

# ***“You’re supporting the whole person”***

## **A grounded theory study of quality support according to close others of people with neurological disability**

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### **Overview**

What close others (e.g. family or partners) of people with disability value in quality disability support was explored by La Trobe University and the Summer Foundation. A new peer-reviewed article presents qualitative findings of interviews with 10 close others of adults with neurological disability and complex needs<sup>1</sup>. Close others identified the importance of support workers recognising the person as an individual, as well as the person with disability and their support worker working well together. In addition, close others highlighted the impact of the broader support team and the accountability of the wider sector on quality support provision.

### **What is the context?**

Acquired neurological disabilities can have significant impact on a person’s physical, cognitive and communication capacity. Consequently, many adults with acquired neurological disability require quality paid disability support to live the life they want to live. In Australia, the National Disability Insurance Scheme (NDIS) was introduced in 2013 with the promise of reforming the disability sector and creating a market-based support system centring on the needs and preferences of people with disability<sup>2</sup>. However, almost 10 years on there is still limited data from the perspective of those with lived experience as to what people want from disability support.

### **What is the problem?**

Disability support is costing the Australian public upwards of \$27 billion per annum<sup>3</sup>, yet the quality of support provided by NDIS funded workers varies a great deal. For the scheme to achieve its objectives, there is a need to better understand what good disability support looks like and improve the quality and consistency of the support delivered to people with disability in Australia. Considering the often complex needs of people with neurological disability, close others (e.g., family or partners) often play a substantial role in supporting their family member to access and manage their disability supports. Consequently, close others tend to have valuable insights and perspectives on what constitutes quality disability support.

### **What was the study’s goal?**

- To understand the experiences and perspectives of close others on what facilitates quality paid disability support.
- To gain a better understanding of the experiences and perspectives of people with complex needs who are unable to participate in an interview about quality support provision.

## What are the main findings?

A multi-level system model characterising quality support was developed from analysing the 10 interviews with close others. The key factors facilitating quality support were situated in the dyadic level, that is, the interactive space between the person with disability and their support worker. Fundamentally, the support worker needs to recognise the person as an individual and the dyad needs to work well together. At the support team level, close others deemed it important for the support team, close others, and support providers to engage constructively together. Finally, at the disability sector level, building quality systems to develop the support workforce was identified by close others as essential to quality support provision.



## What are the policy implications?

The findings complement the perspective of people with disability and disability support workers in our earlier studies<sup>4,5</sup> and support the key notion of quality support honouring the person's autonomy. This study also highlights the pressing need to raise the standards and expectations of the disability support sector. This research highlights the demand for micro-credentials for specific technical competencies, and support workers coming prepared to engage in personalised training, rather than relying on broad formal qualifications. These findings, alongside our earlier studies<sup>4,5</sup>, should be used as a foundation for co-design work to produce resources that assist with navigating support systems, screening, training workers and managing support teams.

## Notes

1. Topping et al. (2022). "You're supporting the whole person": A grounded theory study of quality support according to close others of people with neurological disability. *Neuropsychological Rehabilitation*. <https://doi.org/10.1080/09602011.2022.2153149>
2. National Disability Insurance Scheme Act 2013, Pub. L. No. C2013A00020, 180 (2013).
3. National Disability Insurance Agency. (2022). *NDIS Quarterly Report to disability ministers - March 2022*.
4. Topping et al. (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://doi.org/10.1080/09638288.2022.2086636>
5. Topping et al. (2022). "Let the people you're supporting be how you learn": a grounded theory study on quality support from the perspective of disability support workers. *Disability and Rehabilitation*. <https://doi.org/10.1080/09638288.2022.2148300>