

Building an evidence-based multi-level system of quality disability support for adults with acquired neurological disability

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What is the context?

People with acquired neurological disability experience a range of physical, cognitive, and communication impairments, and in turn often require paid support provided by a disability support worker. People with disability have the right to receive quality disability support to help them to live the life they want to live.

Encouragingly, these rights were stipulated by the UN Convention on the Rights of Persons with Disabilities in 2006¹. In Australia the National Disability Insurance Scheme (NDIS) was introduced in 2013 aiming to provide people with disability access to the support they need². However, disability support is costing the Australian public upwards of \$27 billion per annum³, yet the quality of support provided by NDIS funded workers varies a great deal.

What is the problem?

Despite the importance of paid support for many adults with acquired neurological disability, there is limited evidence from the perspective of people with lived experience of support as to what facilitates quality support. Promisingly, in Australia, the NDIS has transformed the landscape of disability support services in the past decade, ushering in a new era of individualised funding and person-centred support^{2,4}. However, the recent Disability Royal Commission, alongside inquiries into NDIS complaints, have evidenced the risks associated with poor quality support and in turn, the extent of work needed to ensure quality services^{5,6}.

What was the study's goal?

This study aimed to develop a comprehensive understanding of the factors that influence the quality of paid disability support for adults with acquired neurological disability. The key objective was to bring the perspectives of people with acquired neurological disability⁷, disability support workers⁸, and close others of people with complex needs⁹ together to construct a holistic model of quality support grounded in lived experience.

What are the main findings?

The model of quality support captures several interconnected themes across multiple levels including the interaction between the person with disability and their support worker (the dyadic space), individual support workers, the support team, service providers, and finally the broader context encompassing the sector, system and society. Most importantly, people with disability need to have authentic choice and the opportunity to lead their support.

Support workers must recognise the person with disability as an individual and the expert in their own needs and preferences. It is crucial that support workers are doing the role for the right reasons, are willing to learn, and engage in reflective practice. It is also important that support teams work well together, and service providers are engaged and responsive to the needs of the person with disability. Finally, there is a need for greater accountability and improved working conditions across the sector to attract and retain quality workers and improve the overall quality of the workforce.

What are the policy implications?

This research indicates the need for tools and resources to support people with disability to recruit, train, and manage their support workers. Moreover, resources are needed to assist support workers in engaging in reflective practice and maintaining accountability.

To ensure these tools and resources are useful, it is paramount that they are co-designed and co-produced with people with lived experience. We also recommend the co-production of a measure designed to evaluate the quality of support provided by support workers.

This measure could be used by people with disability to help manage their workers, by support workers to assist with reflective practice, and also to objectively assess the impact of practice and policy initiatives on support quality. Moreover, opportunities for training and professional development are required to develop the workforce, specifically we recommend micro-credentials and targeted funding available for people with disability to facilitate appropriate opportunities for their support workers.

Finally, this research highlights the need for better remuneration regulation in the support workforce, and a better community understanding of the diversity and value of the support worker role.



References

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