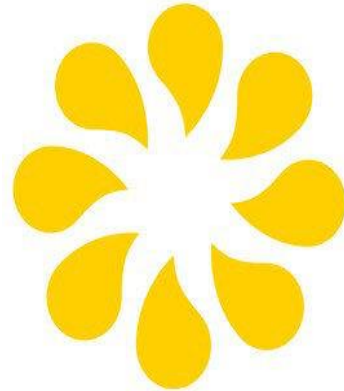


Family roles in adult's lives: Views of service managers

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THE UNIVERSITY
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CREATE CHANGE

Rationale



Overall aim

- ❖ Multipart study of the construction of futures of individuals with intellectual disabilities, with a particular focus on self-determination and decision making



Specific aim

- ❖ Understand the views of service managers regarding the role of families in the lives of adults with intellectual disability specifically related to decision-making

Background

Family-centred practice

- ❖ Prioritises collaboration and places the preferences and choices of the individuals who are receiving services and of their families at the core of services delivered

Role of families

- ❖ Many adults with intellectual disabilities live with their families well into adulthood
- ❖ Families are often involved in decision making regarding the lives of their adult with intellectual disabilities

Importance of managers

- ❖ Managers are an important influence on the types and quality of services (Beattie, et al., 2014; Olivier-Pijpers et al., 2019; Rice et al., 2009)

Study details

- Focus on the construction of futures of individuals with intellectual disabilities aged between 18-30 years
- Surveyed parents and staff of service organisation
- Interviewed individuals, parents, support persons and service managers

Managers

- 28 managers (16 females)
- Range of roles

Data collection and analysis

Interviews


- M = 37 minutes

Transcriptions

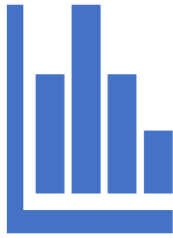
Focus question:

- What role do you think families play in constructing the future of young people with intellectual disability?

Data extraction

- Response to direct questions regarding families
 - Other mentions of family
- 

LEXIMANCER ANALYSIS



Text analysis program

Content analysis

Thematic analysis



Evidence of utility

(Nunez-Mir et al., 2016)

**At least as good as manual
coding**

Reduced bias

**Outperformed other text
analysis tools**



**Transcripts from interviews
were text used for analysis**

29,404 words

Leximancer Process

(adapted from Lee, 2022)

Step 1

- Load the relevant data set

Step 2

- Decide on any textual manipulations

Step 3

- (Re)run analysis

Step 4

- Explore core themes through colour and centrality on map

Step 5

- Explore relationships and proximity of themes to understand co-occurrence of the themes in the text

Step 6

- Identify concepts underlying the themes

Step 7









- Identify evidence for each concept to understand context in text

Step 8

- Explore relevant quotes that exemplify concepts and provide further context.

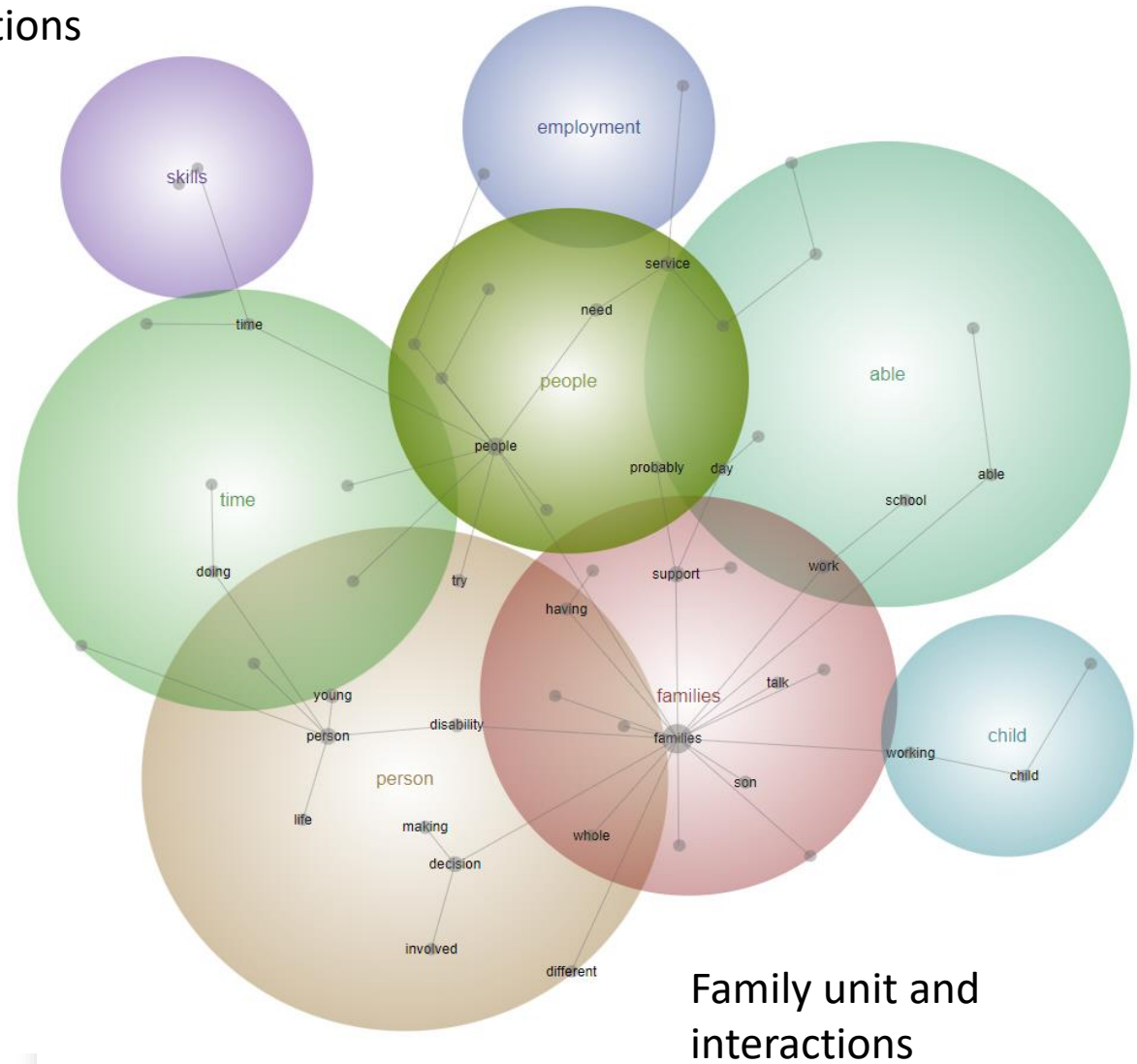
Analyst Synopsis

Detail Level Export

Theme	Hits	
families	506	
person	304	
people	278	
able	78	
time	70	
child	59	
employment	20	
skills	19	

Concept map – Managers’ views of families

Services and service
functions



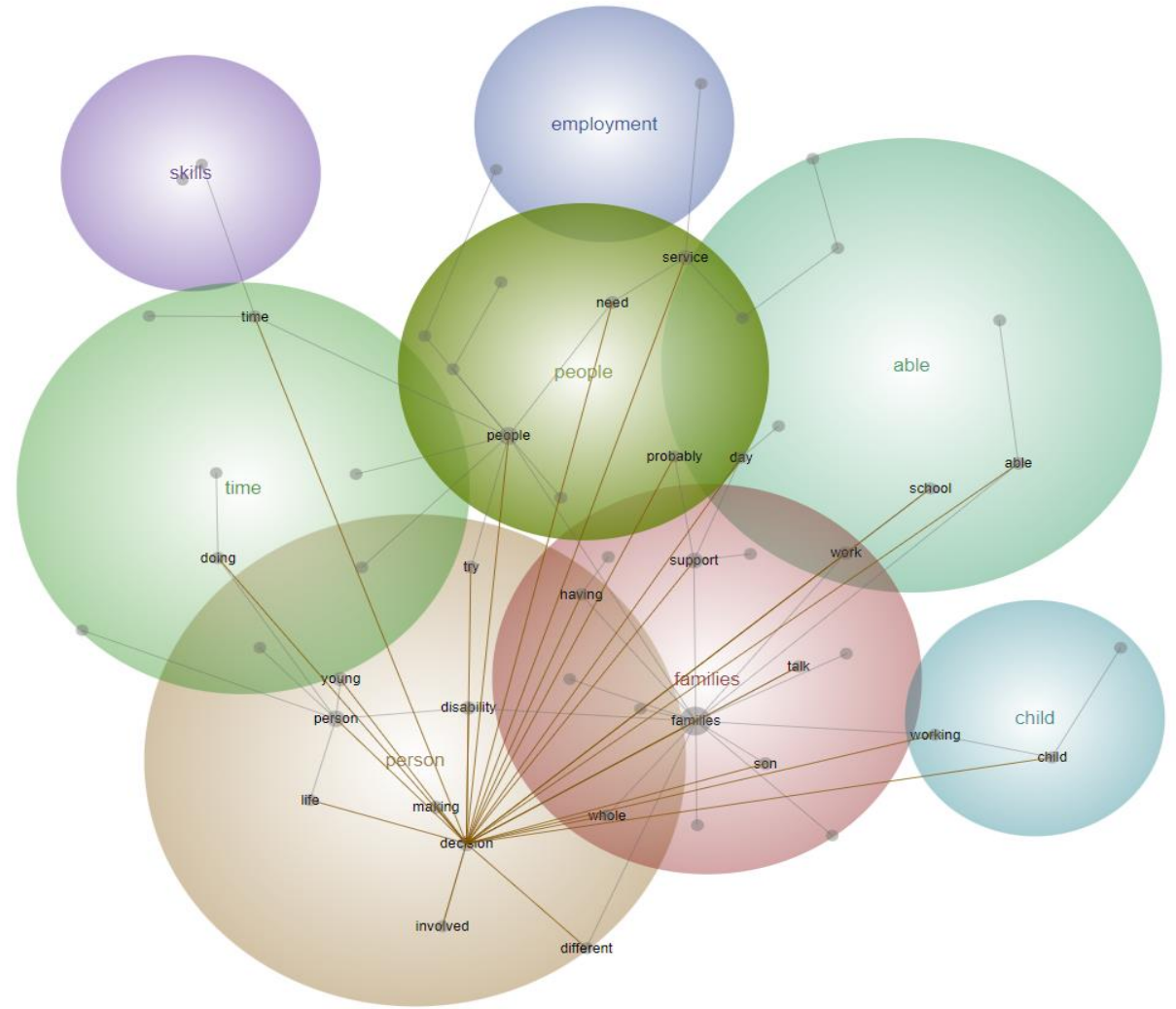
Family unit and
interactions


Theme	Concepts	Exemplars
Families (506)	families, support, work, son, having, talk, whole	<p>Assuring the mother than these things are okay and that we're supporting and we're going to be there. ...but her daughter has just grown in the last six months because she's done more things that she never used to do.</p> <p>But when families talk about they'd like their son or daughter to work they don't mean necessarily, or generally almost invariably don't mean in the short term they mean like when they're a little bit older and they'd like those opportunities.</p>
Person (304)	person, decision, young, disability, making, try, involved, different, life	<p>I think that the majority of families do the right thing and I think that with the consent of the person with the disability they should be involved as much in that person's life as required, or not.</p> <p>Of course they want what's best for that person but they might think what the best is from their perspective instead of the perspective of the person whose life it is that they are making decisions for</p>

Theme	Concepts	Exemplars
People (278)	people, service, need, day, probably, provide	<p>We quite often are working with people with quite complex needs, and sometimes their families are ageing and stuff, and sometimes they need to revisit multiple things, where we're happy to provide our expertise and support around –</p> <p>We need to go and be sitting with families and having those aspirational meetings and all of that with people and getting in to think like that. Because they're constantly just thinking day to day at the moment</p>
Able (78)	able, school	<p>Mum was very clear about that, yeah, that's what they wanted. They want him to learn to be able to do that all on his own.</p> <p>She wouldn't be able to do that. I think one of the bigger challenges for us is to prove to them that they can.</p>
Time (70)	time, doing	<p>I have been doing here is educating the parents about how you can teach and support their children to make choice and decisions ...What I've found with families, if you're giving them that input they'll push it through...over time they'll see [unclear] people become more independent.</p> <p>we have to be really, really careful about - parents get quite attached to the full time work and supported employees get very comfortable with the work they're doing</p>

Theme	Concepts	Exemplars
Child (59)	child, working*	<p>It's really important that you have a ... great working relationship and a real understanding of where you're going to and a recognition of actually if you're a support provider the child has to come first because of their age, which is really hard.</p> <p>and they're the experts around how that child communicates, whether ... things are working well, things are not working well</p>
Employment (20)	employment	<p>Families often resist that. Once they've been with us for a while, even talking to them about open employment is quite a difficult conversation.</p> <p>So it's good if they can get a volunteering job somewhere. Like they're not talking about paid employment or whatever</p>
Skills (19)	skills	<p>We would be designing programs to give them basic life skills.</p> <p>It's also an agreement about what we will capture. We're not going to say that - look if we're trying to develop this person's skills in living independently around buying foods and knowing what foods and how to cook and that.</p>

Links with 'decision' highlighted





Decision-making

The parents certainly make the actual decision, I think to a large degree, but they're very much guided by the children, by their son or daughter who is - almost invariably if they don't like what we've got that comes through.

The parent is the customer and the [unclear] is the consumer.
So you cannot tell your customer you couldn't come.
But we try to get the person have more say before this kind of meeting involves the parents.

Other things in the data

Some managers held positive views of parents:

Some families, and of course, all families are a little bit different, but in my experience most families are very supportive of that [person developing control].

It's amazing the difference a supportive family can make and a family who really is involved in the lives of people with a disability.

Some managers held negative views of parents

Sadly, often a lot of resistance comes from families to change.

Dad's got his reasons, because he's bleeding his son's income, his disability pension goes into general household revenue.

Change is coming (or has arrived)

I think older families can sometimes be a bit more protective

The new parent group coming through so the students just leaving school they are very involved, they want the best outcome for their sons or daughters. Their expectation of the organisation is a lot higher

Other things in the data

Recognition of range of parental involvement:

- Some folks are supported by their families to be as independent as possible. On the other end of the spectrum you get families that just control everything they do, everything in between

Assumption of educative role of staff:

- So education and support for families, trying to yeah, sort of educate families as to the place of the changing perspectives on disability. Yeah that's probably one of the ways we could really improve, but it's always been a hard thing to think about let alone influence. How do you say to a family, you guys have got it all wrong, this is the way you should be thinking. It's a bit of a confronting thing.
- We want to try and build the person's decision-making capacity, we want to try and expand their abilities and work with their strengths, and we try to focus on their abilities not their disabilities. Putting that stuff out there, it's having those conversations, just touching on those subjects with families, just introduce them as concepts.

Discussion

- Limitations
 - One organisation and cultural elements will be influential
 - No capacity to understand the influence of role on manager views, although there evidently was some influence
 - No information from families about how views are expressed or impact them
- Variation in views
- Perceptions re age of cohort of parents (and clients)
- Role of schools

Implications

- Useful to have an understanding of the transmission of beliefs and attitudes from managers to other staff members
- Managers' roles are likely to be influential both with respect to level of interactions with families and in their expectations
- Need to pay attention to the family/manager dynamic
- Reduction in centrality of the type of service provision reflected in this study

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