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# All kinds of clever

**Understanding the factors that influence the quality of paid disability support for adults with acquired neurological disability and complex needs: a scoping review and thematic synthesis**

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# Outline of Presentation

**Setting the scene**

**Research aims**

**Methodology**

**Review findings**

**Thematic synthesis**

**Expert consultation**

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# Setting the scene

- Individualised funding - NDIS
- Person-centred support
- International rights legislation (UN-CRPD)
- Paid disability support is often key to living an ordinary life and exercising fundamental human rights.

# Disability support worker role

- Build the capacity of PWD to make own lifestyle choices, participate in the community and achieve their self-described goals
- Range of responsibilities
- Range of employment arrangements
- Disability support workforce problems:
  - High turnover
  - Low value in role
  - Little barrier to entry (qualifications or experience)
  - Limited training or formal performance monitoring

# Population

## PEOPLE WITH ACQUIRED NEUROLOGICAL DISABILITY

- ABI, stroke, spinal cord injury, multiple sclerosis, Huntington's disease
- Severe and profound core activity limitations
- Cognitive, communication and physical impairments
- Distinct from intellectual disability

# Need for the proposed research

- Support is integral to quality of life and health outcomes (AIHW, 2017)
- More demands on workforce within individualised funding schemes – training initiatives
- Limited guidance for people with disability to navigate support systems
  - PWD may prioritise relatability over capacity, qualifications or experience (Harry et al. 2017)
  - Mixed evidence around whether a better relationship = higher quality support (Miller & Opie, 1987; McCluskey, 2000; Opie & Miller, 1989)
- Critical to build the evidence base around what facilitates high quality support

# Research Aim



To examine the existing peer-reviewed literature around the factors that influence the quality of paid disability support for adults with acquired neurological disability from the perspective of:

- people with acquired neurological disability,
- close others, and
- the disability workforce.

Protocol published BMJ Open 2019

Topping M, Douglas J, Winkler D. Understanding the factors that influence the quality of paid disability support for adults with acquired neurological disability and complex needs: a scoping review protocol. BMJ Open. 2019 Dec 29;9:e034654. <https://doi.org/10.1136/bmjopen-2019-024654>

# Search strategy

- Five databases: MEDLINE, CINAHL, PsycINFO, Scopus & Embase
- Two concepts:

1. Acquired disability

*brain injuries (MeSH), head injuries, penetrating (MeSH), cerebral haemorrhage (MeSH), brain injur\*, intracranial injur\*, TBI, ABI, cognitive dysfunction (MeSH), cognitive disorders (MeSH), cognitive impairment, cognitive disab\*, acquired disab\*, communication disab\*, severe disab\*, profound disab\*, stroke (MeSH) AND young adult, multiple sclerosis (MeSH), cerebral palsy (MeSH), spinal cord injuries (MeSH), huntington's disease (MeSH)*

2. Paid support

*disability support, disability work\*, support work\*, attendant care\*, paid care\*, paid support\*, support staff, care assistant, direct support\*, home care\*, professional support\*, active support\*, social care, home health aide, quality adj2 support, quality adj2 care*

# Eligibility criteria

- Inclusion criteria
  - Published 2009 – 2019, English language, all study designs
  - Peer-reviewed journal articles with extractable data on the factors that influence the quality of support for people with acquired neurological disability
  - Research population: adults (18-65) with acquired neurological disability; close others; disability workforce
- Exclusion criteria (added during screening)
  - Reporting only on informal support (e.g. from family or friends)
  - Focused on mild disability, or less than 30% population eligible for review
  - Population not described sufficiently
  - Only inpatient or palliative care

# Study selection process

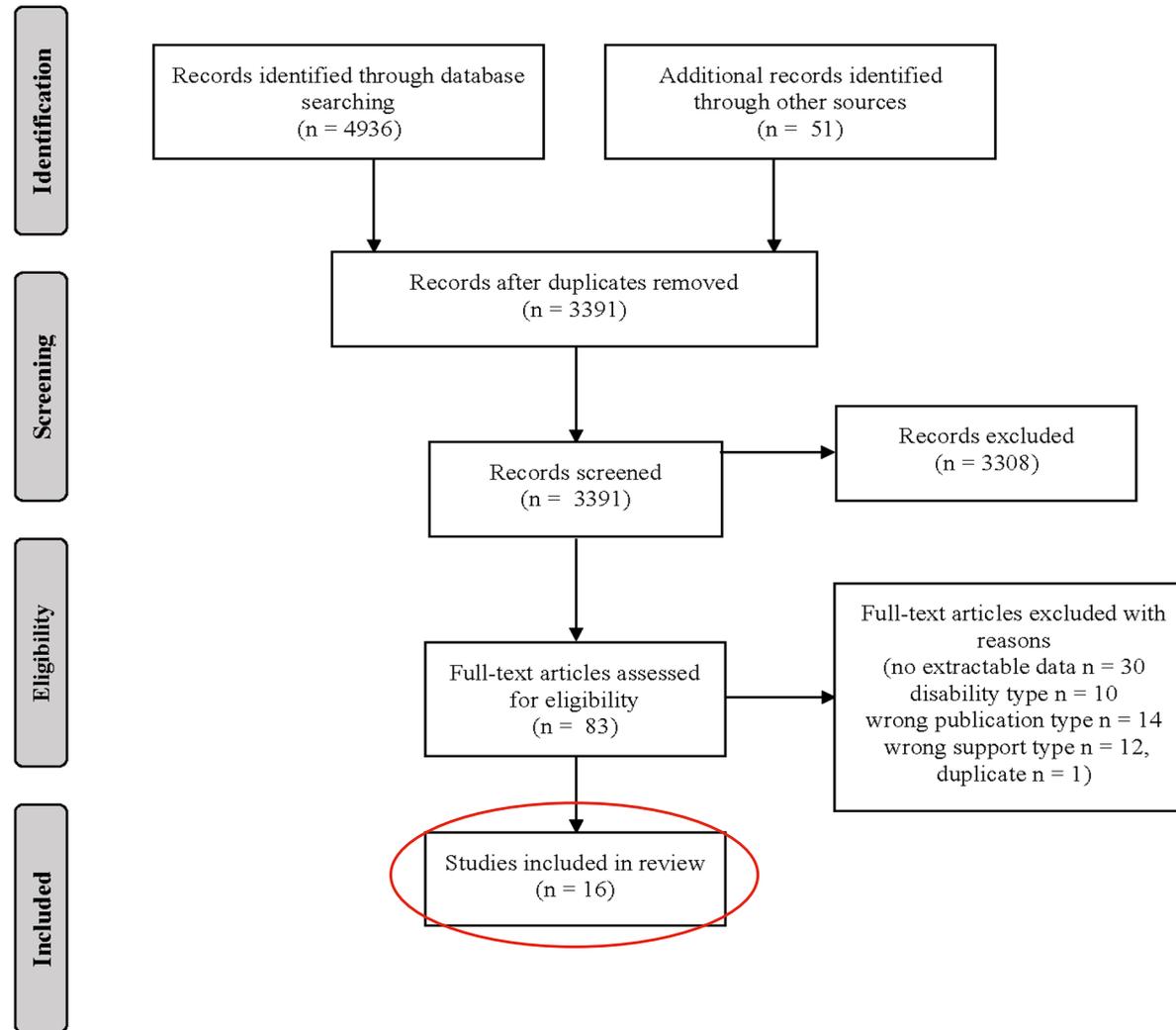


Figure 1. PRISMA flow diagram

# Review findings

## STUDY CHARACTERISTICS

- Sweden (7); Australia (3); New Zealand (3); United Kingdom (2); Denmark (1)
- Publication years: 2009-2019
- Qualitative: direct interviews (15); focus groups (3); surveys (1); observation (1)
- Varying aims
- Perspective of people with disability (10), DSWs (7), informal supports (2), family members (3)

## PARTICIPANT CHARACTERISTICS

- 519 participants across all studies (ranged 12-72)
- Disability types: ABI; stroke; spinal cord injury; cerebral palsy; MS; other neurological disorders
- Support needs: 4-24 hours per day, 3-41 months prior to the study

# Thematic synthesis: Method

Thomas & Harden's three stage thematic analysis:

1. Line by line descriptive coding
2. Descriptive codes → descriptive themes
3. Descriptive themes → more conceptual understanding in relation to review question

# Thematic synthesis: Findings

- Six key interrelated themes with 18 subthemes
- *Choice and control* emerged as the overarching theme
- Most factors were endorsed by all three perspectives

SIX KEY THEMES	18 SUBTHEMES	PWD	CO	DSW
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 competencies	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	✓✓	✓✓	✓

# Key themes

## CHOICE & CONTROL

	PWD	CO	DSW	U/S
• <i>Choosing &amp; managing support</i>	✓✓✓✓	✓	✓	
• <i>Being involved in decision making</i>	✓✓✓✓✓✓	✓	✓	✓
• <i>Using own capacity</i>	✓✓	✓	✓	

*“Well yeah, I mean it’s about you isn’t it? It’s about your life, you know, it’s about what’s important to you, and it’s a process, I mean for some people there is a feeling of loss of power.” (Person with disability in Fadyl et al., 2011)*

# Key themes

## INDIVIDUALISED SUPPORT

	PWD	CO	DSW	U/S
• <i>Person-centred approach</i>	✓✓✓✓✓	✓✓		✓
• <i>Responsiveness to needs</i>	✓✓✓✓✓✓	✓✓✓	✓✓	
• <i>Meeting language and cultural needs</i>	✓✓			

*“Participants instead argued for flexible care pathways, imaginative approaches to assessments and to be able to alter support arrangements once in place. This is particularly important because when needs are complex, it can be difficult to foresee which arrangements will work best.”*

(DSW in Gridley et al., 2014)

# Key themes

## DISABILITY SUPPORT WORKER QUALITIES

	PWD	CO	DSW	U/S
• Willingness to listen & learn	✓✓✓✓✓	✓✓		✓
• Empathy & understanding	✓✓✓✓	✓✓	✓	
• Respect	✓✓✓	✓	✓✓	

*“I’ve really appreciated receiving what I felt was really good care from someone with a true attitude that they wanted to help me, and they actually really cared about the outcome of that care, and then the details didn’t matter so much. I could inform them along the way if they were doing something that wasn’t quite appropriate or whatever, but it was really that attitude.” (Person with disability in Fadyl et al., 2011)*

# Key themes

## DISABILITY SUPPORT WORKER QUALITIES

	PWD	CO	DSW
• <i>Willingness to listen</i>	✓✓✓✓✓	✓✓	
• <i>Understanding</i>	✓✓✓	✓✓	✓
• <i>Empathetic</i>	✓✓✓	✓	✓✓
• <i>Respectful</i>	✓✓✓	✓	✓✓
• <i>Patient</i>	✓		✓✓
• <i>Flexible</i>			✓✓
• <i>Reliable</i>	✓✓		
• <i>Optimistic</i>			✓
• <i>Considerate</i>			✓
• <i>Trustworthy</i>		✓	✓
• <i>Creative</i>			✓
• <i>Perceptive</i>			✓
• <i>Focused</i>	✓		
• <i>Friendly</i>	✓		

# Key themes

## DISABILITY SUPPORT WORKER COMPETENCE

	PWD	CO	DSW	U/S
• Knowledge, training and experience	✓✓	✓✓	✓✓	✓✓✓
• Practical skills	✓✓✓	✓	✓✓	✓

*“knowledge about spinal cord injuries is needed: hygiene, infection control... Just knowledge, understanding, skill development, self-development...”* (Person with disability in Braaf et al. 2017)

# Key themes

## PWD – DSW RELATIONSHIP

	PWD	CO	DSW	U/S
• <i>Personal chemistry</i>	✓✓✓	✓	✓✓	
• <i>Knowing the individual</i>	✓✓✓✓✓✓	✓✓		
• <i>Trust</i>	✓✓✓	✓	✓	
• <i>Boundaries &amp; friendship</i>	✓✓✓✓✓✓	✓	✓✓	

*“I need to have somebody around that I can relate to on some level or other. Even though it’s a working relationship, the boundaries get very blurred between where work starts [and ends] and there needs to be some sort of personal relationship as well.” (Person with disability in Gridley et al., 2014)*

# Key themes

## ACCESSING CONSISTENT SUPPORT

	PWD	CO	DSW	U/S
• Continuity of support	✓✓✓✓✓✓✓✓	✓✓	✓	
• Funding	✓✓✓✓✓	✓	✓	
• Availability of support	✓✓	✓✓	✓	✓

*“And there is a different care worker every time so I never get any sense of continuity. They don’t seem very caring. They just come to do the job, and it isn’t a very human experience”*

(Person with disability in Yeung et al., 2015)

# Expert Consultation

## FEEDBACK ON FINDINGS

- Accurate reflection of the disability support work experience for people with disability
- Choice and control is crucial
- Striking the professional/personal balance is difficult in the relationship

## FACTORS MISSING FROM THE REVIEW

- Accountability of DSW – best practice and service provision
- Broader systemic context impacting support e.g.
  - Student placements – supervisor is considered the expert, not the PWD
  - PWD not recognised as credible referees by agencies or government
  - Ideologies of organisation can impact support

# Limitations

- Cannot infer a comprehensive model from the findings
- Only three studies aimed to understand the quality of support
- Potential for overgeneralisation
  - Six studies included broader populations
  - Five studies on the same cohort
- Excluded articles when it was difficult to establish the type of support
- No critical appraisal – cannot determine the weighting of the results

# Summary of findings

- Little research directly investigating the quality of paid disability support
- Complex mix of interrelated factors
- Factors are consistent with international legislation on the rights of people with disability, policy ideals and individualised funding principles
- Need further research to understand how the factors intersect and the weighting of factors in influencing the quality of support

# Future research implications

Need to better understand how to make the human rights legislation, funding principles and policies a day to day reality for people with disability and close others

## FURTHER RESEARCH QUESTIONS

- Do the attributes & competencies evident in this review predict quality support?
- What is the relative importance of the factors and how do they intersect?
- What are the priorities are for quality improvement?
- What are the systemic factors this review has not captured?

# Next steps

## FOCUS GROUPS

- To characterise the factors that influence the quality of paid disability support
- Grounded in the lived experience of adults with acquired neurological disability, close others and DSWs

## IN-DEPTH INTERVIEWS

- To explore the relationships between the factors that influence the quality of support
- To develop an understanding of the relative importance of each factor
- To identify quality support indicators (e.g. what quality support looks like in practice)

# Anticipated practical outcomes

## RESOURCES FOR PEOPLE WITH DISABILITY AND CLOSE OTHERS

- Guidance for recruiting and managing DSWs
- Performance monitoring guidance for monitoring the quality of support

## RESOURCES FOR DISABILITY SUPPORT WORKERS

- Training modules
- Guidance to improve working practices and overall performance
- Defining the desired characteristics to attract and select the appropriate workforce

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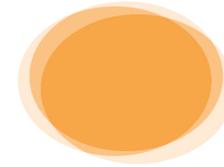
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**Thank you**

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