“They treat you like a person, they ask you what you want”
Exploring factors that influence the quality of paid disability support

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Presentation Outline

- Background and aim
- Doctoral research overview
- Scoping review
- Data collection methods
- Preliminary interview findings
- Potential benefits of research
Background

Adults with acquired neurological disability

- Acquired brain injury (incl. stroke), spinal cord injury, multiple sclerosis and other neurological disorders
- Cognitive, communication and physical impairments
- Severe and profound core activity limitations
- Often require paid disability support to live an ordinary life

Disability support workers

- Build the capacity of PWD to make own lifestyle choices, participate in the community and achieve self-described goals
- Range of responsibilities
- Different employment arrangements
- Workforce problems: undertrained & under supported, high turnover, variable quality
Background

Individualised funding schemes

- choice and control for people with disability
- person-centred support
- limited guidance for people with disability
- demands on disability workforce

Need better understanding of what quality support looks like in order to...

- improve the quality of support and,
- build the capacity of PWD to choose support workers in line with their needs and preferences
Research aim

To develop a comprehensive theoretical understanding of the factors that influence the quality of paid disability support grounded in the lived experience of:

- people with acquired neurological disability,
- close others, and
- disability support workers.
Doctoral research plan

Scoping review
To examine the existing peer-reviewed literature around the factors that influence the quality of paid disability support for adults with acquired neurological disability.

In-depth interviews: three perspectives
To characterise the factors that influence the quality of support, and develop a comprehensive theoretical understanding of the quality of paid disability support grounded in lived experience of
• people with acquired neurological disability,
• close others, and
• disability support workers.

Bringing perspectives together
Analysing the three perspectives together to investigate areas of convergence and divergence, and develop a theoretical framework of the quality of paid disability support.
Scoping review

Research Aim
To examine the existing peer-reviewed literature around the factors that influence the quality of paid disability support for adults with acquired neurological disability


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**Expert consultation**

✅ Accurate reflection of the support experience for PWD

✗ Missing from the review:
- Accountability of DSW
- Broader systemic context impact support
In-depth interview studies

Methods

- Constructivist grounded theory (Charmaz, 2006)
- 1:1 in-depth semi-structured interviews
- Purposive and theoretical sampling via Summer Foundation and La Trobe University

Participant recruitment

- 12 people with acquired neurological disability
- 8 disability support workers
- 7 close others

Focusing on each perspective independently, starting with people with acquired neurological disability
Data collection methods

- In-depth interviews via Zoom or telephone
- Semi-structured interview schedule:
  - Experiences of support
  - What makes an excellent support worker
  - Other factors that influence the quality of support
- Online interviewing considerations informed by narrative review
  - E.g. distress protocol, strategies to build rapport, options for participation

Interview participants

12 adults with acquired neurological disability

- Mean age = 46 (4 male; 7 female; 1 agender)
- Multiple Sclerosis (5); Acquired Brain Injury (4); Stroke (1); Spinal Cord Injury (1); Other Neurological Disorder (1)
- Own Home / Private Rental (8); Shared Supported Accommodation (3); Residential Aged Care (1)
- Service Provider – self-selected (8); Service Provider – housing (3); Direct Employment (4)

Interviews

- Zoom (7); telephone (5)
- Duration ranged from 30 – 70 minutes
- 1 participant chose 2 sessions
- Interviews audio-recorded and transcribed verbatim
- Participants names replaced with pseudonyms
Data analysis

Constructivist grounded theory

- Three main coding phases
- Constant comparison method
- Memos, journal and field notes
- Data verification strategy
- NVivo software
Preliminary interview findings

- Individual, interactional and institutional levels of impact
- Echoing scoping review themes
- Three key *interrelated* themes with nine sub-themes, in terms of:
  - what the support worker needs to do (*You need to...*),
  - what the PWD wants to have themselves (*I need to...*) and,
  - how the PWD and support worker need to interact together (*We need to...*)
“...the words dignity and respect are something that people just don’t even think about, they just kind of just treat me like I’m their job, not a person”  Lauren

“They didn’t know your name, treat you like you’re just a body in a bed ... Here they treat you like a person, they ask you what you want. It makes you feel a lot better.”  Charlie
"And, you know, if they’re very curt ... you can pick up that they don’t want to work here, you know - that’s difficult... That they don't really want to be there... They're just doing it for the money."  Kelly

“Oh, well maybe someone who’s interested in helping [me], someone who asks a lot of questions."  Tony

"They have to have a happy disposition and - and, you know, be happy to do things to help you. It’s horrible to need help at this age."  Charlie
“If I say something’s important, to just trust me that it’s important. Trusting ... Respect my perspective.”  

Alex

“I wouldn’t mind if they’d had lots of experience if they come in and were like “okay, this is a different situation, I can adapt, I can apply my knowledge ... This is how we do it here, not this is how I do it” and it’s wrong, so wrong to come into someone’s house and tell them what to do.”  

Lesley

“That I’m articulate and that I’m – I’m the boss. I want things done my way. It’s my life and you’re here to help me.”  

Lauren
"I've got a variable condition that changes from day to day so they need to pick up on - on the job, you know, whether or not I'm strong enough to actually do something or that I kind of can do something, et cetera, et cetera."  
\textit{Kelly}

"I look for the skill of being able to handle a body that doesn't necessarily behave the way bodies do. Because my body will spasm and get tired and can sort of have - what's the word? ...It's involuntary. Involuntary spasms."  
\textit{Lauren}

"be helpful when you can see that I need some of your support."  
\textit{Isabella}
Support worker skills and attributes

**Treat me as a person**
- Empathy; understanding; respectful; kind; positive attitude

**Want to support me**
- Understanding the role; work ethic; motivated; positive/happy disposition

**See me as the expert**
- Willing to learn; listening; following instructions; reflective; responsive to feedback

**Respond to my needs**
- Attentive; flexible; reliable; intuitive; responsive; problem solving; knowing the basics
“I think it’s better now than it was in the past. **Because I have more choice about who’s here.** So, if someone isn’t giving the quality of support that I want, **I have the option of not having them work with me.**”  Alex

“**‘cause nobody should be able to choose support workers that I want to have** and bringing a couple along for me to give approval for. It shouldn’t be that way, it should be me to approve in the interview and me to approve them, whether they are good enough...”  Darren
"It’s horrible when people are trying to run your life for you and you’re like, excuse me, I’m here, I can run my life perfectly well."  Alex

"I want to be the one calling all the shots. It’s my life why the hell would anybody else call the shots."  Isabella

“I think that’s the first thing they need to be taught, is that we’re the client. They work for us.”  Sarah
"Somebody who’s friendly, happy to like be like a mate... Yeah. Like enjoys the things that I do, like going to the footy or going to the cricket. Or going out to the clubs."
Tony

"And never once have I asked to see her resumé or her qualifications. And I really don’t care what she’s got. I care about how we gelled."
Sarah

"I don’t waste time on the ones that I don’t - if I don’t click with them, if I don’t get that vibe I’m like swipe left."
Georgie
"it’s a big part of your day and they become a big part of your life. With some of them you can become friends but it’s always good to keep that sort of line in there between work and friendship."  Paula

"Yeah, I prefer the relationship to be flexible, you know... for boundaries. You know, it's better - like it being fluid and flexible."  Kelly

"it’s really, really hard when, you know, if I’ve got this one carer four days a week for the next 10 months, it’s really hard not to make a – make a relationship out of it. And where do you cross the line, you know?"  Will
"That – we’re – we’re both new at this, you’re new to me, I’m new to you, let’s be patient and just if I do anything that you don’t like, please let me know and I would like to do the same.”  Will

"Well it’s an expectation of mine and they understand that and they have respect as I do for them."  Paula

"We have so much fun... but there’s still respect but we – like, we talk dirty – you know, we’re girls"  Georgie
Support worker skills and attributes

BE THE RIGHT FIT

We need to...

Be compatible
Open; personable; sense of humour; easy to talk to

Get the balance right
Effective communicator; trustworthy; respectful; friendly; relationship management

Work well together
Respectful; patient; effective communicator; willing to compromise
RECOGNISE ME AS AN INDIVIDUAL
- Treat me as a person
- Want to support me
- Work well together

QUALITY SUPPORT
- Respond to my needs
- See me as the expert
- Lead my supports
- Get the balance right

FEEL IN CONTROL
- Have authentic choice
- Get the balance right

BE THE RIGHT FIT
- Be compatible

You need to...
I need to...

We need to...
Broader system and support arrangements

You need to...
- Recognise me as an individual
  - Treat me as a person
- Quality Support
  - Work well together
- Be the right fit
  - Be compatible

I need to...
- Feel in control
  - Lead my supports
  - Have authentic choice
  - Get the balance right
- Respond to my needs
  - See me as the expert

We need to...
Support environment
Key learnings so far

- Feeling recognised, in control and the right fit with support workers are key to quality support for adults with acquired neurological disability
- Most important factors sit in the interactional space
- External systemic factors influence the interactional space
- Factors are consistent with scoping review findings and individualised funding principles
- Limitations:
  - Preliminary analysis at this stage
  - Sample characteristics – limited cultural representation

- Next steps:
  - Finalise data analysis
  - Interviews with support workers and close others
Potential benefits of research

- **In-depth understanding** of the factors that influence the quality of paid disability support grounded in living experience

- Practical applications
  - Training and development interventions for support workers
  - Practical resources for people with disability and close others

- Future directions
  - Co-design project to develop framework for practice and improve quality of support
  - Foundations for quality measure development
We wish to acknowledge and thank the research participants who generously shared their experiences and invaluable insights to make this research possible.

Thank you

Questions?

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