranger possesses attributes that make him different to others in the category of persons available for him to be in a negative or less desirable way, he is regarded as a tainted person, or a discounted one. The presenting attribute is considered to be a stigma, a failing, a shortcoming. Goffman explains that this discrepancy offers a difference between virtual and actual identity. He believes the difference between the demands that are made "in effect" of a person we meet, and the character we impute to that individual "in effect", offers a "virtual social identity". On the other hand, the category and attributes he "actually" has constitute his "actual social identity".

Along similar lines to Goffman's model of actual and virtual social identities, a predominant theme that arises from the data in this study may be referred to as the virtual, rather than the actual reflection of adulthood. Another way to describe this would be to suggest that adulthood is projected onto people by some observers, who recognise what they believe to be sufficient characteristics to suggest a person's adult status, despite alternate assessments of this status by the person themselves, or others with different perspectives of what constitutes adulthood. The subsequent artificial structuring of the environment in order to make the young person present as acting autonomously, or the implementation of specific training around particular activities of daily living then allow the person with intellectual disability to be seen to have a measure of independence or to be acting appropriately "adult-like" within the community. Wearing age-appropriate clothes with trendy haircuts, walking, rather than skipping, and listening to latest trends in music are all outward appearances of appropriate "adult" behaviour and can belie the reality of the support that creates this perception. Demands for such presentations have magnified since the concept of age-appropriateness grew from the principles of normalisation introduced by Nirje (1969) and Wolfensberger (1980), and are embedded in the UNCRPD. Age-appropriateness is emphasised particularly in the section of the Convention that mandates that individuals with intellectual disability shall be provided with age-sensitive support in their homes and in the community (Article 16). Wolfensgberger (1980) argued that to achieve normalisation, we need to change the way people with intellectual disability are perceived in society. While he advocated that this required changing the environment, rather than the individual, the intention was to make the life conditions of individuals with intellectual disability as similar to the norm of the community as possible. Nirje offers that acting in age-appropriate ways benefits the individual with intellectual disability by enhancing society's perception of them, ensuring they are treated with more respect and dignity and reducing stigma.

Both parents and support staff actively work to present young people with intellectual disability as functioning independently and according to social norms within the community, recognising that without intervention, acts of independence may not simply emerge as they do in most cases of adolescent development. Left to their own choices, however, the young person with intellectual disability may prefer to listen to The Wiggles, Peter Coombe, or want to wear Spongebob Squarepants t-shirts. The parents in this research noted other pleasures in their sons' and daughters' lives including Pokemon figures, Ben10, The Simpsons, Teletubbies and Banana in Pyjamas. This raises the question of freedom of choice, often supressed in the depiction of the virtual adult with actual child interests.

The case of Doreen's son whose favourite singer is Peter Coombe typifies the dilemma. His residential support workers will not allow him to listen to Peter Coombe in his group home. This has been deemed inappropriate, and banished. He goes home every second weekend, and his mother explains that he spends the first couple of hours at home each time sitting in the corner of the lounge with his headphones on, listening to Peter Coombe. His mother says this is a source of great happiness for her son, and while she understands the principle guiding the DSWs' actions, she is saddened by her son having this simple pleasure denied him in his group home environment, and believes some compromise is called for.

> *You know I have had real disagreements with some carers' views of wanting to make everything age-appropriate, you know. The activities have to be age-appropriate, but J wants to go back constantly to what he knows and what he understands. It is so hard to move him onto things like adult music*

Heenan (2013) explains that while age-appropriateness is well-intentioned, the tenet that individuals must be supported to act according to their chronological age to be accepted by their community ignores their level of intellectual functioning. In Doreen's case, she understands that her son should be presented to the community in a way that promotes his acceptance but also argues for his level of intellectual functioning to be considered:

> *Because I know that to the community, they like to present a person who hasn't got interests in baby things, you know, but when we see that J gets so much pleasure out of that, that it's at his level of understanding, I don't know that he'll ever move onto [adult music].*

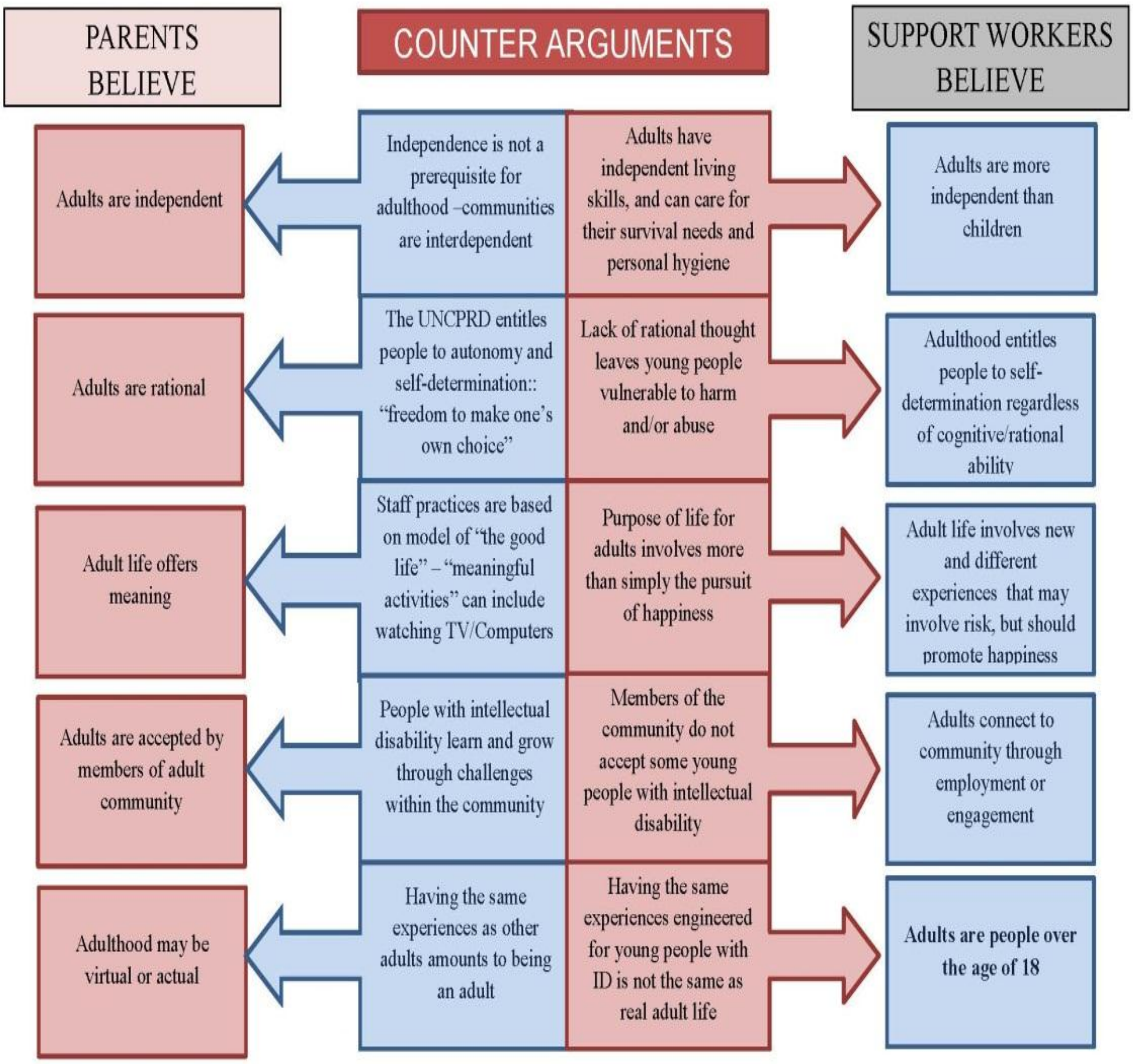
The challenge then is to balance the implementation of age-appropriate and normalisation policies while not infringing on basic rights. One solution could be to develop policies that allow DSWs to adjust their approaches according to each situation, allowing some flexibility based on individual cases. Such a case-by-case approach may offer better protection of the client's rights and dignity by acknowledging the reality of each person's preferences, regardless of their chronological age, respecting the importance of freedom to choose what one wants to do. What needs further investigation is the benefit of age-appropriate policies when compared to the reduction of a person's rights. While there is evidence that age-appropriate activities do indeed enhance the perception of people with intellectual disability, the question remains as to the rights of people with ID to have a back-stage existence such as Goffman (1959) proposes, when they are not required to be "performing".

9.3 Illustrations of the potential for conflict

9.3.1 Arguments and counter-arguments: Parents and Disability Support Workers

The potential for conflict that arises from the alternate perspectives on adulthood is highlighted in Figure 9.1. The diagram graphically illustrates the positions taken by these two cohorts of stakeholders. The pink text boxes offer the arguments and counter-arguments used by parents in defence of their perception of their sons and daughters as "non-adults", or "yet-to-be" adults. The blue boxes offer the arguments and counter-arguments of the DSWs that support their belief that all people over the age of 18, regardless of cognitive functioning, are to be acknowledged as adults.

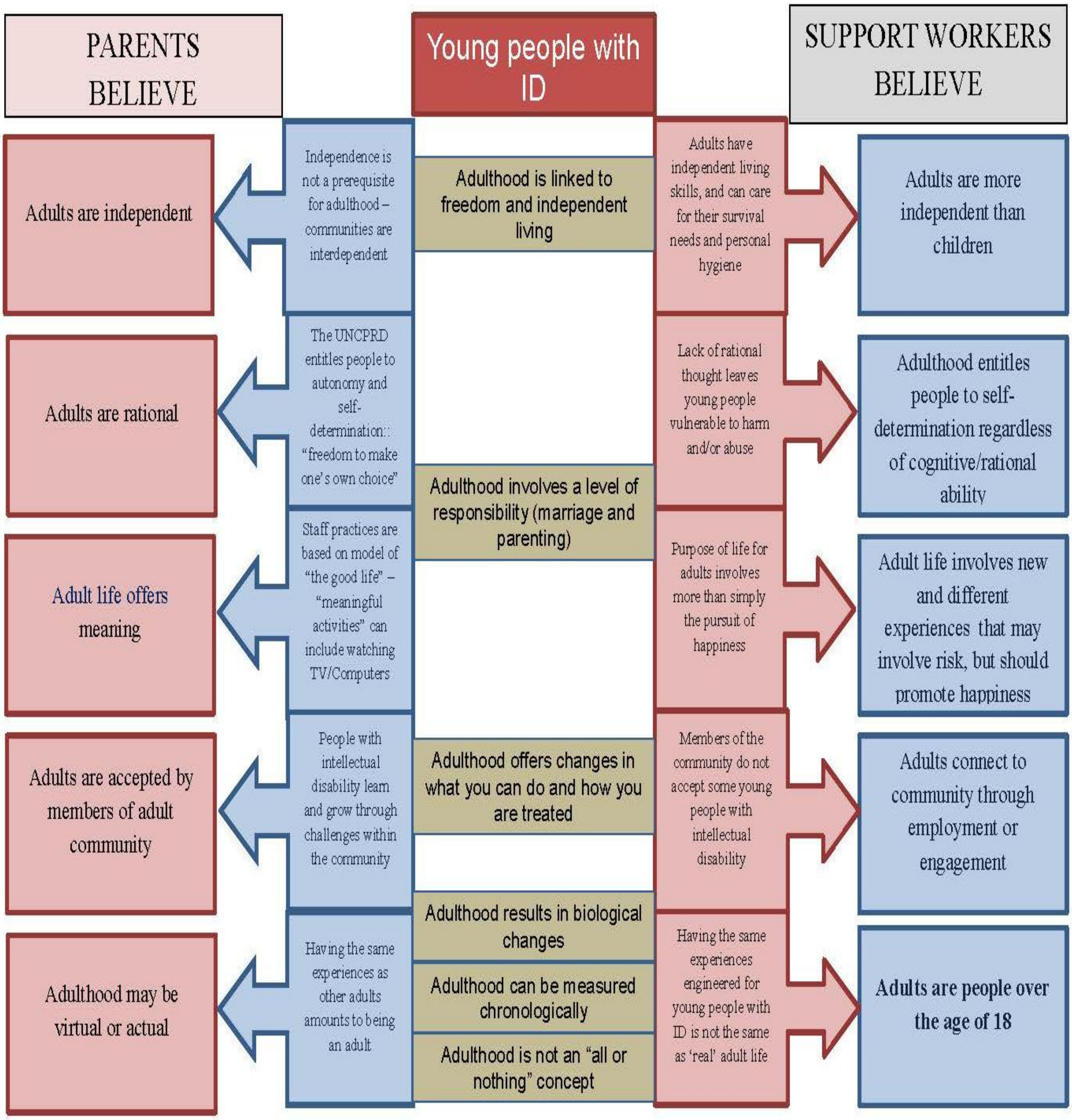
Figure 9.1 Arguments and counter-arguments: Parents and Disability Support Workers



9.3.2 The position of young people with intellectual disability within the potential for conflict between parents and Disability Support Workers

The perspective of young people with intellectual disability in relation to the conflict depicted in Figure 9.1 is illustrated below in Figure 9.2. The six key themes identified by the young people position them between their support staff and their parents, neither firmly aligning with their parents, nor with the support staff. Their perception of adulthood as not being an "all or nothing" concept positions them more closely to the conceptualisations of the parent interviewees. They assume to become adults over time. They recognise they have adult rights, should they wish to uphold these, but are happy to accept that they still seek permission from either parents or support staff to assume the types of freedom young people without disability may take for granted.

Figure 9.2 The perspective of young people with intellectual disability within the potential conflict between parents and Disability Support Workers



9.3 An inadequate definition of adulthood

Adulthood is not an age, it is a condition. (Colin)

To this point this thesis has presented the conflicts that exist between parents and support staff working with young people with intellectual disability that arise as a result of different conceptualisations of adulthood held by these cohorts. A further significant finding from this research is that young people with intellectual disability are disadvantaged by the lack of a term that adequately describes their life stage following the completion of their secondary schooling. Definitions of adulthood do not serve young people with intellectual disability who fail to meet their criteria. There is no terminology that positions them as they see themselves, and as their parents view them, as no longer children, but yet to be "fully adult", meeting some criteria, but not all. Neither of the dichotomous ranges of criteria for status of childhood or adulthood serves these young people. Principles of normalisation demand professionals adhere to a prevailing ideology of human rights and empowerment, rather than assuming a paternalistic and protective approach to their duties. However, either perspective is potentially damaging when their clients have intellectual disability. The inadequacy of the term "adult", and the lack of a term that better describes the developmental life stage of young people with intellectual disability following childhood, disadvantages these young people by compelling them to be positioned in one of two contrasting life stages, either as an adult or as a child. However, they do not fully meet the definition of either, and are seen by parents to be thrust into adulthood simply for the expedience of political and/or social convenience.

The idea of trying to define adulthood in a way that offers any value to young people with intellectual disability or those working or living with them is challenged by the significant points of difference expressed by informants of this study. As Rodney noted, it is easy enough to find a dictionary definition of adulthood, either in legal, social or biological terms, but such definitions are viewed as applying to the majority of typically developing people within the community, not to young people with intellectual disability. The pathways through life for young people with intellectual disability, and the expectations and goals for them do not always follow the same chronological timelines, nor always follow typical life stages. The idea that a typical definition that applies to the general population can be applied to young people with intellectual disability is incongruous with the parents' perceptions of differences between their sons and daughters with intellectual disability, and those young people living without cognitive impairment. This is summed up in Rodney's statement: "Normality can be doing things differently, because doing things normally is really, really difficult." Yet the pathway to adulthood for young people with intellectual disability is rarely measured against currently recognised contemporary life stages.

Arnett's (2000) concept of emerging adulthood is yet to be explored within the context of intellectual disability. Arnett referred to this period as a time when adults do a wide variety of activities, but are not constrained by "role requirements" (Arnett, 2000 p.471). It is described as that time when young people have left the dependency of childhood and adolescence, but are yet to assume the enduring responsibilities of adulthood. The term "emerging adulthood" is applied to typically developing young people who occupy the space between childhood and adulthood; the term describes young people who are neither one nor the other. In current discourses on young people with intellectual disability, though, no such grey area is recognised. These young people are seemingly required to be categorised as either children or adults; but what is missing is a satisfactory definition of adulthood that would serve these young people appropriately. The absence of such a definition is exacerbated by the contrasting discourses that contribute to the conflicts and tension between the rights of these young people and their capacity for autonomy and self-determination. Some professionals wish to position these young people unequivocally as adults, linking this to the concept of autonomy, and rejecting utterly any question of their right to self-determination. However, this right is challenged by parents who are yet to identify these young people as adults, questioning their right to self-determination on the basis of their reduced capacity for practical reasoning. Effectively, then, there is no definition of adulthood that serves young people with intellectual disability, or that can resolve the conflicts identified between parents and DSWs. Service providers are bound by society's concept of adulthood, driven by Kantian libertarianism that supports the rights of people to make their own choices. Parents, on the other hand strive for the welfare and happiness of their sons and daughters, resisting the depiction of them as autonomous adult beings, fearful that such a portrayal potentially jeopardises their wellbeing.

Even though support staff are duty-bound to empower their clients and uphold their adult rights, those DSWs who attempted to define adulthood during the interviews were equally challenged to define the concept in other than legal or chronological terms. Yet DSW interviewees firmly and categorically acknowledged young people with intellectual disability as "adults". Rick summed up this challenge, noting that, "… it's a very vague concept, and a very interesting one." It seems, then, that "adulthood" as a concept becomes a matter of semantics. While it may be a "taken-for-granted" category within sociology, Blatterer explains that it is one of sociology's "avowed aims to deconstruct and reconstruct "taken-for-granted" assumptions" (2008, p. 2). The idea was expressed by Rick, and similarly by others DSWs, that there are, indeed, many "aspects" to young people. Their progress between life stages acknowledges that transitions from school to work, from the family home to one's own home, from single life to cohabitation with a partner, and onto a life as a parent are subject to considerable fragmentation, stops, reversals, and changes in pathways. Such diversity of pathways, alongside the disparity in characteristics, offers questions regarding the "concreteness" of any proposed definition of adulthood that might apply adequately to young people with intellectual disability.

As highlighted in Chapter Two, no longer is the concept of adulthood considered to reflect a position of marriage, parenthood or secure employment, with a lag between the expectations of those from previous generations, and the young people of the 21st century. Many of today's young people prolong their youthful dependence on their parents or extended families, choosing (and supported) to remain relatively irresponsible well into their 20s, as they remain living under their parents' roof, travelling, and often delaying marital and parental responsibilities indefinitely. Arnett's stage of emerging adult has now been widely acknowledged as a distinct period of the lifespan during which adolescents grow towards independence and explore, rather than adopt identities.

Yet, despite this shift in sociological timing of adult roles, and DSWs acknowledging the complexities involved in defining adulthood, most stood by their claim that the young people they supported who were aged 18 and over were adults, and that part of their role as support staff was to help these young people recognise this significant shift in their status from being a child to having suddenly become an adult. It was not assumed that this transition was developmental and could occur over time, but instead was seen as a possibility for all 18-year-olds, provided that they were supported to recognise that this transition had occurred, and were removed from influences, such as parents, that might suggest otherwise. DSWs see their role is to progress this shift by constantly reminding young people of this “fact”. In this research, this was typified by Ross, a DSW in a training college, who commented:

> *We hear our staff saying, “But you are an adult ... so you might like to reflect on that”. It’s in our vocabulary a lot; where we make people aware of the fact, because it is the young people themselves that forget they are young adults.*

This research shows that a shift in identity does not happen automatically for the young people with intellectual disability. They do not identify themselves as adult as they pass their 18th birthday. The suggestion that young people with intellectual disability can simply “forget” that they are young adults speaks to Marcia’s concept of identity status. It seems that DSWs may consider that these young people are locked into a state of identity foreclosure by their parents, assuming an identity more aligned to that of a child, with no sense that adult identity is a choice they can make, and therefore they need to be constantly reminded of the fact. By being provided with opportunities to experience an identity crisis, they could come to explore various commitments involved with their choice of identity, leading to a new sense of “adult-ness”. Whether the young individual fails to assume an adult identity, remaining in a state of identity diffusion, or simply “forgets” they are an adult, either case affirms to parents the young persons’ failure to have achieved adult status. For example, Rodney explained his understanding of the definition of adulthood as requiring that:

> *The person in question to be aware of those [being sexually and socially mature] and not just [having them] laid upon them. They actually have to understand what sexually mature or socially mature means ... and if by that definition she can’t ever actually be an adult ... that doesn’t bother us.*

9.4 What chance resolution?

Throughout this thesis, the terms “adult” and “adulthood” have been used frequently with an underlying assumption that the reader understands the meaning of the terms. The reader, however, will naturally have experiences that guide their understanding of the term, just as those participants in this research have drawn on their personal journeys to form an understanding and comprehension of the terms. But whether we share the same understanding, or agree on the terms by which one may refer to another as an adult or not, we cannot say with any degree of confidence. Conversations such as this rarely occur, as people simply use terms that initially form in their head as a simple naming process. As the Swiss linguist Saussure explains, the letters of the word “TREE” form a sound-image when written, spoken or read, but without the image of the tree, the letters or sounds are meaningless (Carstair-McCarthy, 2005). The word “adult” similarly evokes a mental image that is contextually grounded, and based on the experiences of the person applying the term. Equally it evokes a mental image in the mind of the person hearing or reading the term. Just as the concept “dog” can apply to a Chihuahua or a Bull Mastiff, the mental image of an adult can conjure up extremely different conceptualisations. To the DSW, an adult is simply a client over the age of 18. However, this client remains the parents’ child, and to these parents, as well as to the young people themselves, they are seemingly eligible for the same parental care and protection that has been awarded them since their birth irrespective of their chronological time alive.

Aligning with Colin’s statement that “adulthood is a condition, not an age”, there is little likelihood of agreement between parents and support staff while support staff resolutely adhere to the premise that adulthood is the state of being a non-child, and starts at age 18. For as long as their son or daughter remains within that relationship, the affinity and caring link between parent and child remains intact. This relationship is recognised as one of the most long-lasting and emotionally tense social ties, and whether the son/daughter remains living in the family home, or moves into their own home, the family most times retains a significant role in their lives (Mirfin-Veitch, 2003). As Margie noted: “Parents are emotionally invested” in their children, and want and expect to remain closely connected to their lives. This is not to say that either the parents or the young people with intellectual disabilities necessarily find this relationship totally satisfying, and it is not without normal relational challenges (Mirfin-Veitch, 2003).

The parents in this study were divided between wanting to have their son or daughter remaining in the family home, or moving out in the foreseeable future. Of the 20 families who participated in this research, only three young people had moved into group home accommodation. Whether the young people lived at home or in alternate accommodation, the nature of the relationship that parents wanted in their offspring’s lives was one of care and protection. This included protecting their sons and daughters from the hurt they saw as an inevitable consequence of their intellectual disability. Cassie noted:

> *It’s because of that emotional investment you’ll feel the pain. Our kids who are normal go through these things that I call rituals, or rites of passage—the first love affair, the first job, and there’s a distinct possibility of the kids with disabilities are not going to have any of these—so there’s going to be mourning that that doesn’t happen.*

Parents will continue to care for their sons and daughters, regardless of age. The idea of adulthood does not stop the parent/child relationship, although it doubtless changes it. The emotional ties remain and the desire to see one’s offspring as safe, happy, gainfully occupied, and accepted into the community endures. When the safety or happiness is perceived as threatened by the actions of those to whom they are expected to entrust these young people, there is little wonder that parents are reluctant to hand over the reins to disability services. Their sons and daughters are unlikely to initiate “flying the coop” into independent living; in most cases this will need to be engineered by the parents. While parents do not want to deny their sons and daughters the right to adulthood, they have concerns about the policy agenda that endorses the start of adult life as an opportunity to take risks, with little regard to other frameworks of social, moral or emotional development. Like the study by Murphy, Clegg and Almack (2011), this research positions young people with intellectual disability in a space of non-childhood, but also non-adulthood by parents and the young people themselves. It can be likened to the concept of emerging adult expounded by Arnett, where young people choose to remain financially and emotionally reliant on their parents well into their 20s. The suggestion that they have attained an adult status is likely to do little more than antagonise those who consider otherwise.

The term “adulthood” meanwhile seems to be used as the ammunition to counter this reluctance to relinquish care to others, to label the parents as over-protective, and to secure the young person with an intellectual disability as an autonomous and self-determining member of the community, whether they are ready for this or not. By viewing a young person with an intellectual disability through the materialist lenses of biological development and social structures that provide seemingly unarguable evidence of their attainment of adult bodies and entitlement to access adult services, the DSWs conveniently overlook the idealist positions of individual identity and cultural requirements for acknowledgement as adults, or for the attainment of adult status.

Throughout the research into conceptualisations of adulthood by parents and DSWs working with young people with intellectual disability, a fundamental discrepancy seemed to underpin the divergence in ideas about adulthood and its application to these young people. This thesis highlights the difference between families who view intellectual disability as a biological deficit, in turn attributing incompetent behaviour to physiological causes, while DSWs reflect their understanding of the social model of impairment, open to the thinking of disability theorists who see disability as a societal and political construction (see for example Barnes & Mercer, 2005; Goggin & Newell, 2003; Shakespeare, 2013). Within this framework, DSWs act in accordance with the need for social reform in order to reconstruct perceptions of the world anew. To DSWs, within the social model of disability, society is seen to create disablement, and is the arbiter of understandings of difference in bodies and minds, which can be subject to change. This difference in perception of disability lays the first framework for conflict between those with lived familial experience, and those with theoretical perspectives.

Chapter Ten
Case Study, Conclusion, Limitations and Recommendations

10.1 Introduction

Chapter Ten will conclude this thesis by exploring the implications of the findings of this research from discussions with parents of young people with intellectual disability and with disability support workers (DSWs). This chapter will initially present a case study to explore and highlight issues raised in this research. The case study will explore a hypothetical situation to illustrate the implications of this research in a practical context. The conundrum faced by stakeholders as a result of different conceptualisations of adulthood is exposed through the case study, as is the inadequacy of any definition of adulthood to be effective in facilitating the resolution of the conflict between the support staff and the parents in this case.

Chapter Ten will then present limitations to this study, discuss further research possibilities, and finally present the conclusion to this research.

10.2 Case study: Cathy and Karl

A case study is presented here to highlight issues raised in this research. The case is based on actual conversations that have been witnessed in recent years. It addresses a challenge that is currently presenting to some disability services in Australia that have considered no longer conducting mixed camps or weekends away. Instead some services are now offering men-only camps, or women-only camps for some clients aged 18-25 in response to parental concerns about actual or potential interactions between their sons and daughters on camps.

Cathy (18) and Karl (19) have known each other for a number of years through their involvement with Special Olympics, and their families' engagement with the Down Syndrome Association. Both Cathy and Karl live with Down syndrome and experience moderate degrees of cognitive impairment. They live about one hour from each other so do not have a long history of opportunities to socialise. However they currently find themselves attending the same training program, and see each other three or four days every week. They have recently become a couple, appear to enjoy each other's company, often exclusively, and enjoy public displays of affection. The DSWs who work with Cathy and Karl remind them of appropriate public behaviour, but can see that they would like the opportunity to have time together in private to further their relationship. Two months into their training, (corresponding with two months of this relationship), these two young people attended a three day camp with 12 others from the program. Cathy and Karl approached the support staff at camp and asked whether they could share a bunk in one of the cabins while they are at camp. There were other young people sleeping in the cabin and each had provided their own sleeping bag. The DSW that was approached with this request approved this, explaining to them that they would not be alone in the cabin, but if they wanted some time to be close to one another, then they could share a bunk. During the camp there was chatter amongst other campers that Cathy and Karl were “sleeping together”, but the DSW did not believe that anything more sexual than kissing and cuddling was actually happening.

At a debriefing session with support staff, the camp leader spoke of a phone call he had received after the camp from Cathy’s mother expressing her displeasure at discovering her daughter had been allowed to sleep in the same bed as Karl. Cathy’s family is strongly religious, and her parents were very upset that the support staff had supported this behaviour which was contrary to their religious beliefs. Cathy’s mother also believed this was highly inappropriate as Cathy had little understanding of sexual matters, and was considered very vulnerable to abuse or unsolicited sexual advances. Cathy’s mother was deeply distressed that Cathy and Karl were allowed to sleep together in the company of other young people, and stated that she was considering withdrawing Cathy from the training program. She further noted that her daughter would never attend any other excursions with the training organisation.

The camp leader felt that he had somewhat placated Cathy’s mother by reassuring her that her daughter had not engaged in sexual activities other than kissing and cuddling. He reassured this mother that Cathy and Karl’s welfare had been duly considered in the course of the supervision at camp, and he did not consider Cathy had been at any risk of harm or abuse. He acknowledged the mother’s religious stance, but explained Cathy had expressed her wish to share the bed space with her partner very clearly to him. In the debriefing conversation with support staff, the camp leader noted that the choice of sleeping arrangements had been an issue with parents in previous years, and would presumably be an issue in future years. He questioned whether or not parents should be forewarned in future years that the young people could be sharing cabins, and that even sharing beds was a possibility. The concern was that by forewarning parents, some young people would not be allowed to attend the camp; it was recognised as a sensitive and potentially contentious issue, but one that support staff had supported in the past. During the course of the discussion, one DSW, the father of an 18-year-old daughter (without a disability), stated he would not allow his daughter to go on a camp if he thought this would be permitted. He explained he had felt very uncomfortable about this arrangement while at camp, and would rather this not be allowed in future. In response, one DSW commented: “But these are young adults! We can’t take them away and tell them they can’t have kisses and cuddles during the night, nor should we be supervising them overnight. They should be allowed to sleep where they like”.

So how does this research contribute to an understanding of this dilemma? Are conceptualisations of adulthood contributing to such conflicts, and if so, how? The question in this scenario is whether young people with intellectual disability are viewed as autonomous, rational, and independent adults under current published and accepted definitions of adulthood by lifespan development researchers, and therefore entitled to self-determination and respect for their own decision-making. The alternative position is that they are viewed as non-adults or not fully adults. From this perception, consideration of their welfare should take precedence, and as such negate these entitlements.

The research in this study suggests that most DSWs would consider Cathy to be an adult because of her biological development, and her position within an adult service program. This assumption then recognises all camp attendees as adults, implying they are entitled to the same human rights to liberty, freedom of thought, freedom of expression and so forth, as outlined in The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This convention offers guiding principles for working with all people with disability that form an essential part of staff training packages. DSWs have been trained to promote Cathy's independence and to support her rights, and while the training package for support staff asks for families to be respected and included as part of the support team for their clients, Cathy's DSWs prioritise her wishes over any likely or potential concerns of her family.

Cathy's parents clearly do not agree that these UNCRPD principles apply to her because of their perception of her limited capacity to be rational and autonomous; for her parents, concerns for Cathy's welfare, safety and wellbeing takes precedence. But is it wrong to deny anyone their autonomy and their right to self-determination? If, as Nussbaum (2009) offers, people with intellectual disability are equal citizens for whom the law should show equal respect and equal opportunities to civil rights, how are parents positioned to deny such basic rights? Where is the role of Cathy's mother in Cathy's life now that she has passed the age of 18 within a legal world of citizens whose autonomy is considered a paramount priority? How can her concern for welfare be balanced against Cathy's fundamental rights as an autonomous adult? Is Cathy recognised as an equal adult human being and respected accordingly? What does this mean in the context of intellectual disability when, despite respect for self-determination and autonomy, Cathy remains to some degree or other under the control and supervision of her service providers?

Such dilemmas present themselves through all facets of community services. Jewell (2010) offers three ethical approaches to decision-making within the disability sector, a community-based approach, a consequence approach and a principles-based approach, and notes that the community has to "work out the practical details concerning the best ways to respect each other and care for each other's welfare" (p. 5). The community-based approach guides members of the community to act appropriately, according to one's role, and to respect the "norms, values, agreements, policies, conventions and rules of the community" (Jewell, 2010, p. 20). When organisations have a community-based approach to ethical dilemmas such as this, they would promote democratic processes for constructing rules to govern such arrangements. Such rules then express the shared values of the community. When young people are recognised as adults, their right to make their own decisions is respected and supported; they are entitled to be self-determining, even when the consequences of their actions may not be positive.

However, the scenario offered in the case study included in this chapter suggests that there may be no clear, incontrovertible rules or policies within the broad community that govern how these two young people with intellectual disability should be supported in the case study situation. This conundrum arises as a result of there being no community agreement over what differentiates an adult with intellectual disability from a child. Policies and guidelines within disability support services would presumably support practices of

DSWs working with Cathy on the principle that she is an autonomous being. The focus of policies governing services changes from being family-centred for clients under the age of 18 to being person-centred once they turn 18, based on empowerment models and assuming a rights-based approach. The emphasis is on supporting independence by overcoming barriers, rather than caring for individuals within a medical model that focuses on deficits. As the manager of a support service commented during the DSW focus group: “I would like the banner over our door to read ‘We don’t care, we support’”. This perspective is not shared by some parents who still believe their sons and daughters need at least a reasonable measure of care as a result of their perceived lack of capacity for rational deliberation, and their ensuing vulnerability.

However, while there appears to be no adequate definition of adulthood that is agreed upon by the members of Cathy’s community, such person-centred policies simply will not appease both her DSWs and her family. While the personal values of some DSWs may support Cathy and Karl to share their bed on the grounds of their chronological ages and subsequent adult rights, the values of others may preclude them from upholding this arrangement based on religious, moral or welfare grounds. Some support staff would believe this to be a normal behaviour of people of the same age without disabilities, so should be equally available to those with disabilities. Along with such a belief may go the assumption (rightly or wrongly) that these young people have had similar access to education on sexuality, protective behaviours and sexual health. Others, like the DSW with his own 18-year-old daughter, would find this a difficult situation to support. There would not appear to be agreed rules, or policies or values within the community to assist all staff and parents to come to agreement over the course of action in this case if the decision is based on Cathy being recognised as an adult.

In the absence of clear community agreement on ways to address this quandary, the divergence between conceptualisations of adulthood can be debated using the dichotomy of the other two ethical approaches explained by Jewell (2010); the consequence (welfare) approach and the principle (rights) approach. The dilemma is situated within stakeholders’ conceptualisation of Cathy as an adult or a non-adult, and consequentially whether her rights or her welfare are more important. The terms “adult”, or “adulthood” in this debate are often used to focus attention on the materialist measures of adulthood; the term is used in reference to the social and biological measures of adulthood. For parents, this represents only part of the equation. When the term is used with no mutuality, stakeholders might be seen to deliberately misunderstand one another. If Cathy’s mother claims her daughter is not yet an “adult”, what she may actually be saying is that Cathy is yet to be able to cognitively protect herself from harm, she may not understand the risks she faces by sleeping in a room with her boyfriend and others, and that she is naive and unaware of sexual matters. This anxiety over Cathy’s safety is not an age-related concern, nor does it relegate Cathy to being a child. This concern is based on a mother’s knowledge of her daughter. Her apprehension may, in time, be alleviated by her daughter’s further education, maturation, experience, and guidance. It will not simply be addressed by her daughter’s ageing process. Cathy will be no more ready, in her mother’s view, to engage in sexual experimentation simply by being one or two years older. It is not a matter of “when she is 18, or 21, or 25". Cathy's readiness will depend on the development of her understanding, her reasoning, and her capacity to assume responsibility for any consequences of her behaviour in this area.

However, Cathy's mother risks being criticised by professionals for her failure to recognise Cathy's "adult status", and for continuing to conceive of, and impose her parental control over her as a child. But as this research shows, there is no one agreed concept of "adult status". Cathy's mother's concerns reflect Colin's adage that "adulthood is a condition, not an age". The conditions Cathy's mother places on her daughter's readiness to explore sexual behaviours are not those simply measured by chronology, but are idealist in nature, requiring the development of the mind to a point of rational understanding capable of reasoned control over the situation in which she may find herself. As Rodney stated, for Cathy to be rationally cognisant of the consequences of sexual intimacy "it requires the person in question to be aware of [sexual maturity], not just [to have it] laid upon them. They have to be aware of what sexually mature means."

When DSWs refer to Cathy as a young adult, her mother fears that they fail to recognise Cathy's vulnerability and therefore place her at undue risk. Yet the DSW role exists because of the needs of their client. Support is provided as a result of the client's intellectual disability that renders them with "deficits in … reasoning, problem-solving, planning, abstract thinking, judgement, academic learning and learning from experience" (DSM-5, 2015). Measuring these areas of development can be very subjective, and with little training in such areas of expertise, few DSWs are educated or experienced in such assessment. To simply argue for Cathy's right to share a bunk with the boyfriend from a rights perspective is easier than undertaking a risk assessment, judging her capacity to defend herself in the event of any unexpected eventuality, measuring her understanding of the ramifications of sexual intimacy and so forth. Supporting this young couple on the grounds of the right to do what contributes to their perceived wellbeing and happiness negates the need to calculate consequences. To calculate consequences requires examining all circumstances, to explore short-term and long-term outcomes and predict ramifications into the future. Trying to assess any activity's inherent risk to clients is idiosyncratic and distinctively individual; making decisions based on possible consequences can be problematic for many DSWs.

While some participants in this research indicated that learning and growth can result from making poor decisions, and are happy to believe that good learning can come from experiencing negative consequences, others openly question how to know when to intervene within the ambit of their duty of care. Certainly adhering strictly to a rights-based approach simplifies the decision-making process, and supports the advantages outlined by Jewell (2010) of efficiency, consistency and reliability, moderation, justice, and rationality and impartiality. Cathy is seen as an adult, supported to engage in intimate contact, without extensive examination of any potential harm that may arise from this interaction. This simple support of rights is a primary consideration, but is not the exclusive consideration of the DSWs considered in this study. In the case of known sexual encounters, for example, most support staff realise that informed consent needed to be assured in order to cover their duty of care. As Jewell (2010) points out, a professional has a special responsibility when dealing with clients, alongside a degree of "knowledge, power and authority that the client lacks" (p. 6). It is inherent in the relationship between Cathy and her support staff that she is recognised as having a degree of vulnerability. It is a dereliction of duty of paid employees in the disability sector to simply support a client's rights without at least some due consideration of the client's safety. What this study has highlighted is that while indeed some deliberation is given to possible negative or harmful consequences, the support of rights is the higher priority claimed by most DSWs. Cathy was supported by DSWs who assumed she sufficiently understood the possible consequences of sharing the bunk with Karl, but who also assumed that full sex would not result from the two sharing a bunk in the presence of other peers. Yet even when the idea of pregnancy is a real possibility, some DSWs still support young people's rights to make their own decisions on sexual matters. As Rick noted:

> *If [parents] come in and say, "I trusted you to keep my daughter safe, but she's gone off and had sex now and is 21, has Down syndrome and is pregnant. What the hell have you done?", it would be a very hard discussion to have, but I would have to maintain that I have given all the information I can. We'd done all we could, she's been to [Family Planning], and as service providers I can't prevent her from having these experiences, but it would be heart-wrenching discussion, but I would still support the young woman, my client.*

Jewell (2010) highlights that there are times in the real world when principles may conflict with consequences. He adds:

> There is no simple method for dealing with these conflicts. Sometimes we should respect a person's decision even if we predict the consequence will be undesirable. Sometimes we should take steps to avoid disastrous outcomes, even if that requires manipulation or deception. (p. 75)

The conflict in this case study is predicated on the fact that Cathy is no longer biologically a child; everyone agrees on this point. However, whether she is recognised as either an adult or a non-adult, and whether this status varies, depending on the life domain and issue at hand, establishes the question of whether she is recognised primarily as qualifying for rights as a result of her chronological or biological age, or whether her welfare should take precedence, and possibly overrule her rights. Applying the term "adult" to young clients with intellectual disability requires one to be more focussed on their rights than on their welfare; the term can conveniently be called upon to support the argument for this approach. The inference is that these rights are protected by higher authorities, such as the UNCRPD, strengthening any defence of this DSW's choice to act in accordance with the client's rights, rather than to concern themselves predominantly with their welfare. This is what DSWs are trained to do. On the other hand, parents do not suggest their sons and daughters are children. But nor do they see them as fully adult. The term "adult" is seemingly meaningless if it is considered as an "all or nothing" concept; there seems no point in parents calling their sons and daughters "adults" when they do not meet all the criteria for recognition as such. It serves no purpose. It is simply a matter of there being no better alternative term when these young people are not children. The different conceptualisations of adulthood make the term unserviceable—the use of the term "adult" does not fulfil the function either party intends it to within conversations between support staff and parents. Nor does it reflect the perception of the young people themselves as being somewhere between childhood and adulthood, still learning to become adults.

10.3 Conclusion

This research explored the ethical and practical considerations that influence constructions of adulthood by principal stakeholders that care for or support young adults with intellectual disability. It investigated the proposition that there is potential for conflict between family and unpaid carers, and paid support staff and services supporting young people with intellectual disability immediately following completion of secondary school and as they reach the age of 18 years. This current thesis investigated whether any resulting conflict can be attributed to differences in the understanding of what constitutes adulthood and the ensuing rights and responsibilities linked to attaining 18 years of age. This study found that these differences in understanding of adulthood between stakeholders are the main source of conflict. The intention of this study was to investigate how stakeholders applied notions of adulthood to young people with intellectual disability, and to explore the compatibility of conceptualisations between the two main groups of people in the lives of young people with intellectual disability, and those young people themselves. The research has mapped differences in perceptions of adulthood between family members and DSWs and identified areas of disagreement or incongruity between these notions. Conflict between support staff and families is well documented and noted in the literature review. This thesis investigated whether this conflict is based on a deeper struggle than simple “turf-wars” over the role of stakeholders in the lives of the young people.

The question about *who* and *what* constitutes an adult is not simple, but is indeed important for the person with an intellectual disability and those others within the family and institutions involved with that person. Disability service providers are bound by society’s need for structures that divide and categorise people, and whose practices remain aligned to state instigated accords and guidelines. However, parents’ perceptions of their offspring are less circumscribed by socially or legally based definitions of adulthood, and many remain resistant to suggestions that they need to fall in line with those definitions commonly espoused in the broad community in which they reside. Parents are not professionals with prescribed *modus operandi*, and often see adulthood very differently from those paid to work with their sons and daughters.

In mapping conceptualisations through this thesis, five major areas of discrepancy were identified:
1) independence, 2) rationality, 3) meaning, 4) acceptance in community, and 5) the idea of actual versus virtual adulthood. For parents, seeing their offspring as having insufficient independence, inadequate rational thought, a relatively meaningless life, and limited acceptance in the community, parents believed that pre-emptive talk of their sons and daughters as adults in the years following the end of secondary schooling was a virtual, or erroneous, reflection of their offspring. On the other hand, support staff believed adulthood was an entitlement that should be bestowed regardless of these issues, and by assuming that young people with intellectual disability are adults, DSWs can offer experiences that assist the young person with disability to grow and develop as an adult community member in an actual, or real way. The young people themselves

perhaps summed up the conundrum by agreeing that after they finished their Grade12, and turned 18, they were "adults with P-plates"—adults in some ways, and at some times, but not fully adults. They recognised that they were in the process of becoming adults, a concept that aligns with contemporary recognition of emerging adulthood as a new life stage. The spectrum of positions outlined in this thesis offers a "grey area" between childhood and the assumption of adult status for young people and their families, with unclear borders around how parents and support staff may negotiate support of self-determination for their clients. It also highlights the indistinct boundaries involved with the professional roles of support staff who are working with young people with compromised autonomy, particularly when this compromise may affect some characteristics or areas of their lives, but not others.

As discussed in Chapter Eight, what is needed is acknowledgement that the current definition of adulthood is inadequate and that it does not effectively meet the needs of any of family members, service providers, or, indeed, young people with intellectual disability themselves. Despite the 2006 UNCRPD that proclaims the rights of persons with disability, tension between stakeholders in their lives remains. This study found that service providers try to pull parents into one definition, while parents resist. At the same time, the results suggest that parents attempt to draw service providers into their perceived definition of adulthood, with equal resistance on the part of the support staff. However, this transition into adulthood for those with intellectual disability is not guided by a clear, black and white definition of adulthood. The issue is not centred on unarguable legal or biological frameworks—clearly young people can grow into mature adult bodies and fit the legal chronological requirements adulthood. In terms of more practical considerations however, the way a person is supported or their rights facilitated requires other mainly psychosocial and/or cognitive characteristics be taken into consideration. This study highlights that despite a young person being a legal adult at 18, and having capacity to participate independently in their community in a number of ways, situations also exist in which guardianship or additional support for that person is required. Such support may be necessary for management of money, travelling within the community, or daily living skills such as cooking or personal care. This additional support requirement contributes to the lack of clarity around the recognition of young people as adults by those who staunchly believe independence and autonomy is fundamental to being considered to be an adult. Yet no one lives without the support of others. As highlighted in the review of the literature, interdependence is recognised as essential for societal survival. Perhaps it is not the degree of dependency that is important in this dilemma, but the areas of dependency. We are all, as people who identify as adults, entitled to ignore the advice of professionals, and to choose to be autonomous. But when a person is a recipient of support from either unpaid carers, or paid support services, due to an identified cognitive impediment, the question is whether they can make this same choice. Within Article 3 of the UNCRPD, the General Principles of the Convention include "respect for inherent dignity, individual autonomy including the freedom to make one's own choice, and independence of person", alongside "full and effective participation and inclusion in society", and "equality of opportunity". This thesis has shown that the right to "live in the community, with choices equal to others" (Article 19, UNCRPD) is not universally agreed upon by those entrusted, through either love or duty, to support these people, nor by a group of young people with intellectual disability themselves. Therein lays the conflict.

The United Nations may have felt they had conferred adulthood or citizen rights to those with disability through the UNCRPD, but with no differentiation between those with different types of disability, it has failed to address the conundrum that continues unabated today between unpaid carers and support staff for young people with intellectual disability. The convention is based on normalisation principles and dedifferentiation that reflect the move away from "differentiation of people with disabilities by diagnostic grouping" (Bigby, 2006 p.38), preferring to draw attention to the collective experience of people with disability. But in so doing, the shadowy area for those who, despite turning 18, require some level of support in decision-making remains an area for conflict.

People in the broad community, including parents and DSWs, generally do not think in definitions, but these are essential for policy makers. People instead think in terms of species resemblance; a bird is a bird because it resembles what we understand to be the characteristics of the class of birds. Whether we see a person and recognise them as an adult depends on the lens through which we observe this person. The results of this study suggest that service providers need to have a definition of adults, as they are required to construct social situations for distribution of goods and services, and do not have the time to spend arguing about one's eligibility for these. Quality assurance and standards require service providers to have clear and unambiguous definitions and this contributes to the challenges in resolving such tensions between families, support staff, the individual, and the service support system. For these social structures, it is necessary to be able to identify those whom everyone agrees are eligible for services. Data from this study highlights that where there is much grey area, it is important to stop polarising positions on the concept of adulthood. Stakeholders and policy makers must come to the table with a clear acceptance that there is no one definition of adulthood that adequately serves these young people with intellectual disability and those with caring and supportive roles in their lives.

The data from this research suggests that DSWs believe adult status can result from a projection of adult attributes achieved through careful management of the client and their environment. This belief results in their determination to create an environment for people with intellectual disability within which they act in ways that identify them as adult members of the community who act in accord with social expectations. This is what the parents consider "engineering". They recognise that they also "engineer" experiences in their son's and daughter's lives, fearing that unless opportunities are manipulated and created, their sons and daughters will not initiate these for themselves. Parents' "engineering" is a result of their perception of their sons and daughters as either lacking self-motivation, or having limited capacity to explore adult options without parental intervention. DSWs regard this simply as part of the duty of DSWs under the principle of normalisation; it does not negatively impact their perception of the young person as an adult. For parents though, such engineering of environments in which people with intellectual disability are enabled to act in ways considered "adult" does not change the inherent characteristics that are seen to preclude the young person with intellectual disability from being adult. To parents, there is more to being an adult than simply doing what other adults do. It is more than simply a perception or appearance of adulthood-ness or the reaching of a chronological milestone. Parents see adulthood as a status offered to people in response to what they are intrinsically, and not a measure of how one performs in public; their measure of adulthood aligns with Goffman's (1976) "actual social identity", rather than his "virtual social identity".

As long as there are differences in the fundamental premises by which one may consider young people as adults, there is little chance that a definition of adulthood can be offered that is mutually acceptable to all stakeholders. At best, we can recognise that as young people leave their secondary schools they leave behind their childhood. However, when, or if they are to become adults is a matter of selective judgement that may differ from person to person. There is no satisfactory definition for making this call, and it is potentially more harmful to all concerned to try. Although everyone believes they know what an adult is, there is, in fact, no adequate definition for those living with intellectual disability. We have done an inadequate job of defining their position within the community. They are not children, but more aligned to emerging adults than recognised as fully adult.

10.4 Limitations

All studies contain delimitations, and therefore also contain limitations. There are limitations of this current study that could be considered when planning future research in this area. This study was undertaken in Tasmania, the small island state to the south of mainland Australia. The participants included three mainland residents, with all others resident of Southern Tasmania who lived within 45 minutes' drive from the central business centre of Hobart. Over half of the parent participants (12), and six of the DSW interviewees are considered residents of rural communities. There was no discernible difference between responses from those living in metropolitan areas (including participants from other states) and those living within the rural regions on Tasmania. It is assumed the participants are representative of the Australian population. Centring the research within this population addressed the limiting factors of time and financial support for this research, along with the single researcher used for its entirety. There were no apparent differences between conceptualisations of interviewees from either rural or metropolitan areas, or from other states of Australia.

The investigation explored fundamental human rights issues, which are assumed to be universally applicable. However, while 17 per cent of Tasmania's population identifies as Aboriginal or Torres Strait Islander (Australian Bureau of Australian Bureau of Statistics, 2012), the research explored in this thesis did not include any interviewees from more remote parts of Australia such as areas with exclusively or predominantly indigenous populations. The theoretical framework on which the research is based considers cultural determinants of adulthood, and the perceptions of Australians living in areas relatively close to capital cities are not assumed to represent those of the more remote indigenous communities of Australia. The researcher in this study asserts that further research involving larger numbers of participants, and more diverse cultures, could confirm the universality of the findings from this study, both from parental perspectives and those of DSWs.

While the pre-service education of DSWs involves nationally accredited training packages that apply in all states of Australia, and is recognised across the national disability sector, the culture of disability services may influence DSW conceptualisations of clients as adults in unforeseeable ways, particularly in more remote areas of Australia.

Further limitations involve the paucity of demographic information gathered on participants in relation to age, ethnicity, income, education level or other areas of sociological difference, such as marital status, or the age of the parent when the child was born. Views of male participants or female participants were also not isolated for examination in this study, but may be worth further exploration in future studies. No distinction was made between the severity of the intellectual disability of the parents' sons and daughters which ranged from mild to profound, and no information regarding socio-economic backgrounds was sought from participants. These limitations also lend themselves to further exploration of this subject with consideration given to cross-cultural differences.

The experiences of parents in Tasmania that contribute to their conceptualisation of adulthood for young people with intellectual disability are assumed to be essentially similar to the experiences of parents throughout Australia. The process of identifying participants via newsletters and parent organisation websites meant that only those parents who were affiliated with these bodies were initially included in the invitation to participate. While some snowballing helped identify other participants, a broader approach to identifying potential participants through health and human service agencies, such as the National Disability Insurance Agency (NDIA) may yield a broader cohort of participants for future research of this nature.

The idea of adulthood is an abstract concept. The participants with intellectual disability had to be capable of understanding some information based on abstract questions, and required an understandable communication system firstly to consent to participate in the research, and secondly to contribute within the focus group meeting. While the participants in this research were all assessed as having this capacity for understandable communication, the reliance of two participants on communication devices conceivably restricted their full contribution to a discussion held within a limited time frame. Further research might develop tools by which young people with communication limitations can be offered means to participate more fully within this research, such as through individual interviews that allow time for responses, or the opportunity to provide answers to pre-prepared questions.

As this research dealt with the abstract concept of adulthood, some preparation of visual tools for guiding discussion within the focus group may have assisted participants with limited capacity for abstract thinking. It is possible that participants with intellectual disability responded to the facilitator of the focus group in ways that they believed she wanted them to respond (Kaehne & O'Connell, 2010). It is also possible that participants simply agreed with comments made by fellow members of the group, and did not express their true ideas about the concept of adulthood (Kaehne & O'Connell, 2010). Exploring this topic in more depth through individual interviews with young people with intellectual disability could provide further confirmation of the ideas they have about what makes a person considered to be an adult.

Other limitations inherent in the use of focus group methodology for research with those with intellectual disability have already been discussed in Chapter Four. However, with these in mind, this methodology with a purposive sample group of young people of the right age, and who identified as living with intellectual disability, offered rich data for analysis and met the requirements for this study.

Despite some minor limitations, this study was able to illuminate significant insights into the understanding each of the three cohorts of participants has of the terms “adult”, “adulthood”, or “grown up”. These insights give rise to recommendations for further research, and consideration by policy makers within health and human services and for management of disability support agencies.

10.5 Recommendations:

10.5.1 Recommendation for further research

This study used convenience sampling and identified a group of young people aged 18-22 who identified as having an intellectual disability. All of these young people were students of the TasTAFE Training Institute. A recommendation for future study would be to explore a broader range of young people with intellectual disability, aged up to 30 years of age, which included young people in the work force as well as those who may attend recreational or day option centres, or who remain at home with their families and do not attend any services. The voice of young people with intellectual disability is a valuable addition to this research into whether conceptualisations of adulthood contribute to tension between parents and DSWs during the transitional phase of the young person’s life. However, this life stage is likely to extend upwards to age 30 for these young people, so understanding more about the perceptions of others and how these develop beyond the training colleges would contribute further to this discussion. This would offer broader illumination of the conceptualisation of adulthood by the population of young people with intellectual disability of adulthood. It would extend findings to include the thoughts of non-students living with intellectual disability. The contribution of young people with intellectual disability allows the complexity of this concept of adulthood to be recognised. When there is an obvious discrepancy between the perceptions of adulthood and its applicability to young people with intellectual disability by those with vastly more experience of this concept, and with vested interests, it is important to acknowledge the insights and observations of those who are personally experiencing this life stage and trying to navigate potentially conflicting frameworks.

A second recommendation for further study is to investigate cultural differences amongst the diverse Australian population. The cohort of parents and DSWs in this research were overwhelmingly Caucasian (only one DSW is known to identify as having indigenous heritage), and generally middle class. This may be reflective of those willing to be interviewed for research of this kind, and equally reflective of those who have given this conundrum some consideration in their working or private lives. Targeting a demographically wider range of participants and examining participant details could produce further insight into this period of conflict and tension. Identifying a broader range of participants through the use of other recruitment paths would expand on the findings from this study.

10.5.2 Recommendations for management and policy development

The findings for this study show that there are significant differences in the conceptualisation of adulthood and the application of this term to young people with intellectual disability. These differences present opportunities for conflict between the parents and DSWs over young people's choices and rights to freedom and decision-making in the years following their 18th birthday. Conflict has long been recognised between these two groups during the transition to the adulthood life-stage, but this research provides clear evidence that the use of the term "adulthood" can position these two sets of stakeholders in different, and incompatible, mindsets. Policies reflect the philosophy and guiding principles that form the framework under which support is offered and provided to those with disability by social services. This is revealed in first of the National Standards for Disability Services (NSDS) (Australian Government Department of Social Services, 2013) that supports the rights of a person with disability to "freedom of expression, self-determination and decision-making". Parents are not averse to their sons and daughters having these rights introduced, slowly and over time as they negotiate their path into adulthood and a more independent life, and renegotiate their relationships with their family. It is the sudden onslaught of these rights that causes the tension for families. To alleviate the tension within this life-stage transition, thought must be given to alternate ways these young people can be referred to in policy documents. Then as a result, consideration should be given to the nature of the support framework by which DSWs assume to provide support. Support needs to be provided in such a way that it is more likely to respect the second of the NSDS standards that requires services to work with their clients and their "families, friends and carers" in promoting meaningful participation in their society. This is difficult to achieve when each cohort perceives the other to offer potentially negative outcomes for the young people, viewed either as undue freedom and risk-taking, or conversely, over-protection and shielding from the outside world.

The life stage of young people without disabilities, defined as "emerging adulthood" by Arnett, and now gaining popular acceptance amongst sociologists, needs to be acknowledged as being equally (if not more) relevant to the lifespan process of young people with intellectual disability. This concept should be at the forefront in determinations by policy makers in the field of intellectual disability, allowing rights to become assumed by young people when they are ready, rather than being "thrust",on them, and demanded for them, on their 18th birthday. The young people in this study did not wish to be considered adult, did not wish to assume all their rights, but talked of a time "when they are adults …". It needs to be acknowledged that there is no adequate definition of adulthood that serves young people with intellectual disability constructively. The work of support staff in disability support networks should be to help develop the skills of young people to become the most independent, autonomous and self-determining adults they can be, and to work with the families in this process. The second of the National Standards for Disability Services (2013) demands that services “work with individuals and their families … to promote opportunities for meaningful participation and active inclusion in society”, but this collaborative approach can be undermined by the simple lack of an agreement about when young people with intellectual disability become adults, and as such have greater rights under the first of the NSDS standards. These two standards should not be competing. The transition to adulthood is a process towards adult rights for both those with and without disability. This process can be a lengthy journey that may start in the late teens, but continue well into the 20s. Further research is needed into how to reframe the UNCRPD and the NSDS to accommodate young people with intellectual disability in a way that does not result in friction and conflict between their families and their DSWs.

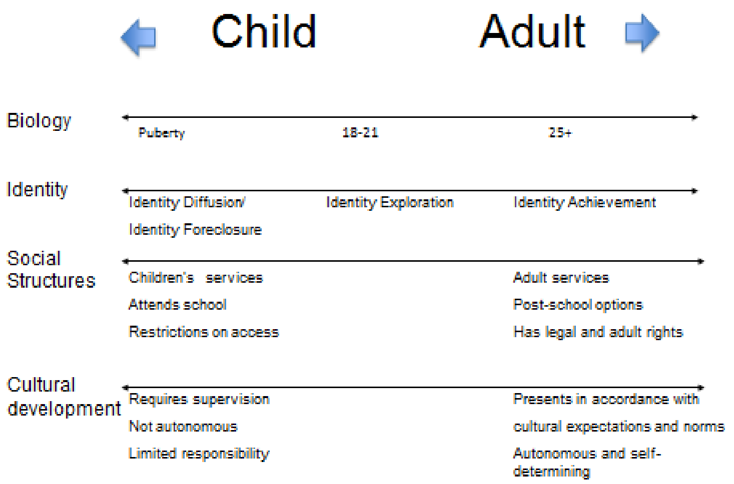
10.5.3 Recommendations for introductory level training

The findings in this current research from the focus group and individual interviews with DSWs reflect the content and intent of the training they have presumably undertaken within the compulsory units of the current pre-entry Certificate III Individual Support training course, or the now superseded Certificate III in Disability Support program. This training may well guide the culture of the disability sector. Pre-service training uses a human rights framework throughout its core units, including “Support independence and wellbeing”, and “Work legally and ethically”. The disability-specific units in this training are focussed on empowerment, behaviour, community participation and skills development, and little (if any) specific attention is given to working with families. It is only within the Home and Care Specialist electives or further in-service training that students may be offered any training to “support relationships with carers and families”. This is not compulsory training required of disability support staff. Adulthood is seen as a rights issue. Young people with intellectual disability are seen to have the right to be recognised and treated within the same legal framework as those without disability. The interpretation, or perception of “adulthood” is assumed to offer membership to the community of adults that offers them the right to the same respect to freedom of choice as similar aged peers without disability. This assumption of age-based adulthood that flows from the training of support staff needs to be balanced by a respect for families, and recognition of the differences in perceptions that parents may have on their sons and daughters as adults. This could be included in compulsory pre-service training for DSWs in two ways. Firstly some training on the sociological aspects of parenting young adults with intellectual disability should be included to help develop a healthy respect for this challenging life stage within a broader acknowledgement of the concept of emerging adulthood. Alongside this should be some further exploration of this comparatively recently described life-stage of emerging adulthood and how contemporary young people may grow towards adulthood over a number of years as a result of sociological changes. Such training may help to reduce the conflict between DSWs and parents as young people with intellectual disability in their care continue to develop towards adulthood as it is assumed to be by the young people and their parents.

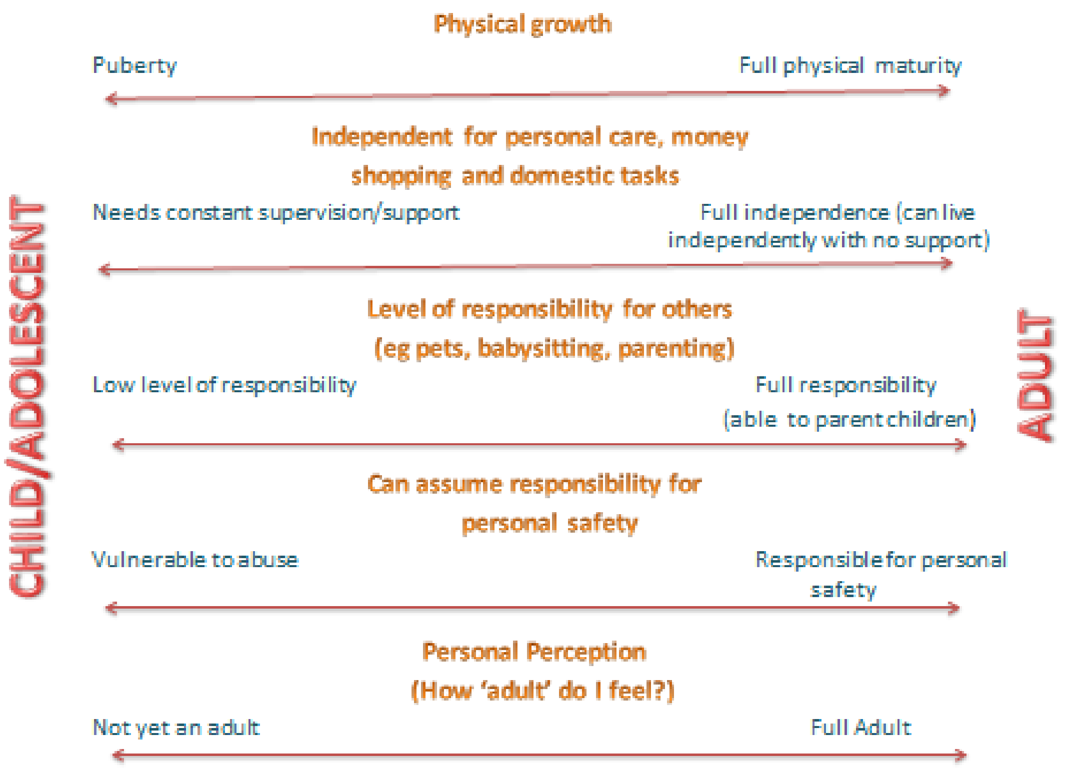
10.5.4 How these findings can be used by stakeholders

Possibly the most notable idea offered by the young individuals with intellectual disability in this research is that adulthood is not an “all or nothing” concept. It can indeed be likened to a process similar to wearing P Plates until such time one identifies oneself as fully adult. While DSWs rely heavily (although not exclusively) on a legal framework that recognises the age 18 as the end of childhood and the beginning of adulthood, parents and young people with intellectual disability see the development of adulthood occurring over an unspecified time. A means of visually representing one’s perception of themselves or others as adults may provide a useful tool that could aid communication and collaboration between the three stakeholders. While adulthood could be argued as a state ultimately determined by the person to whom the term is applied, and within the context that the term is being used, this perspective may not be shared by others. The position of stakeholders in young people’s lives, and the language they use in reference to them, should be considered relative to the perspective of the person living with ID. Instead of asserting that one is an adult with comments such as “You are over 18 now, so you are an adult, and can do what you like” as was suggested in the conversation highlighted in Chapter 1, stakeholders need to explore a broader framework on which to determine adult status. This may involve considering a person’s position on a continuum which could be adjusted for various contexts, such as the home, the work place or the community.

Effectively, what needs to be considered across the four domains of adulthood is illustrate below:



However, this could be of little value to the person with an intellectual disability, for whom a simplified representation of the continuum is offered:



Reflective consideration about where a person may be positioned on each continuum would offer a focus for discussion on their adult status in each area, while also allowing open discussion about the continuing development of skills needed to work towards a more adult status. Such discussions would reflect how people are observed, how they are treated, and the skills area that need focus in the development of personal plans. Such a visual outline of various continuums helps to present adulthood as a stage of development, while not suggesting that people remain in a childlike state during this developmental process. It highlights the concept of emerging adulthood as journey which all young people experience as they transverse through Marcia's stage of identity exploration, and offers a tool for use by support staff, parents, and staff in senior secondary colleges when developing transitional plans.

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Appendix One
Letter of Introduction

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Faculty of Health Sciences
School of Medicine
Department of Disability Studies
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http://som.flinders.edu.au/FUSA/disabstud

CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

Dear Sir/Madam

This letter is to introduce Ms Fiona Redgrove, who is a Master of Science student in Disability and Community Inclusion, Faculty of Health Science, at Flinders University. Fiona will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis on the topic of “Discourses of Adulthood and Autonomy as they apply to young people with intellectual disabilities”. This research will compare and contrast frameworks and ideologies around the concept of adulthood used by parents and primary carers of young people of post-school age with intellectual disabilities, and the frameworks and ideologies of those services that provide support for these young people.

Fiona would be most grateful if you would volunteer to assist in this project, by granting an interview which covers certain aspects of this topic, or by participating in a focus group, also addressing aspects of this topic. It is anticipated that in either case, approximately 1½ to 2 hours would be required of your time.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time, or to decline to answer particular questions.

Since Fiona intends to make a tape recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed, and to make the recording available to other researchers on the same conditions. It may be necessary to make the recording available to secretarial assistants for transcription, in which case you may be assured that such persons will be advised of the requirement that your name or identity not be revealed and that confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to Fiona’s main supervisor, Dr Paul Jewell. Dr Jewell can be contacted at the address given above, or by telephone on 08 8201 2576, or via e-mail at Paul.Jewell@Flinders.edu.au
Thank you for your attention and assistance.
Yours sincerely

Dr Caroline Ellison
Disability and Community Inclusion
Flinders University

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Appendix Two
Letter of Introduction Focus Group

Dr Paul Jewell
Disability & Community Inclusion

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CRICOS Provider No. 00114A

LETTER OF INTRODUCTION

Dear Sir/Madam

This letter is to introduce Ms Fiona Redgrove, who is a PhD student in Disability and Community Inclusion, Faculty of Health Science, at Flinders University. Fiona will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research about the concept of adulthood and how this applies to people with intellectual or developmental disabilities. She is comparing and contrasting different ideas about adulthood that are held by parents and support staff, and wants to include your thoughts about adulthood as a person living with a level of disability.

Fiona would be most grateful if you would volunteer to assist in this project by participating in a focus group which will address things about this topic. It is expected that this will involve about 3-4 hours, but will be in your normal class time at TasTAFE, so you won't be expected to give up any of your free time.

The information you provide in this focus group discussion will be treated in the strictest confidence and only the other students in the focus group will know what you say. You don't have to say anything unless you want to, and can leave the group at any time if you are not comfortable with the things that are being said. As part of the focus group, you will be invited to add to a mind map, or to draw about your ideas. These mind maps or drawings will be collected by Fiona and shared with others, but your names will not be included on the pictures, so no-one will know whose ideas are on the paper.

Fiona will tape record the final hour of the focus group, so she needs your consent, on the attached form, to use the recording or a transcription of what you say in her work on her thesis or in other publications, on condition that your name or identity is not revealed to anyone. Confidentiality of the material Fiona produces will be respected and maintained.

If you have any concerns about this project, you should direct these to Fiona's main supervisor, Dr Paul Jewell. Dr Jewell can be contacted at the address given above, or by telephone on 08 8201 2576, or via email at Paul.Jewell@Flinders.edu.au

Thanks you for your assistance.

PD Jewell

Dr Paul Jewell

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee. For more information regarding ethical approval of the project the Secretary of the Committee can be contacted by telephone on 8201 5962, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

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Appendix Three
Information for Participants (TAFE Students)

Flinders
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CRICOS Provider No. 00114A

INFORMATION SHEET
(for Focus Group Discussion on Adulthood)

Title: ‘Between Love and Duty: An exploration of discourse of adulthood and autonomy as they apply to young people with intellectual disability’

Researchers:
Mrs Fiona Redgrove
Department of Disability and Community Inclusion
Flinders University
Ph: 03 61655806

Supervisor(s):
Dr Paul Jewell and Dr Caroline Ellison
Department of Disability and Community Inclusion
Flinders University
Ph: 08 8210 2576 (Dr Jewell) and 08 8201 3422 (Dr Ellison

Description of the study:

This study is part of the project entitled ‘*Between Love and Duty.* This project will investigate the conceptualisation of adulthood as it applies to people with intellectual disability. This project is supported by Flinders University’s Disability and Community Inclusion Department in the School of Health Science.

Purpose of the study:

This project aims to find out when people believe that turn into adults. I have been asking lots of parents and people who support people like you when they think you should be considered as an adult – so now I want to know what you think.

Now that you are over the age of 18, sometimes people will talk to you about being an adult, but sometimes people might talk to you or treat you as though you were still a child. I want to know what you think – do you think you are adults yet, and what does that mean for you? Sometimes people might argue about whether you should be allowed to do

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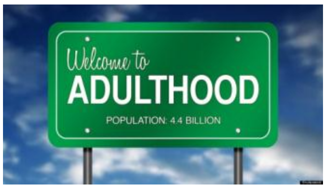
things that adults do, so it is important to know what you think makes someone an adult, and whether you think of yourself as an adult.

What will you be asked to do?

You are invited to be part of a group discussion (called a "focus group") to talk about what you think makes someone an adult or not. The discussion will take about one hour. The discussion will be recorded using a digital voice recorder to help with looking at the results. Once recorded, the transcript of the meeting will be transcribed (typed-up) and stored as a computer file and then destroyed once the results have been finalised. You don't have to be part of this discussion. You can sit quietly and not say anything, or you can even leave the room and work with the VETSAs on another project if you want.

Before we start the focus group, I am going to let you have some time with some other students to write down some of your thoughts on a mind map. I will ask you to just write some thought on this mind map that can guide the questions during the focus group. You won't write your names on these mind maps, as all the information collected for this research needs to be anonymous – which means no one knows who said or wrote anything on the topic.

I might ask you questions such as:



- What do you think makes someone an adult?
- When do people become adults?
- What things change when you are an adult?
- What can adults do that children can't?
- Do you think of yourself as an adult yet?

You will then be able to listen to what other people think, and you will have the chance to discuss this and say whether you agree with their ideas or not.

What benefit will I gain from being involved in this study?

The sharing of your experiences will improve the planning and delivery of future programs for people who are leaving Grade 12 and moving on to their post-school lives. Now that you are over the age of 18, sometimes people will talk to you about being an adult, but sometimes people might talk to you or treat you as though you were still a child. I want to know what you think – do you think you are adults yet, and what does that mean for you? Sometimes people might argue about whether you should be allowed to do things that adults do, so it is important to know what you think makes someone an adult, and whether you think of yourself as an adult. This is your opportunity to let people know your thoughts about when people should be considered to be an adult.

Will I be identifiable by being involved in this study?
(In other words, will anyone know what I have said in the focus group meeting?)

We do not need your name and you will be anonymous. This means your name is not ever used when I am writing about, or talking about this research. Other group members may be able to identify your contributions even though they will not be directly attributed to you. No one, except the other members of the group, will know what you said, but they will be asked to keep your comments confidential. Confidential means that we don't talk about this focus group or what we discussed with anyone outside this group. Once the focus group discussion has been typed-up and saved as a file, the voice file will then be destroyed. Any identifying information will be removed and the typed-up file stored on a password protected computer that only the researcher (Fiona Redgrove) will have access to. Your comments will not be linked directly to you.

What you say to us remains confidential, except if in the course of the discussion, you tell us that you have been doing anything that is illegal (which means against the law), we are obliged to tell your guardians, or the courts, about this. This would have to be something very serious, and we would talk to you about this in a private place so you understand why we need to pass on such information. I think this is very unlikely, but it is best you know this in advance.

Are there any risks or discomforts if I am involved?

If you do not feel comfortable being part of this focus group discussion, you can choose to go to the library for the mornings that this is happening, and work on computers with one of the TasTAFE VETSA staff members.

We promise you that if you don't want to participate, you will not be disadvantaged, or in trouble, and no-one at TasTAFE will treat you any differently. You might choose to start in the group, but find that you want to leave during the class. That is okay as well.

Fiona anticipates few risks from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with Fiona or another staff member that you feel comfortable talking to.

How do I agree to participate?

Participation is voluntary. You may answer 'no comment' or refuse to answer any questions and you are free to withdraw from the focus group at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form and send it back to me at 82 Flakemore's Road, Eggs and Bacon Bay, 7112.

How will I receive feedback?
The findings from this focus group with be typed up ready to be included in my final thesis paper. I will summarise the outcomes from this research and share them with you in another class if you would like to see them. I will be happy to discuss any of the points in my paper with you then.

Thank you for taking the time to read this information sheet and I hope that you will accept our invitation to be involved.

Fiona Redgrove

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 7169). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 08 8201 3116, by fax on 08 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix Four
Consent Form for Participation in Research

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(by interview or focus group)

I ………

being over the age of 18 years hereby consent to participate as requested in the Letter of introduction for the research project on Discourses on Adulthood and Autonomy as they relate to young people with intellectual disability conducted by Fiona Redgrove.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction
3. I agree to audio or video recording of my information and participation
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment of service that is being provided to me
    - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage

Participant's signature ……………………………………………….Date …………………

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name …………………………………………………....………………….

Researcher's signature …………………………………………….Date ……………………

NB: *Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Item 6, as appropriate.*

6. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained

Participant' signature ……………………………………………………….Date ………………………