Constructing grounded theory (2nd ed.).

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


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 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 theory
- 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 adults with acquired neurological disability. From healthcare professionals and informal carers. Only 3 studies focused directly on quality of support.

- We wish to acknowledge Mr Jonathan Bredin, our expert consultant, who provided valuable insights interpreting the results of the review.

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 ideas in practice.

SCOPING REVIEW REFERENCES


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We wish to acknowledge Mr Jonathan Bredin, our expert consultant, who provided valuable insights interpreting the results of the review.