

Topping, Megan^{1,2}, Douglas, Jacinta^{1,2} and Winkler, Di^{1,2}

¹ Living with Disability Research Centre, La Trobe University, Melbourne, VIC, Australia; ² Summer Foundation, Melbourne, VIC, Australia

BACKGROUND AND OBJECTIVES

Adults with acquired neurological disability often experience severe cognitive, communication and physical impairments and rely on paid disability support to live an ordinary life. Theoretically, individualised funding schemes empower people with disability (PWD) to choose high quality support services that meets their needs and preferences. However, little is known about what influences the quality of support. **The aim of this research is to understand the factors that influence the quality of paid disability support for adults with acquired neurological disability.**

METHODS

Scoping review



A comprehensive scoping review framework^{1,2,3} was applied to answer the research question:

What are the factors that influence the quality of paid disability support for adults with acquired neurological disability?

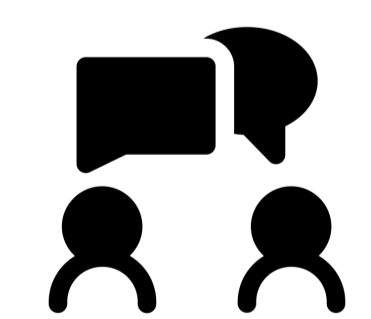
SEARCH STRATEGY

- Search concepts: *acquired disability AND paid disability support*
- Databases: MEDLINE, CINAHL, PsycInfo, Scopus and Embase

ELIGIBILITY CRITERIA

- Peer reviewed, English language, primary research published 2009-2019
- Population: adults with acquired neurological disability, close others, DSWs
- Extractable data on the factors that influence the quality of support
- Studies focused on mild disability, informal support or support from healthcare professionals

In-depth interviews



To characterise the factors that influence the quality of support grounded in the lived experience of adults with acquired neurological disability

- Constructivist grounded theory⁴
- Semi-structured 1:1 interviews via Zoom or telephone
- Adults with acquired neurological disability
- Analysis: initial and focused coding, using constant comparison

RESULTS

Scoping review

- 3391 records (after duplicates) □ 83 full-texts assessed
- 16 qualitative articles included in the review
- Varying research aims e.g. disability support worker (DSW) and PWD relationship, DSW work stress, comparing formal and informal support. Only 3 studies focused directly on quality of support.
- 519 participants across all papers including adults with acquired neurological disability, close others, DSWs, service providers and informal carers.
- Thematic analysis revealed six key themes with 18 subthemes:



CHOICE AND CONTROL

Choosing and managing support
PWD involved in decision making
Chance to use own capacity



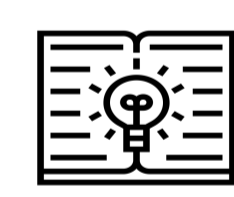
INDIVIDUALISED SUPPORT

Person-centred approach
Responsiveness to needs
Meeting language and cultural needs



DSW QUALITIES

Willingness to listen and learn
Empathy and understanding
Respect



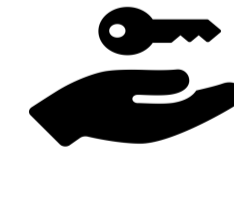
DSW COMPETENCE

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

We engaged with an expert consultant, who has lived experience of disability, for feedback on the scoping review findings:



- Accurate reflection of the support experience for PWD

- Missing from review: Accountability of DSW
Broader systemic context impacting support

Preliminary in-depth interview findings

- 10 adults with acquired neurological disability
- Early analysis reveals **three key foundational factors** to quality disability support, with emphasis on the PWD and DSW relationship...

1. WANTING TO BE A DSW

"I would want someone that wants to actually be a carer as their job. Like don't just use it as a filling employment" P07

"it was, like, not actually listening to what I was trying to say, it was just assuming what I was trying to say. And it drove me mad." P04

2. LISTENING TO ME

"and I really don't care what [qualifications] she's got. I care about how we gelled" P08

3. BEING COMPATIBLE

CONCLUSIONS

- The quality of paid disability support is determined by a complex mix of interrelated factors, and preliminary interview findings suggest there are some necessary foundational factors.
- The identified factors thus far are consistent with international legislation on the rights of people with disability, policy ideals and individualised funding principles.
- Further interviews and in-depth analysis will help us understand
 - how the factors intersect,
 - the weighting of the factors, and
 - how to implement these ideals in practice.

SCOPING REVIEW REFERENCES

- Ahlström, G., & Wadensten, B. (2012). Enjoying Work or Burdened by it? How Personal Assistants Experience and Handle Stress at Work. *Journal of Social Work in Disability and Rehabilitation*, 11(2), 112–127.
- Ahlström, G., & Wadensten, B. (2011). Family members' experiences of personal assistance given to a relative with disabilities. *Health and Social Care in the Community*, 19(6), 645–652.
- Ahlström, G., & Wadensten, B. (2010). Encounters in close care relations from the perspective of personal assistants working with persons with severe disability. *Health and Social Care in the Community*, 18(2), 180–188.
- Bourke, J. A. et al. (2019). Relationships and the transition from spinal units to community for people with a first spinal cord injury: A New Zealand qualitative study. *Disability and Health Journal*, 12(2), 257–262.
- Braaf, S. C. et al. (2018). Experiences of hospital readmission and receiving formal carer services following spinal cord injury: a qualitative study to identify needs. *Disability and Rehabilitation*, 40(16), 1893–1899.
- Cornwell, P. et al. (2009). Supporting the needs of young adults with acquired brain injury during transition from hospital to home: The Queensland service provider perspective. *Brain Impairment*, 10(3), 325–340.
- Fadyl, J. K. et al. (2011). Perspectives on quality of care for people who experience disability. *BMJ Quality and Safety*, 20(1), 87–95.
- Gridley, K. et al. (2014). Good practice in social care: The views of people with severe and complex needs and those who support them. *Health and Social Care in the Community*, 22(6), 588–597.
- Martinsen, B., & Dreyer, P. (2012). Dependence on care experienced by people living with duchenne muscular dystrophy and spinal cord injury. *Journal of Neuroscience Nursing*, 44(2), 82–90.
- McPherson, K. M. et al. (2014). Improving the interface between informal carers and formal health and social services: A qualitative study. *International Journal of Nursing Studies*, 51(3), 418–429.
- Mitsch, V. et al. (2014). The provision of brain injury rehabilitation services for people living in rural and remote New South Wales, Australia. *Brain Injury*, 28(12), 1504–1513.
- Nilsson, C. et al. (2016). Meanings of balance for people with long-term illnesses. *British Journal of Community Nursing*, 21(11), 563–567.
- Pettersson, I., & Fahström, G. (2010). Roles of assistive devices for home care staff in Sweden: A qualitative study. *Disability and Rehabilitation: Assistive Technology*, 5(5), 295–304.
- Wadensten, B., & Ahlström, G. (2009). Ethical values in personal assistance: Narratives of people with disabilities. *Nursing Ethics*, 16(6), 759–774.
- Wadensten, B., & Ahlström, G. (2009). The struggle for dignity by people with severe functional disabilities. *Nursing Ethics*, 16(4), 453–465.
- Yeung, E. Y. W. et al. (2016). Satisfaction with social care: the experiences of people from Chinese backgrounds with physical disabilities. *Health and Social Care in the Community*, 24(6), e144–e154.

For further information, please refer to the published scoping review:

Topping, M., Douglas, J., & Winkler, D. (2020). Factors that influence the quality of paid support for adults with acquired neurological disability: scoping review and thematic synthesis. *Disability & Rehabilitation*, 1–19. <https://doi.org/10.1080/09638288.2020.1830190>

Other references: ¹Arksey, H. & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *Int J Soc Res Methodol*, 8(1), 19–32. ²Levac, D. et al. (2010). Scoping studies: Advancing the methodology. *Implement Sci*, 5(69), 1–9. ³Tricco et al. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Ann Intern Med*, 169(7), 467–473. ⁴Charmaz, K. (2014). *Constructing grounded theory* (2nd ed). Sage Publications.

Acknowledgement: This work was supported by a grant made available by Summer Foundation. We wish to acknowledge Mr Jonathan Bredin, our expert consultant, who provided valuable insights interpreting the results of the review. Icons created for Noun Project by Vectors Point, Larea, B Farias, Blake Thompson, Eucalypt, Wichai Wi, Sumit Saengthong, Adrien Coquet & Larea (left to right).