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"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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LiDS Seminar October 2021

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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

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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

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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.*

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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.

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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

Open access   **Protocol**

BMJ Open Understanding the factors that influence the quality of paid disability support for adults with acquired neurological disability and complex needs: a scoping review protocol

Megan Topping [1,2] Jacinta Douglas [1,2] Di Winkler [1,2]

Topping, M., Douglas, J., & Winkler, D. (2019). doi: 10.1136/bmjopen-2019-034654

DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2020.1830190

Taylor & Francis
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REVIEW ARTICLE   OPEN ACCESS   Check for updates

Factors that influence the quality of paid support for adults with acquired neurological disability: scoping review and thematic synthesis

Megan Topping[a,b], Jacinta M. Douglas[a,b] and Dianne Winkler[a,b]

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Topping, M., Douglas, J., & Winkler, D. (2020). doi: 10.1080/09638288.2020.1830190

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Key themes	Subthemes
Choice and control	Choosing and managing support
	PWD involved in decision making
	Chance to use own capacity
Individualised support	Person-centred approach
	Responsiveness to needs
	Meeting language and cultural needs
DSW qualities	Willingness to listen and learn
	Empathy and understanding
	Respect
DSW competencies	Knowledge, training and experience
	Practical skills
Relationship	Personal chemistry
	Knowing the individual
	Trust
	Boundaries and friendship
Accessing consistent support	Continuity of support
	Funding
	Availability of support

Expert consultation

✓ Accurate reflection of the support experience for PWD

✗ Missing from the review:
- Accountability of DSW
- Broader systemic context impact support

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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

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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

Regular Article

General Considerations for Conducting Online Qualitative Research and Practice Implications for Interviewing People with Acquired Brain Injury

International Journal of Qualitative Methods
Volume 20: 1–15
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DOI: 10.1177/16094069211019615
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Megan Topping[1,2] [iD], Jacinta Douglas[1,2], and Dianne Winkler[1,2]

Topping, M. et al (2021). General Considerations for Conducting Online Qualitative Research and Practice Implications for Interviewing People with Acquired Brain Injury. *International Journal of Qualitative Methods, 20*, 1–15. https://doi.org/10.1177/16094069211019615

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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)
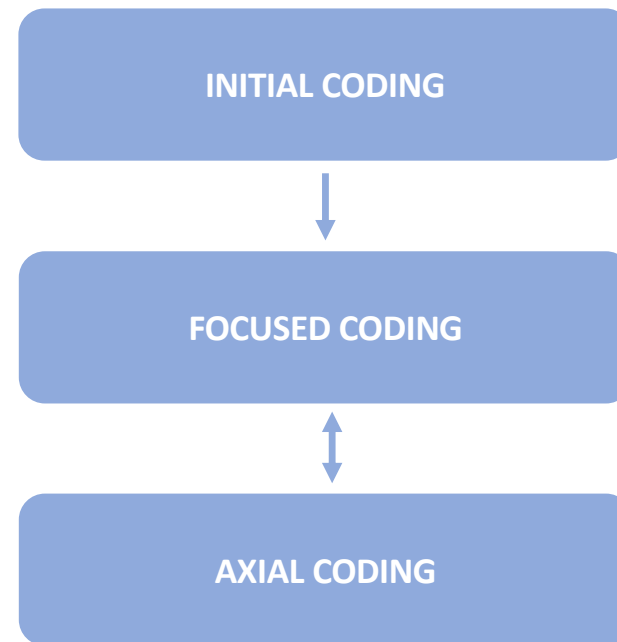- Service Provider – self-selected (8); Service Provider – housing (3); Direct Employment (4)

Interviews

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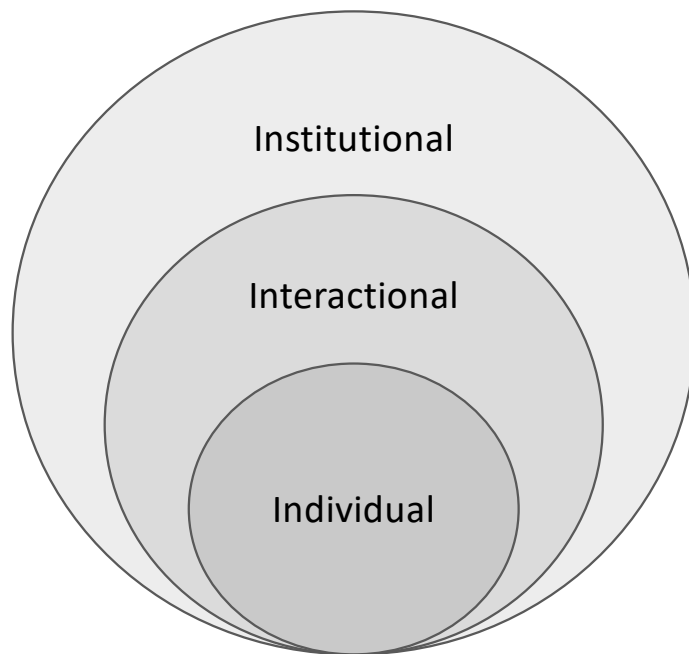- Participants names replaced with pseudonyms

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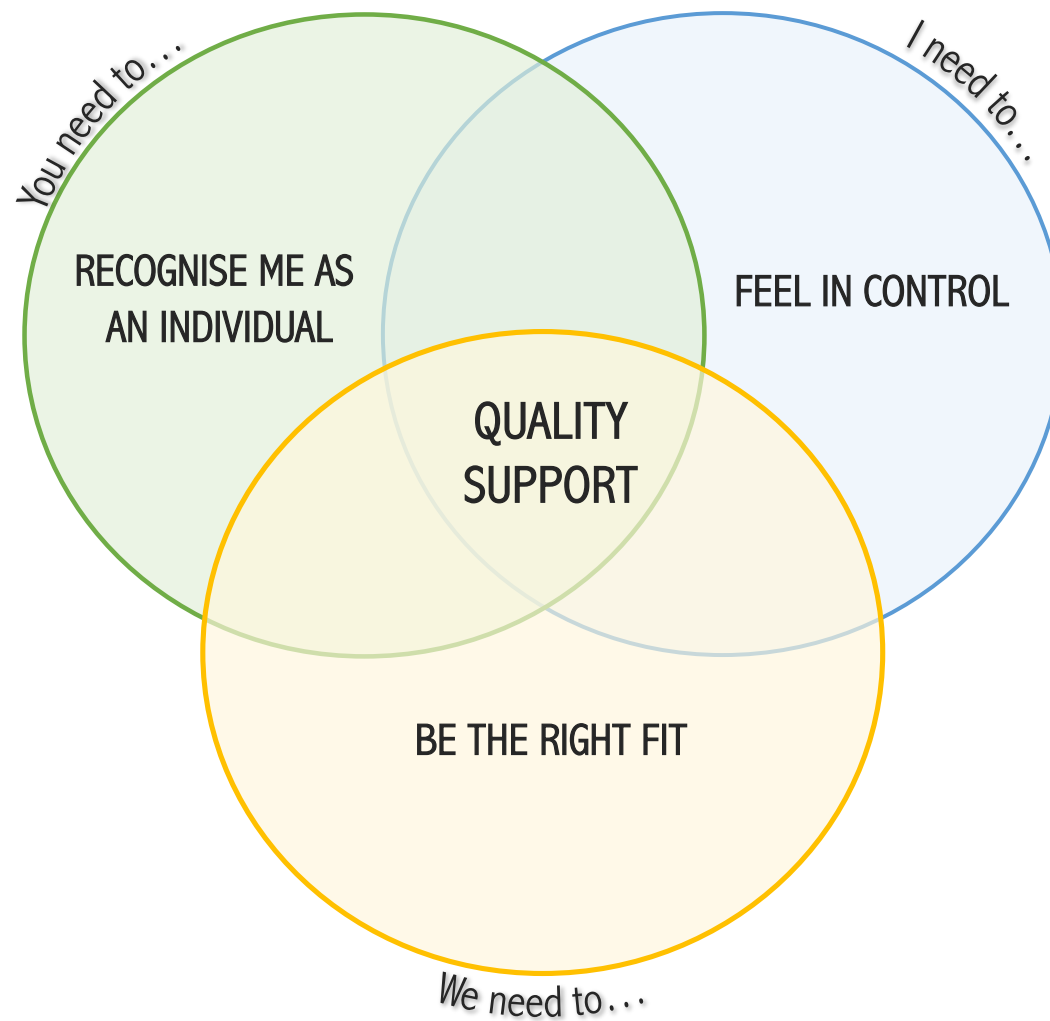All kinds of clever

Data analysis

Constructivist grounded theory

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

INITIAL CODING

FOCUSED CODING

AXIAL CODING

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Preliminary interview findings
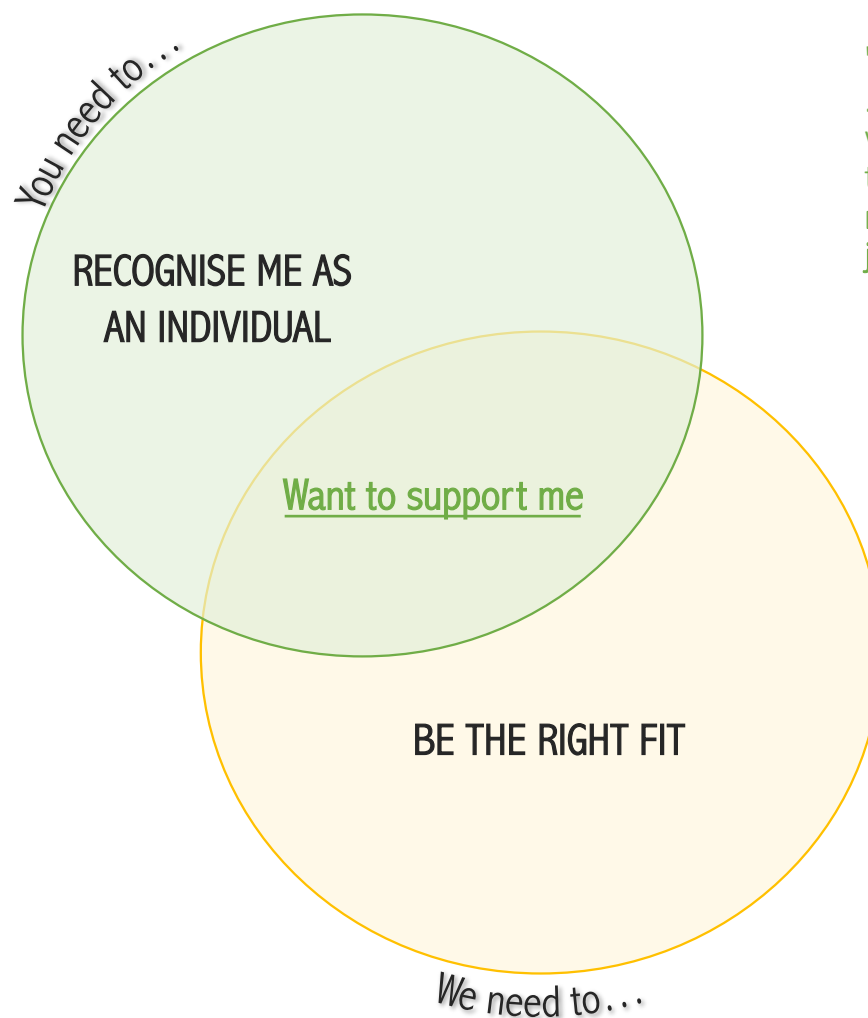

Institutional

Interactional

Individual

- 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…)*

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You need to...

I need to...

RECOGNISE ME AS AN INDIVIDUAL

FEEL IN CONTROL

QUALITY SUPPORT

BE THE RIGHT FIT

We need to...

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You need to...

RECOGNISE ME AS
AN INDIVIDUAL

Treat me as a person

"...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*
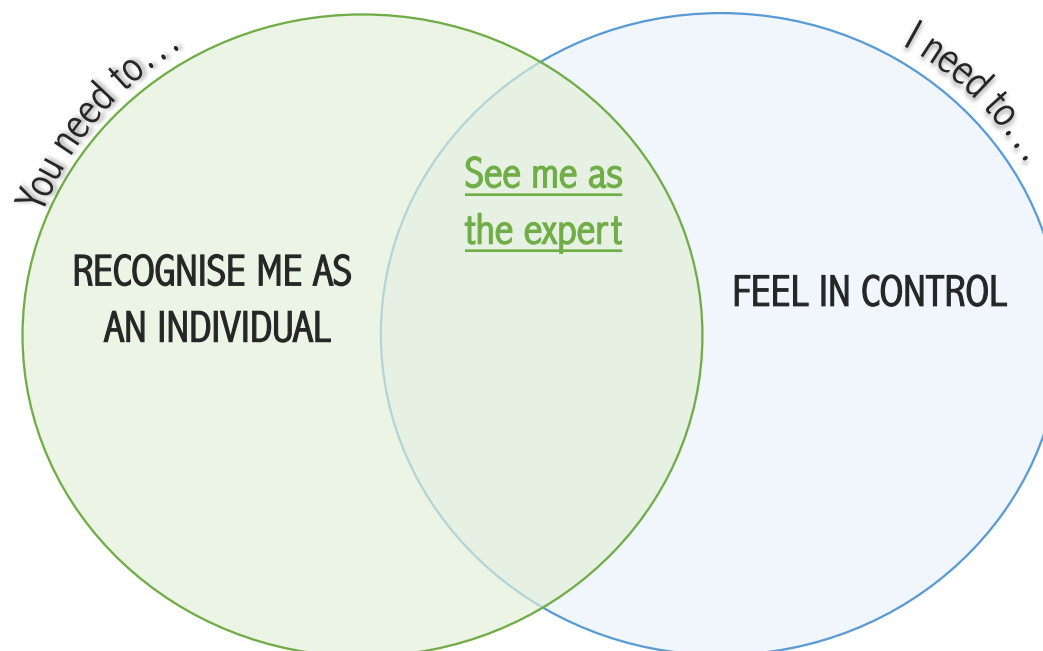
"They didn't know your name, treat you like you're just a body in a bed ... **Here they treat you like a person, they ask you what you want**. It makes you feel a lot better." *Charlie*

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You need to...

RECOGNISE ME AS
AN INDIVIDUAL

Want to support me

BE THE RIGHT FIT

We need to...

"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*

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You need to...

I need to...

RECOGNISE ME AS
AN INDIVIDUAL

See me as
the expert

FEEL IN CONTROL

"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*

"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*

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You need to...

I need to...

RECOGNISE ME AS AN INDIVIDUAL

Respond to my needs

FEEL IN CONTROL

"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." *Kelly*
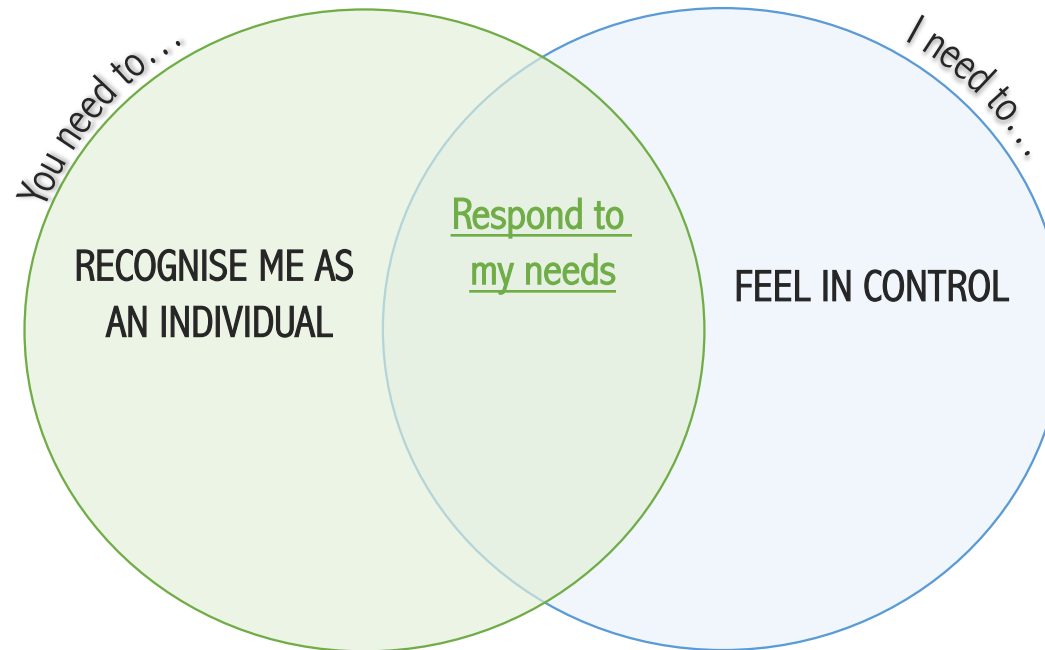
"be helpful when you can see that I need some of your support." *Isabella*

"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." *Lauren*
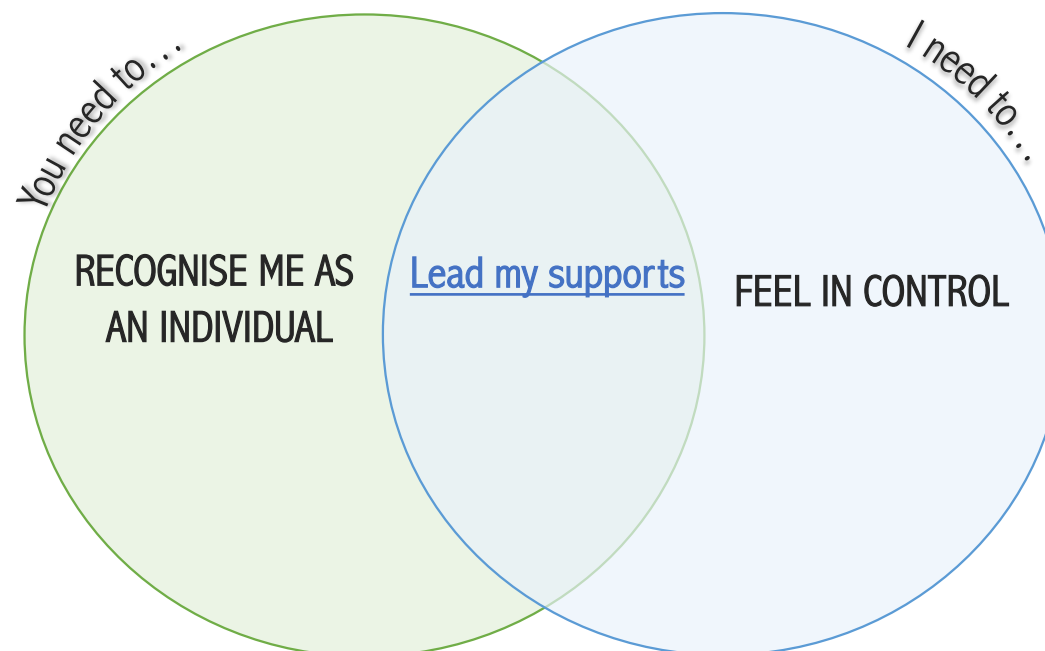
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Support worker skills and attributes

You need to...

RECOGNISE ME AS AN INDIVIDUAL

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*

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I need to...

FEEL IN CONTROL

Have authentic choice

"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*
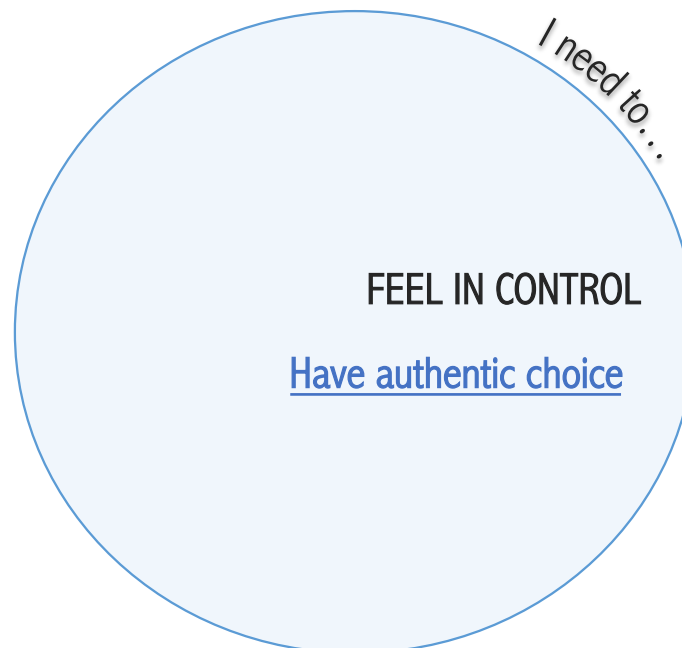
"'cause **nobody should be able to choose support workers that I want to have** and bringing a couple along for me to give approval for. It shouldn't be that way, it should be me to approve in the interview and me to approve them, whether they are good enough..." *Darren*

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You need to...

RECOGNISE ME AS AN INDIVIDUAL

Lead my supports

FEEL IN CONTROL

I need to...

"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*

"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*

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"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."
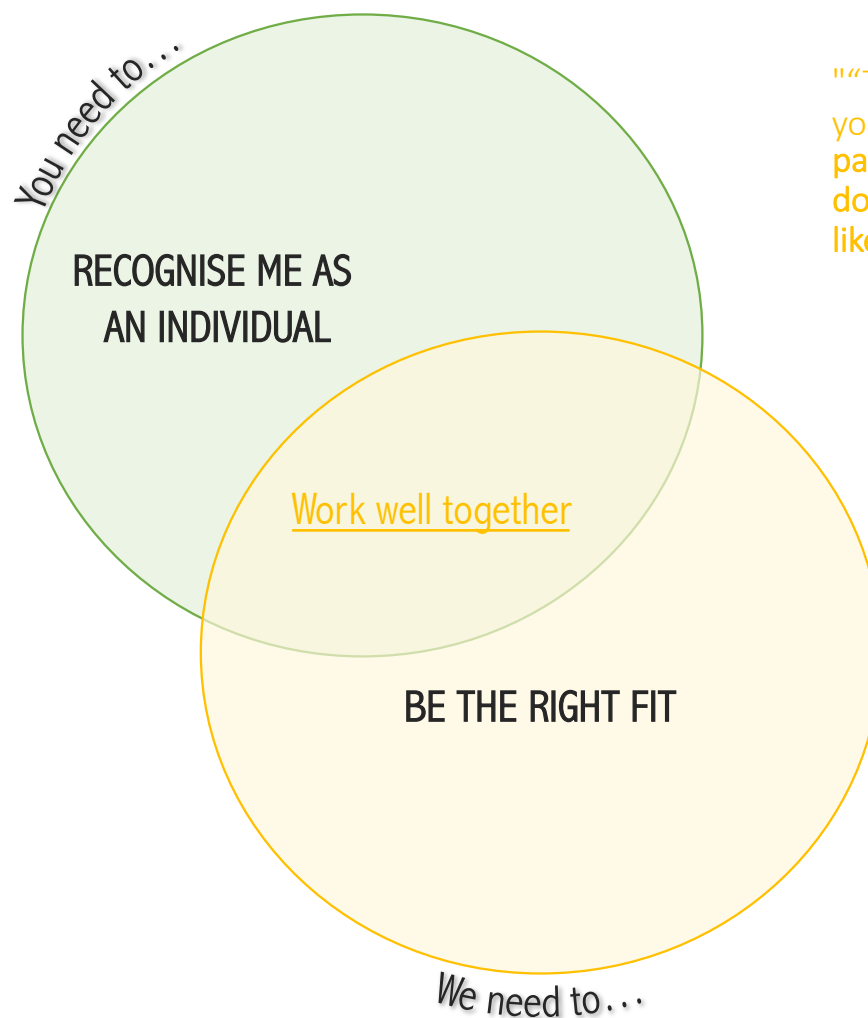*Georgie*

BE THE RIGHT FIT

Be compatible

We need to...

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I need to...

FEEL IN CONTROL

"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*

Get the
balance right

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

BE THE RIGHT FIT
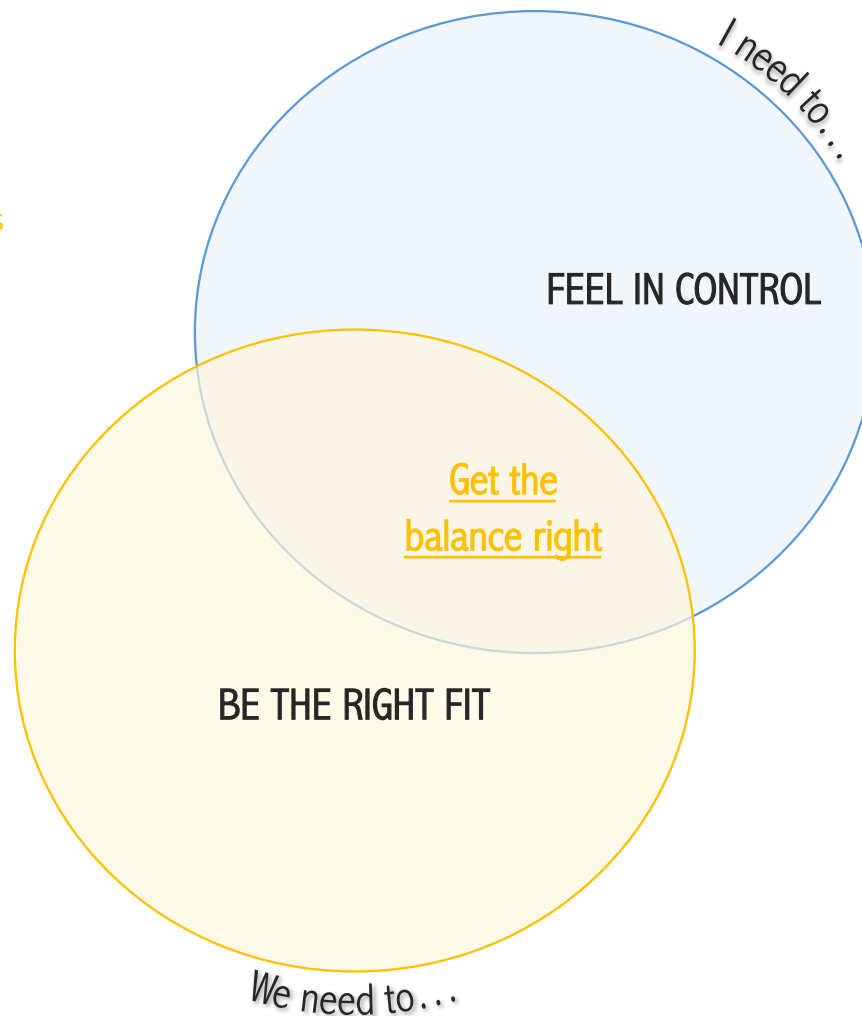
"it's really, really hard when, you know, if I've got this one carer four days a week for the next 10 months, **it's really hard not to make a – make a relationship out of it. And where do you cross the line, you know?**" *Will*

We need to...

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You need to...

RECOGNISE ME AS
AN INDIVIDUAL

Work well together

BE THE RIGHT FIT

We need to...

""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*

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Support worker skills and attributes

BE THE RIGHT FIT
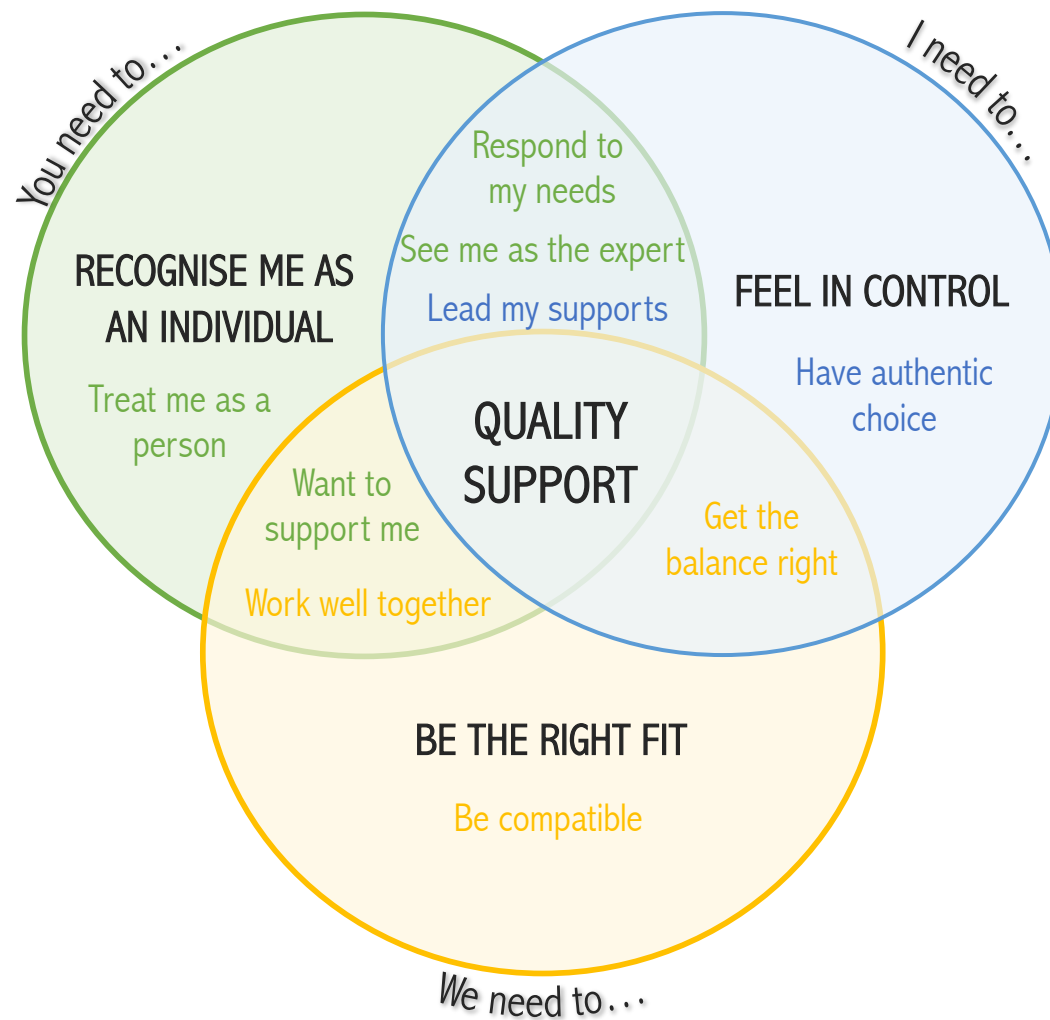
We need to...

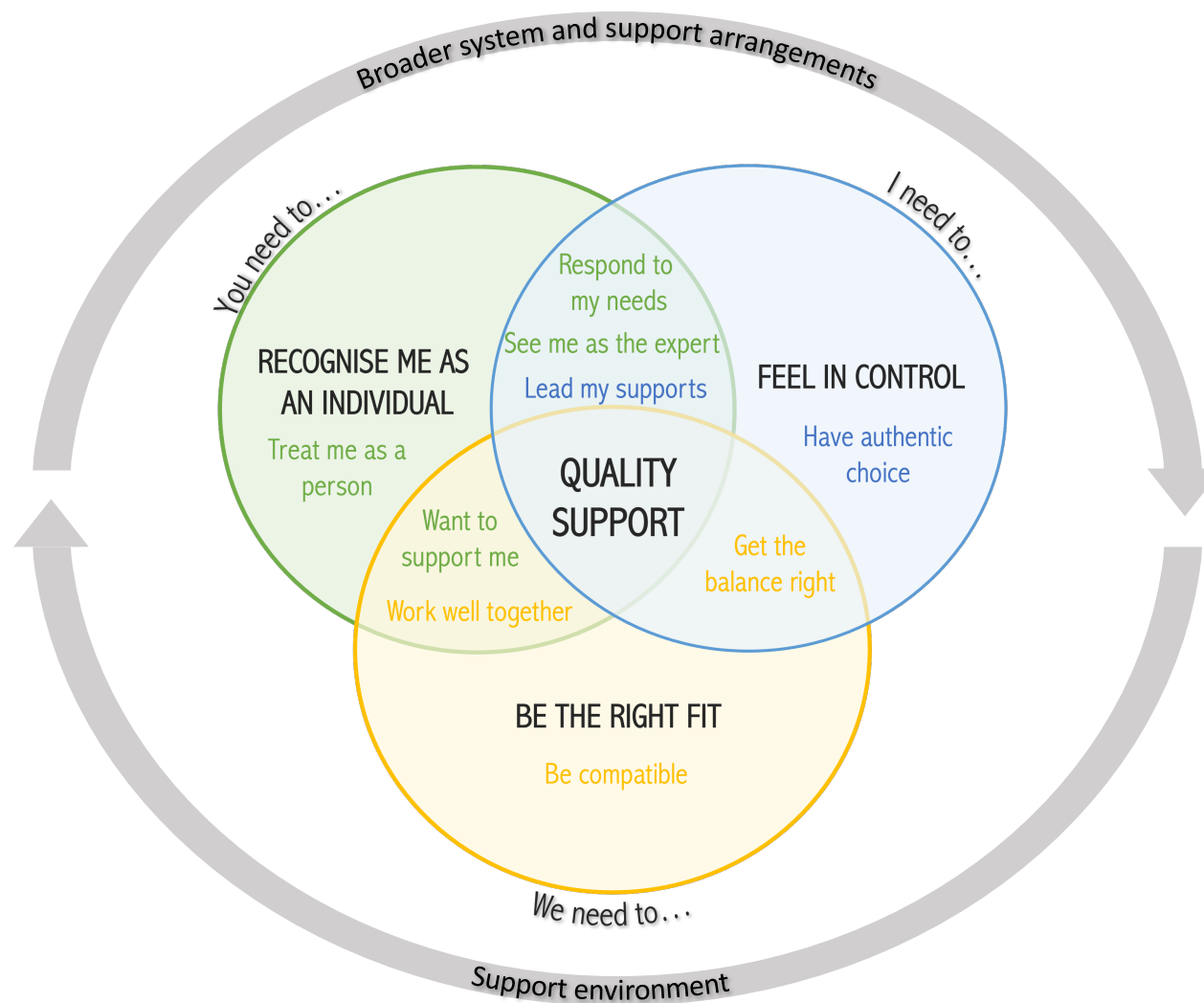**Be compatible** — *Open; personable; sense of humour; easy to talk to*

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

Work well together — *Respectful; patient; effective communicator; willing to compromise*

You need to...

I need to...

RECOGNISE ME AS AN INDIVIDUAL

FEEL IN CONTROL

Respond to my needs

See me as the expert

Lead my supports

Have authentic choice

Treat me as a person

QUALITY SUPPORT

Want to support me

Get the balance right

Work well together

BE THE RIGHT FIT

Be compatible

We need to...

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Broader system and support arrangements

You need to…

I need to…

RECOGNISE ME AS
AN INDIVIDUAL

Treat me as a
person

Respond to
my needs

See me as the expert

Lead my supports

FEEL IN CONTROL

Have authentic
choice

QUALITY
SUPPORT

Want to
support me

Work well together

Get the
balance right

BE THE RIGHT FIT

Be compatible

We need to…

Support environment

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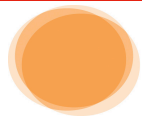All kinds of clever

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

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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

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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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