

Conceptualising Positive Relationships Between Disabled People and Support Workers:

What Works, for Whom, and in What Circumstances?

Johnny Bourke Ph.D.

Research Fellow - Implementation Science

John Walsh Centre for Rehabilitation Research

Johnny.bourke@sydney.edu.au



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BACKGROUND

- In New Zealand, approximately 24% of people live with disability¹
- In Canterbury, approximately 20% of the population live with disability²
- Disability support workers are **vital and necessary** for many people to³⁻⁶:
 - Mobilise
 - complete personal care
 - activities of daily living
 - participate in their communities
 - Enable whānau to live and function well

BACKGROUND

- **The disability support worker sector is complex³⁻⁶:**
 - Different people, different roles, different expectations
 - Different job roles, work environments
 - Different funding and employment arrangements
- **The disability support worker sector^{7,8} is under pressure:**
 - Support workers report they are undervalued and prone to burnout
 - Disabled people find it increasingly difficult to connect with ‘good’ support workers

BACKGROUND

- BAT has been conducting work in this space in recent years^{4,9,10}

Spinal Cord Series and Cases (2021)7:3
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ISCoS
 The International
 Spinal Cord Society



ARTICLE

Access to community support workers during hospital admission for people with spinal cord injury: a pilot study

Joanne L. Nunnerley^{1,2} · Rachele A. Martin^{1,3} · Matthew Aldridge¹ · John A. Bourke^{1,4,5} · Ian Simpson¹

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CLINICAL PRACTICE: CURRENT OPINION

The Lived Experience of Interdependence: Support Worker Relationships and Implications for Wider Rehabilitation

John A. Bourke¹

Burwood Academy Trust, Christchurch, New Zealand, Menzies Health Institute, Griffith University, Southport, Queensland, Australia and Preventive and Social Medicine, University of Otago, Dunedin, New Zealand

Email: johnny.bourke@burwood.org.nz

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Research Paper

Relationships and the transition from spinal units to community for people with a first spinal cord injury: A New Zealand qualitative study

John A. Bourke, PhD^{a,*}, Joanne L. Nunnerley, PhD^{a,b}, Martin Sullivan, PhD^{a,c}, Sarah Derrett, PhD^d

^a Burwood Academy of Independent Living, Private Bag 4708, Christchurch 8140, New Zealand

^b Department of Orthopaedic Surgery and Musculoskeletal Medicine, University of Otago, Christchurch 8140, New Zealand

^c School of Social Work, Massey University, Palmerston North 4442, New Zealand

^d Injury Prevention Research Unit, Department of Preventive and Social Medicine, University of Otago, Dunedin 9054, New Zealand

BACKGROUND

Topping et al.^{11,12,13}

- That autonomy and ability for the disabled person to exercise choice and control is prioritised
- That context surrounding each person is unique circumstances is respected
- That those involved within relationships work constructively together.
- At the sector level, building quality systems to develop the work force emerged as essential.
- Highlighted the need to raise accountability in the disability sector

THIS STUDY

- This study employed a realist, participatory methodology to identify **the factors that influence the quality of community support** with three participant groups (disabled people, their whānau, and support workers)
- Data was collected via a short writing activity, and two face-to-face workshops for each participant group.
- Analysis focused of CMO configurations alongside tensions and resources
- July 2022 – July 2023
- Funding from Canterbury Medical Research Foundation
- Julianne Johns and Rachelle Martin

RESULTS

- Majority of participants had >5 years experience
- Majority of participants worked for/received agency
- Mix of conditions
- Whānau were a mix of parent/partner

	Plex (n=5)	Whānau (n=5)	SWs (n=6)
Age			
25-34	1	0	2
35-44	0	0	4
45-54	1	1	0
55-64	1	2	0
65+	2	2	0
Gender			
Male	2	0	1
Female	4	5	5
Years with/as a SW			
< 2	0	0	0
2-3	1	0	0
3-4	0	1	0
3-5	0	0	0
5+	4	4	5
Type of support			
Agency support	3	5	4
Private support	2	0	1
Both	0	0	1
Relationship type			
Parent	-	2	0
Partner	-	3	0
SW for Plex	-	3	0
Live with Plex	-	2	0
Have whanau as SW	1	-	-

RESULTS

Workshop one (Dec 22')

- Semi-structured
- Transcribed
- Reflexive thematic analysis
- Eight themes/CMO configurations for each group

Workshop two (Mar 23')

- rank/prioritise/discuss the eight CMO
- Established priority areas
- Subsumed all data to most appropriate area

Final synthesis of data

- A final framework describing three CMO configurations and tensions/resources for each participant group

RESULTS

Communication

To be able to share and access information and experiences

Flexibility and Scope

The extent to which tasks and timeframes can be modified to everyone's needs

Expertise, Skill and Training

Having knowledge and ability to carry out physical and personal care, solve problems and handle equipment safely and smoothly

Trust

Being certain of support, care, ease and safety

Rapport and Relationship

Getting on well together

Responsibility and Accountability

Who puts their hand up to ensure the care is completed or not?

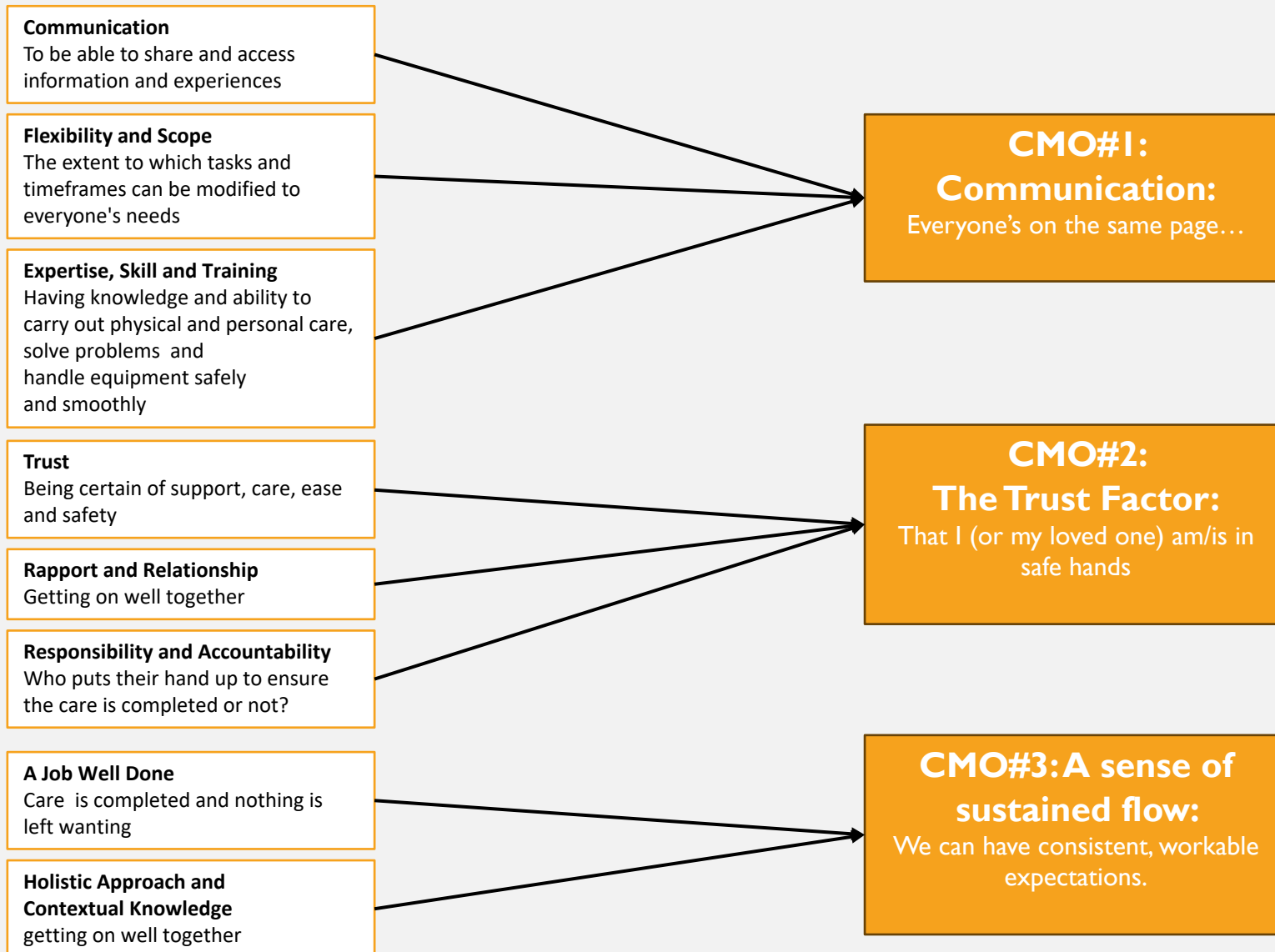
A Job Well Done

Care is completed and nothing is left wanting

Holistic Approach and Contextual Knowledge

getting on well together

RESULTS



RESULTS

	Contexts	Mechanisms	Outcomes	Tensions	Resources
<p>CMO#1: Communication: <i>Everyone's on the same page...</i></p>	<p>If groups have clear and open communication about what needs to happen, when and where...</p>	<p>... then there's space for discussion, negotiation and understanding of the expectations and boundaries required of each role...</p>	<p>...which helps PLEX feel in control of care that's required</p> <p>... which helps foster a feeling of reciprocal respect, knowledge of boundaries</p> <p>... which helps have flexibility within limits (e.g. different food or bedtime)</p> <p>... WHAN feel the boundaries of our domestic space of our lives are understood</p> <p>... SWs are matched by personality not just skills (e.g. we've got a level 2 male)</p> <p>... SWs have everything I need to do my job....</p> <p>... SWs know there clients, and feel helpful, feel supported...</p>	<p>When people read/interpret 'the page' a little different</p> <p>Establishing boundaries: being over-involved, or over-sharing</p> <p>Sharing bio-info inevitable, but not the 'big stuff' (a semi-permeable membrane)</p> <p>taking too much initiative and PLEX/whānau excluded; protective behaviours and shielding</p>	

CMO#1: communication:
Everyone's on the same page...

PLEX: communication is kind of key, that supports, how you're gonna work together

WHĀNAU: you know you've made a connection if you can communicate some things that you're sharing and not going into a big long explanation or whatever.

SW: I think this kind of goes on top of everything, communication. I think it all kind of starts and ends there

CMO#1: communication:
Everyone's on the same page...
tensions

PLEX: *'I just need to get out of here. I don't need to get into the, you know the whys and wherefores of Donald Trump at seven in the morning or whatever, you know?*

WHĀNAU: *we're all in the house together at times and things happen, but I don't wanna hear, I don't want my husband to be telling me about someone's marriage problems, or someone's, you know, their child's in trouble with the law*

SW: *there's some carers who have already stepped over that boundary and then it's hard for the ones who are sticklers for sticking to the rules and you know, you're getting abused by the clients*



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RESULTS

	Contexts	Mechanisms	Outcomes	Tensions	Resources
<p>CMO#2: The Trust Factor: <i>That I (or my loved one) am/is in safe hands</i></p>	<p>If groups trust that their own (or their loved one's) SWs can complete tasks in a competent, confidential manner way...</p>	<p>...then relationships have acknowledged, reciprocal trust...</p>	<p>... which enables PLEX to feel their privacy and confidentiality is managed...</p> <p>... enables PLEX to trust SWs are competent/able to complete tasks and ensure my safety...</p> <p>...then whanau can trust SWs/respite so I can have genuine break</p> <p>...then SW feels that someone is looking out for their interests</p> <p>Having trust to have 'serious' talks</p>	<p>... if SWS are not component; different groups can have different expectations</p> <p>(neg)poor/no SWs – feel guilty if loved one is neglected – can't trust in care</p> <p>(neg) ...going away on trips – feel guilty if loved one is neglected - can't trust in care</p>	<p>Competent/able SWs who really knew my own/my loved one's needs</p> <p>Adequate funding for whanau to have guilt free time out</p> <p>Access to appropriate training and equipment</p> <p>Access to agency support</p>

CMO#2:

The Trust Factor:
That I (or my loved one) am/is in safe hands

PLEX: It's trust, mutual trust and empathy. If you've got those two, you're a long way down the track

WHĀNAU: trust is a huge thing, 'cos my partner has no short-term memory... so having trust in that person who's supporting him, they're not just leaving him to flounder on his own

SW: That there's that trust there that they can leave their family member with us

CMO#2:

The Trust Factor:

That I (or my loved one) am/is in safe hands
tensions

PLEX: *you need to be comfortable in yourself, if you need to be comfortable with that person*

WHĀNAU: *... he's [husband] had toenails ripped off recently and stuff. Just the way they're handling him. And I feel so guilty because if I'd done it, it wouldn't have happened. I know that for certain*

SW: *...you know, nobody's communicating well together. Something's not right. How can I trust the people around me?*

RESULTS

	Contexts	Mechanisms	Outcomes	Tensions	Resources
<p>CMO#3: A sense of sustained flow: <i>We can have consistent, workable expectations.</i></p>	<p>If all groups feel 'known' (empowered/valued) through clear communication and trust helps to manage</p>	<p>... then people have a space in which feel 'known'</p> <p>... then people feel that their contribution is valued</p> <p>... then issues such as privacy, confidentiality and safety for all those involved exist</p>	<p>... people can progress toward consistent, workable expectations</p> <p>... doing so ultimately allows disabled people to flourish</p> <p>... whanau feel to pursue, engage in, 'time out' and 'own life'</p> <p>... then SWs feel valued in their work.</p>	<p>Unequal funding: Same care expectations</p> <p>No synergy between SW, PLEX, whānau and agency</p> <p>Struggle to find good SWs</p> <p>Having SWs who not responsive to household context: cannot 'read the room'</p>	<p>Flexible SWs who can be trained, not stuck on preconceived ideas</p> <p>SWs who can take overall context into account</p> <p>Access to appropriate training and equipment</p> <p>A shared care plan on App</p>

CMO#3:

A sense of sustained flow: We can have consistent, workable expectations.

PLEX: they've been there a while, there is a natural rhythm to it, they know what needs to be done when and how and that's why if you can keep someone good, you do

WHĀNAU: ... a good carer obviously knows that it's your home and they don't pick up things and move them, or a good carer is respectful of their workplace being your home

SW: ... that, you know, they [client] are comfortable. They have had all their activities of daily living provided, you know, in an adequate way... we know that they are safe and warm and looked after

CMO#3:

A sense of sustained flow: We can have consistent, workable expectations.
tensions

PLEX: I'm tolerant, but I'm not gonna put up with that on a long term basis. Because I'm just, I'm just living my life

WHĀNAU: I'm tired of it, I'm tired of worrying about caregivers not showing up for shifts, or texting at the last minute, 'I'm sorry, I'm not well... So I live on a knife's edge, constantly worrying about whether he'll have a caregiver

SW: I think we're just here to provide the same level of care but the situation around that isn't always the same



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DISCUSSION

- Contexts which facilitate high levels of communication, trust and validation activate mechanisms which promote positive, sustainable relationships.
- In particular, results suggest that clear communication and trust helps to manage issues such as privacy, confidentiality and safety for all those involved. Doing so, ultimately allows disabled people and whānau to flourish and SWs to feel valued in their work.
- Our findings support previous research on this topic which has identified that communication, trust, and validation care contribute to positive support worker/client relationships^{3,5,13}

DISCUSSION

Boundaries & Trust

- Having agreed upon expectations surrounding boundaries was a key tension identified by all participant groups in our study.
- Particularly regarding the line between work and friendship, becoming too familiar in family affairs, and over sharing of personal information
- Negotiating boundaries and understanding an individual's unique set of circumstances, can be helped by having SWs and disabled people establish regular and consistent visits, and matching SWs to clients based on personality and shared interests^{4,11,14}

DISCUSSION

Casting a wide net

- Even though SWs are employed to assist one person, their presence in a family environment, ultimately impacts on the entire family unit, impacting on spousal identity, distribution of domestic roles, boundaries, privacy, confidentiality and on general routines about the household.
- Pullin and McKenzie⁶ found that participating in long-term care, was complex, all-encompassing and lifelong, and involves: *'the development of complex personal and social processes aimed at keeping the family unit together, protected from intrusions to privacy and sustainable into the future'* (p. 1629).
- Solutions...
- These included competently trained SWs
- Adequate funding for sufficient SWs for family members to have respite breaks
- Agency support. Support Worker agencies (an extra layer of resource, and a trail of accountability.)
- These resources needed to be flexible for different circumstances.

DISCUSSION

The long game

- **PLEX** can feel that needs are met in a way that recognizes their wholeness and can exercise autonomy to pursue their life roles.
- **Whānau** can feel the needs of the overall family unit are considered and feel free to pursue the life roles without guilt or feeling they are abdicating responsibility.
- **SWs** can feel supported to express their compassion and problem solving, and feel satisfied, significant, and accomplished.
- Tensions identified in this space relate more to systematic areas such as overall availability of SWs, sector funding, and having infrastructure support that can facilitate a sense of security for all involved. Such issues have been raised in the literature.
- Topping et al.,¹¹ called for a renewed focus on personal training to complement broad-skill industry qualifications, and for employers to care for their staff while also ensuring SWs are maintaining consistent performance.
- Mosko et al.,¹⁴ argue the skills and competencies taught to SWs need to move from task-focused to person-centred care.

WHAT'S NEXT?

- Findings be used to guide support worker workforce development initiatives/programmes in the future, pointing to what should be paid attention to and what might work; in what circumstances.
- **More research??!** (Fifteen people in Canterbury, lack of Māori/Pasifika perspective)
- Methodological: this work informed an 'initial-theory' which now requires more work/testing
- Future work in this area requires partnerships between researchers, those with lived experience and advocacy

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THANK YOU!



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Johnny.bourke@sydney.edu.au

Research Fellow - Implementation Science
John Walsh Centre for Rehabilitation Research