



THE CONCEPTUALISATION OF ADULTHOOD AS IT RELATES TO PEOPLE WITH INTELLECTUAL DISABILITIES
– **A SOURCE OF TENSION**

Fiona Redgrove B Ed., Grad Dip Spec. Ed., M Dis Stud., PhD
Candidate, Flinders University



A father's protest...



- *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 is not capable of understanding the risks of wandering the streets with men she hardly knows. That's what her disability means! What does her age have to do with the fact that she doesn't have the sense to know when her actions could result in something terrible happening to her?*



So.... what is adulthood?

People with Intellectual Disability and adulthood – a challenging concept

- *“Thinking about disability helps to problematize our understanding of what it means to be an adult in society, and reveals more about the way in which both disability and adulthood have been socially produced.....”*
 - (Priestley 2003 p. 116):
- *“Adulthood as an emergent status is realized through the gradual acquisition of certain rights and privileges and responsibilities. For young people with an intellectual disability such a natural progression cannot be taken for granted”.*
 - May (2001, pp 75-76)



What we know...



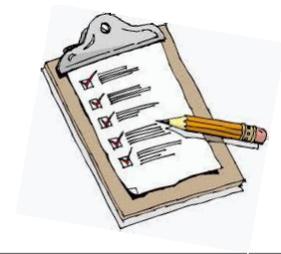
*Parents and Disability Service staff having
“different future visions” for young people
with ID* (Hanley-Maxwell, 1998)

...but why the difference?

Could it be....



- ... that ethical position of stakeholders in the lives of young adults with intellectual disabilities impacts discourses of *adulthood*, with tensions arising from the incompatibility of such discourses?



Data collection

□ Focus groups

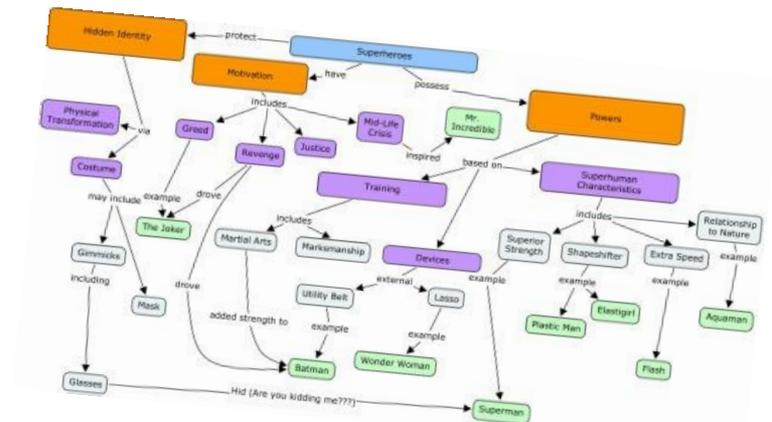
- Parents (sons and daughters 18-25)
- Staff in services for clients with ID 18-25

□ Semi-structured individual interviews

- Parents (sons and daughters 18-25)
- Staff services targeting clients with ID aged 18-25,
 - respite,
 - day options,
 - employment,
 - recreation and
 - training

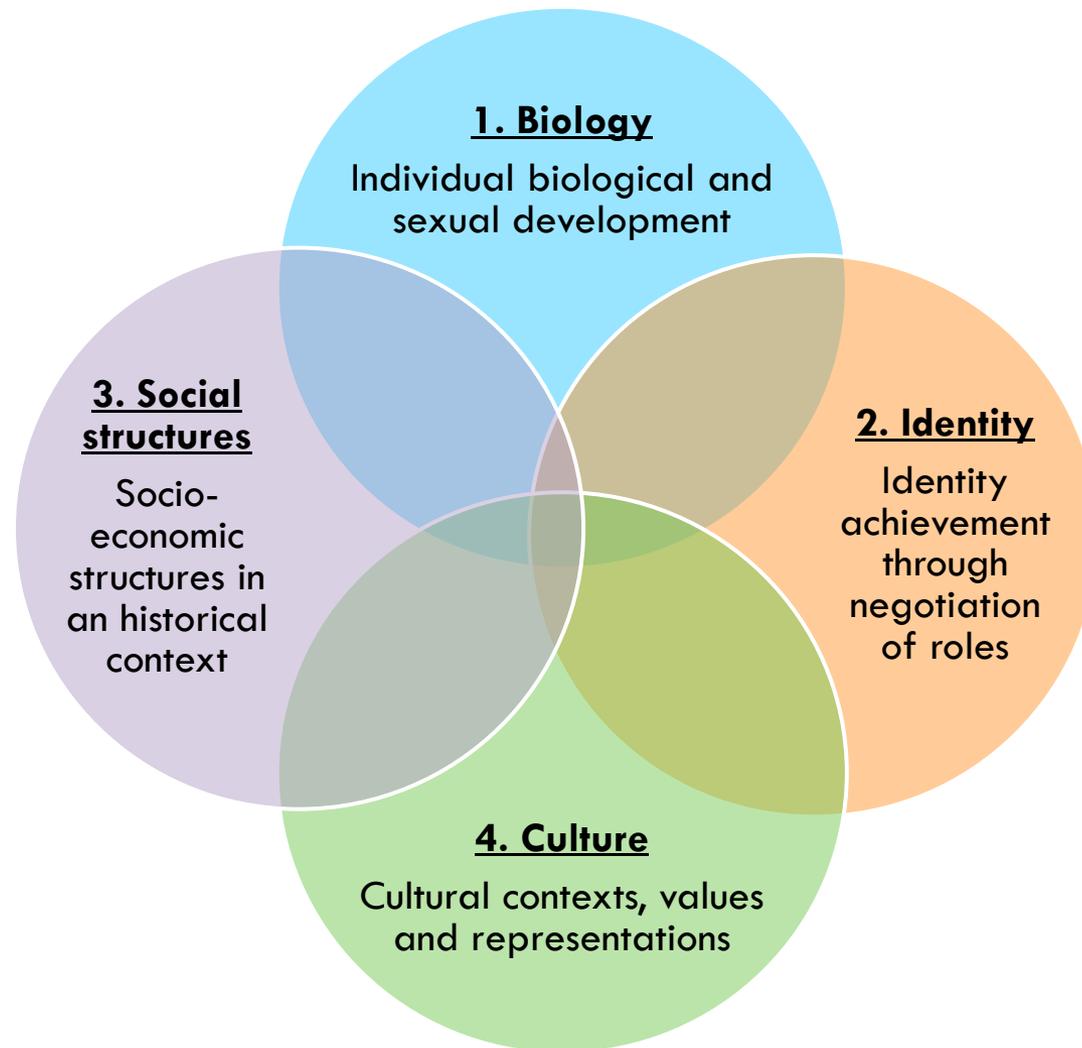
Concept Mapping

- Concepts mapped to represent relationship between conceptualisations of adulthood by the two groups.
- Concept mapping identifies problems, rather than finding solutions



Primary Conceptual Framework

Adapted from Priestley's Life Course Approach to Disability



Findings:

Parents believe the features of adulthood are:

Domain	Characteristics
Biology	Physical development/sexual maturity
Identity	Recognition as experiencing identity moratorium or identity achievement status (Marcia) <u>Driven by internal motivation</u>
Social Structures	Finished secondary schooling Over 18 years – legal rights Accesses adult services and social venues
Cultural Factors	Not a child Capacity for safe relationships with other adults in the community Shares characteristics and is accepted by others in the community – <ul style="list-style-type: none">• independence, problem-solving, responsibility, decision making, self-determining, assumes right, can physically and cognitively defend oneself, rational thoughts etc

Findings

Staff believe the features of adulthood are:

Domain	Characteristics
Biology	Physical/Sexual/Biological Maturity
Identity	Identity Foreclosure or Identity Diffusion accepted as adult states of identity development Identity can be <u>driven by external forces</u> (rather than self-motivation)
Social Status	Finished secondary schooling Chronological age (over 18 years) Accesses adult services and social venues
Cultural Norms	Not a child Interest in relationships and sexuality Entitlement to equal treatment within legal/ethical framework for adulthood Has a rightful place in the community despite differences <ul style="list-style-type: none">• Not essential to be independent or autonomously self-determining

Common Ground:

Biology	Physical/sexual/biological maturity
Identity	<i>[Little common ground on Identity development]</i>
Social Structures	Has finished secondary schooling Over 18 and ineligible for children's services Accesses adult services and social venues
Cultural Norms	No longer a child Has a place in the community of adults Contributing members of the community Self-determining, (with or without support)

Differences in perceptions

PARENTS	STAFF
<ul style="list-style-type: none">• ..tend to see deficits in cognition as permanent barriers to acceptance as adults• .. see their sons/daughters as non-children, but also as non-adults, (not yet adults) - they wish to continue some level of their caring/supporting role• ..tend to see sons and daughters in stage of identity foreclosure or diffusion conforming to expectations of others, or with little interest in exploring alternate options	<ul style="list-style-type: none">• ..tend to see clients' progress towards adulthood stunted by overprotection, which can be overcome through experience• ..see clients as adults, who do not require 'care', but rather need to be supported to live independently.• ..tend to see young adults with ID as capable of exploring identity options on which to base adult identity.

Areas of tension

5 main themes emerged as sources of tension:

- Independence
 - *can they do it on their own?*
- Rationality
 - *do they understand the consequences?*
- Meaning from activities
 - *will they get anything out of it?*
- Acceptance in the community
 - *will they be welcomed by others?*
- Actual vs Virtual adulthood
 - *will it happen in the real world?*

THEME ONE –

Adults are independent beings



□ Parents **object to the perception of their son/daughter as adult** when they are reliant on others for personal support:

- P: “We know he is an adult, ...adult body, and ... adult sexual needs, .. he can’t stay at home ... or cook his meals, we still even need to run his bath. ...he is an adult in some ways, we know that, but he’s **not independent**”

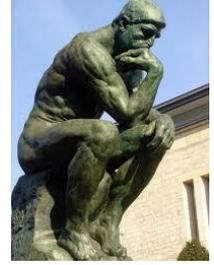
□ Staff **object to the**

perception of their clients as children.

- S: “...anyone, no matter how they look – whether they have small stature, or look cutish, **no matter what they can and can’t do for themselves, are adults, or become adults, and have adult rights.**”

THEME TWO –

Adults are rational beings



- ▣ *Parents want young people with ID to be supervised and protected as they are unable to make rational decisions and choices*

- *P: “He is still profoundly vulnerable, ... He misunderstands what people are trying to tell him...*

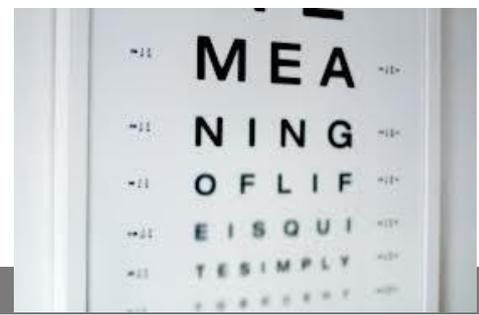
Letting someone else help him make his decisions is a worry – he would agree to things that wouldn’t be what he needs, or even what he wants”

- ▣ *Staff have a duty of care, but*

believe they must offer dignity and opportunity for growth through risk taking

- *S: We treat everyone ... as adults, putting our safety measures all around them, and then 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”.*

THEME THREE – Adult life offers meaning



- Parents want a “good life” that offers meaning for their sons and daughters that is **not necessarily achieved through normative adult activities;**

- P: “What are the benefits of a [day] program [when] three hours of this are spent on a bus? Does she have to go to some type of institutionalised centre to make her life fulfilled .., or meaningful?”

presentation of clients as members of the adult community

- S: “I feel it is important to promote pwid at any age as meaningful participants in society, I think it’s about presenting an image, ...promoting respect and understanding..., respect for place in community”

- Staff are concerned about the

THEME FOUR –

Adults are accepted members of society



- ▣ *Parents - interactions with member of the general community may have **potentially detrimental effects** on young people with ID*

- *“Parents of little children don’t like him hanging around, ... 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.”*

- ▣ *Staff - young people with ID have a right to a place in the adult community, and are **more likely to have beneficial consequences** from their interactions with others*

- *“...a sense of citizenship, and ..rights, that all people, ..., have basic rights, whether that is accessing the community, using the community, making adult decisions. I allow people to take risks because that’s what everyone does. If I want to do something – ...why should I deny that same chance for someone else?”*

THEME FIVE –

Adulthood can be actual or virtual



▣ *Parents: the environment in which young people with ID are adults is artificial, young people are adults only within a context which is not authentic.*

■ *P: “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 young adult”.*

▣ *Staff: having the same*

experiences as other adults in an authentic environment equates to real adulthood

■ *S1: “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”*

Five major points of contention

PARENTS BELIEVE:

- Adults are **independent** in personal hygiene, self-help and activities of daily living skills
- Adults have **rational cognitive functioning** which allows them to assume responsibility for their actions
- Adults have the capacity **to locate meaning** in their daily activities
- 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**
- Adulthood for people with ID is **more virtual** (contrived or engineered) than actual (naturally occurring)

STAFF BELIEVE:

- Adulthood is **not synonymous with independence**. It involves interdependence - reliance on support from others does not preclude one from adulthood
- Adulthood is an **entitlement** for all people over 18 **regardless of cognitive functioning**
- Adults **do not necessarily gain meaning** from their activities, but should gain acceptance in the community through their activities
- Adulthood entitles one to partake in a degree of **risk taking** from which it is assumed **learning** will occur
- Adulthood for people with ID is **more actual** than virtual

“Emerging Adulthood”

- “emerging adulthood” stage for those aged between 18 and 25-30 (Jeffery Jenson Arnett)
- ...is “neither adolescence nor young adulthood but is theoretically and empirically distinct from both”
- Would this alleviate the tensions between parents and disability support staff?



Kim & Jason by Jason W. Kotecki

Get comics free by e-mail www.KimandJason.com

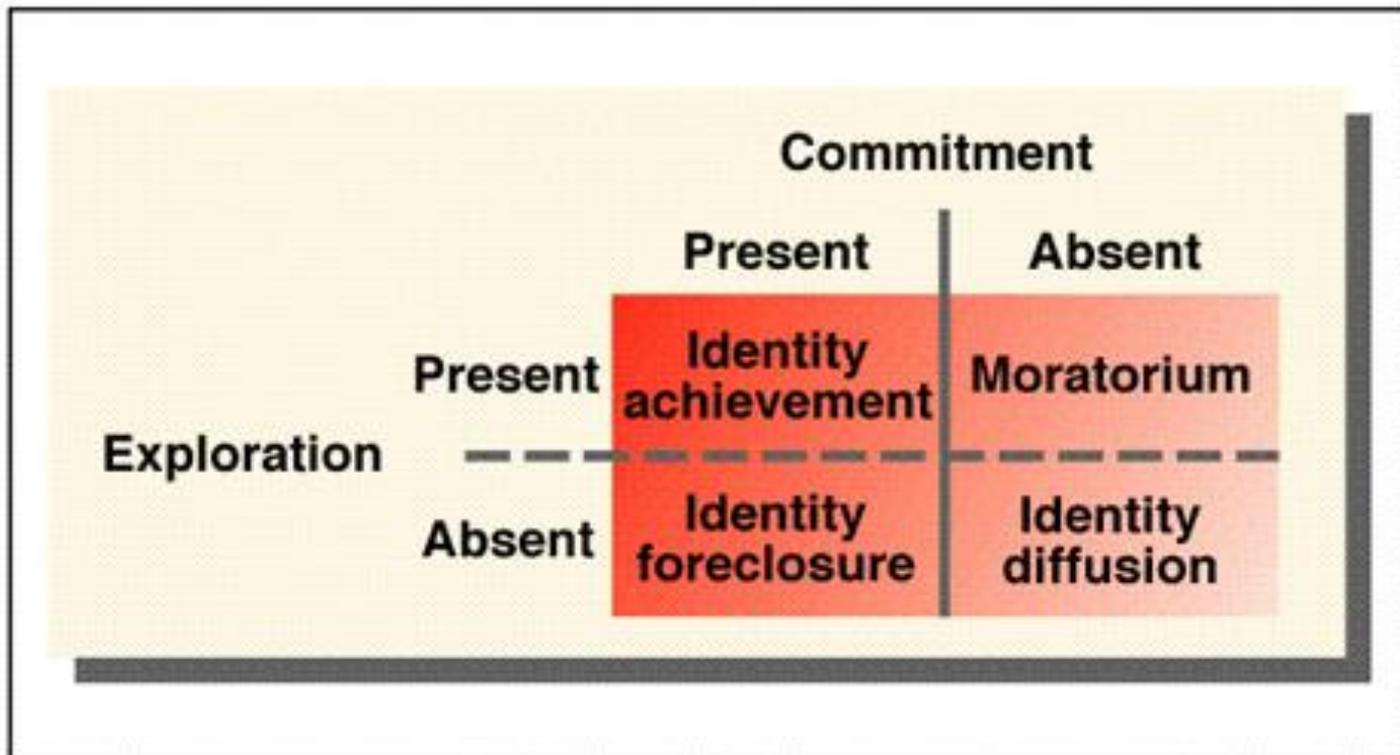


Any questions/comments?

Marcia's identity status

Steinberg, Adolescence, 7e. Copyright © 1998. McGraw-Hill Companies, Inc. All Rights Reserved.

Identity Status Categories



Theme 1: Independence

Observation	Issues	Research translation
<p>Parents believe adults are independent in personal hygiene, self-help and activities of daily living skills. Staff believe adulthood is not synonymous with independence, but can involve interdependence and reliance on support from others</p>	<p>Parents object to the perception of their son/daughter as adult when they are reliant on others for personal support: Staff object to the perception of their clients as children.</p>	<p>No adequate definition of 'adulthood' to support either proposition</p>
	<p><i>P: we know he is an adult, 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 an adult, we know that, but he's not independent</i></p> <p><i>S: 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 DS, and no matter what they can and can't do for themselves, are adults, or become adults, and have adult rights.</i></p>	<p><i>P: We 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 its pretty straight forward. Normality can be doing things differently, because doing things normally is really, really difficult</i></p> <p><i>S: it's a very vague concept, and a very interesting one. With young "adults" I work with on a daily basis – they are still kids, still children, in many respects..... 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?"</i></p>

THEME2 : Adults are rational beings

Observation	Issue	Research Translation
<p><i>Parents believe adults have rational cognitive functioning which allows them to assume responsibility for their actions</i></p> <p><i>Staff believe adulthood is an entitlement for all people over 18 regardless of cognitive functioning</i></p>	<p><i>Parents want young people with ID to be supervised and protected as they are unable to make rational decisions and choices</i></p> <p><i>Staff 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</i></p>	<p><i>Parents are reluctant to relinquish the support of their sons and daughters with ID to staff in support services</i></p>
	<p><i>P: 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</i></p> <p><i>S: 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.</i></p>	<p><i>P: the program wants to treat him like an adult, with the rights to privacy and these sorts of things, and to me that's the worry. He's a vulnerable human being. He's there because I've got him there, but there's also all these other things in between, and knowing how to negotiate these things without being cast as the overprotective mother role, is, I think, for me, a really difficult transition.</i></p> <p><i>S: 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, as service providers, I can't prevent her from having these experiences, but it would be a heart-wrenching discussion, but I would still support the young woman, my client.</i></p>

THEME 3: Adult life offers meaning

OBSERVATION	ISSUES	RESEARCH TRANSLATION
<p><i>Parents believe that adults have the capacity to locate meaning in their daily activities</i></p> <p><i>Staff believe adults do not necessarily need to gain meaning from their activities, but should gain acceptance in the community through their activities</i></p>	<p><i>Parents want a “good life” for their sons and daughters that is not necessarily achieved through normative adult activities, while staff are concerned about the presentation of clients as members of the adult community</i></p>	<p><i>Parents do not value programs offered by adult support services, while services recognise their programs may run in conflict to parent values</i></p>
	<p><i>P: 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?</i></p> <p><i>S: One of the things I feel is important is promoting pwid 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</i></p>	<p><i>P: He doesn't understand the ethic of work, so what's the point! There's no way we can persuade him to do a job if he doesn't understand that it's about money, and that money can make your life different or better, and you might get something out of that occupation, but because he doesn't have that idea of the whole concept of work, then we can't get him to work.</i></p> <p><i>S: We are “parent-friendly”,but we also don't allow the parents to be controlling – we negotiate. It doesn't sit 100% comfortably with me if I know there are going to be issues with the family, but at least I can say “I understand where you are coming from, but as an employee of this organisation, and under the organisation's brief, I am sanctioned to support the person..</i></p>

THEME 4: Acceptance in community

Observation	Issue	Research Translation
<p><i>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</i></p> <p><i>Staff 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</i></p>	<p><i>Staff support young people with ID's right to a place in the adult community, and believe they are more likely to have beneficial consequences from their interactions with others, while parents believe the interactions with member of the general community may have potentially detrimental effects.</i></p>	<p><i>Parents fear the consequences from the interaction between their sons and daughters and adults in the broad community, and don't trust staff to protect them as they would want them protected.</i></p>
	<p><i>P: 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.</i></p> <p><i>S: 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?</i></p>	<p><i>P: 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. B'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.</i></p> <p><i>S: Taking risks is all about new knowledge and learning and having a better life because we are better for it. Whatever the circumstances, we will learn from it. We learn from the consequences That's the underlying principle, but not to run to their rescue straight away, but to allow things to happen. If things go wrong, well ok, as long as you have ensured their personal safety, and the safety of others....</i></p>

THEME 5: Adulthood may be actual or virtual

Observation	Issue	Research Translation
<p>Parents believe that adulthood emerges naturally for young people without ID but that it is engineered for those with ID, Staff believe that there is some imagery involved in the presentation of people with ID as adults, but that they are still real adults</p>	<p>Parents believe that the environment in which young people with ID are adults is artificial, and that their children are adults only within a context which is not authentic. Staff believe that having the same experiences as other adults in an authentic environment equates to real adulthood</p>	<p>Parents want acknowledgement that reality for them is that within a quasi- adult framework, their sons and daughters have intrinsic needs/capacities that align with those of children, while staff believe that childlike behaviours are the result of parents treating them like children</p>
	<p><i>P: 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.</i></p> <p><i>S1: 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</i></p> <p><i>S2: 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.</i></p>	<p><i>P: We went with all the paperwork we needed, and the "professional" was interviewing M ! Which is great, but when something comes up in the interview and the person you are interviewing has the intellectual capacity of a 4 or 5 year old – well!! And every time I went to offer something I was told firmly, but politely, to "Please let M answer".</i></p> <p><i>S: We see that when particularly older people come into the service for the first time when they are like 40, and they have wanted freedom but haven't had a chance. We've even had a 40 year old who couldn't wipe his own bum, because mummy had always done it.</i></p>

Interview questions

Address:

- Stakeholder definitions of adulthood, and surrogate terms such as 'manhood'/'womanhood', 'grown-up', 'of age', or 'majority'
- Stakeholders definitions of autonomy, self-determination and quality of life
- Guiding principles in assistive or substitutive decision making with young people with ID