

“They treat you like a person, they ask you what you want”

New study identifies factors influencing the quality of paid disability support

Support workers provide assistance across a range of activities, including daily and domestic living tasks, employment, housing and community participation. However, in Australia the support workforce is heavily casualised and under-trained, which can have negative impacts for people with disability. Furthermore, there is a lack of evidence on what constitutes ‘best practice’ in the area of disability support.

A study by La Trobe University and Summer Foundation asks people with disability what they want in a support worker. The research reveals the most important qualities of a ‘good’ support worker, which should be used to inform future policy and practice in the area.

What is the context?

In Australia, at least 5% of people have a cognitive impairment due to developmental or neurological disability and are likely to require support to live and participate in the community.

Paid support is primarily provided by a disability support worker. The support worker role is to assist and build the capacity of people with disability. The role involves providing help across a range of activities, including daily and domestic living tasks, employment, housing and community participation. The role of support workers is complex, and yet there are limited opportunities for the workforce to train and gain additional competence.

What is the problem?

The National Disability Insurance Scheme (NDIS) aims to increase choice and control for people with disability by providing access to tailored support packages. This shift to individualised funding has meant that the support worker workforce is highly casualised. In turn, this lack of structure leads to under-trained workers, high turnover, and potential risks to people with disability as a result.

The lack of support worker training is compounded by the lack of clarity about what quality support looks like in practice.

To date, few studies have directly investigated the factors that influence the quality of support from the perspective of adults with acquired neurological disability. To better conceptualise quality support, it is vital to understand the lived experience of people receiving paid support and what they want in a support worker.

What was the study’s goal?

This study aims to obtain the perspective of people with acquired neurological disability on the factors that influence the quality of support. It is the first in a series of studies developing a holistic understanding of quality support, grounded in the lived experience of people with disability, close others and support workers.

Main findings

In-depth interviews were conducted with 12 adults with acquired neurological disability. Data analysis followed an iterative process to understand the factors that underpin quality support. Broadly, these fell under 3 categories:

1. What the support worker needs to do
2. What the person with disability needs to do
3. What both need to do together

What do support workers need to do?

Of most prominence was what the support worker needs to do, with 'recognising the person as an individual' emerging as fundamental to the realisation of all other factors. Further, the support worker must:

- Want to support the person
- Treat them as a person
- See them as the expert
- Respond to their needs

What do people with disability need to do?

In order to maximise their choice and control, people with disability need to be empowered to *take control over and lead their supports*:

"I have made the decision to take control of hiring and firing my staff ... I'm going to do it myself."

–Lauren*

"I do all the rostering and the choosing of who comes and when they come, which is great."

–Alex*

**Pseudonym has been used*

What do support workers and people with disability need to do together?

Together, the person with disability and the support worker need to be the right fit and work well together.

Implications for policy and practice

To provide quality support, disability support workers need to recognise the person with disability as an individual and the expert in their support needs and preferences.

The quality of paid disability support is primarily determined by the way the person with disability and support worker work together.

Ensuring people with acquired neurological disability have authentic choice over their support arrangements and daily living is critical to facilitate quality support, and in turn help the person with disability to feel in control.

Notes

1. Topping, M., Douglas, J., & Winkler, D. (2022). "They treat you like a person, they ask you what you want": A grounded theory study of quality paid disability support for adults with acquired neurological disability. *Disability and Rehabilitation*. <https://www.tandfonline.com/doi/full/10.1080/09638288.2022.2086636>

