AUT CENTRE FOR
PERSON CENTRED RESEARCH

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How do we do person-centredness? Building connectivity, trust and capability in the midst of an unstable reality

Associate Professor Nicola Kayes

@nickayes4

ASSBI, Adelaide, May 2018

AUT CENTRE FOR PERSON CENTRED RESEARCH

2004, Professor of Rehabilitation

2018, Multidisciplinary team

- **Rehabilitation**
- **Health, Social and Clinical Psychology**
- **Physiotherapy**
- **Speech and Language**
- **Occupational Therapy**
- **Nursing**
- **Sociology**
- **Medical Anthropology**
- **Disability**

Three core interrelated purposes

- Rethinking rehabilitation
- Embedding person-centredness
- Making a difference

Extensive and growing body of research…

Open Access Research

BMJ Open

Establishing a person-centred framework of self-identity after traumatic brain injury: a grounded y study to inform measure opment

l Levack,[1] Pauline Boland,[1] William J Taylor,[1] Richard J Siegert,[2,3]

RESEARCH ARTICLE Open Access

Are physiotherapists employing person-centred care for people with dementia? An exploratory qualitative experiences of people their carers

Abigail J. Hall[1*], Lisa Burrows[2], Iain A. Lang[1], Ruth Er

REHABILIATION IN PRACTICE

Impact of a person-centred community rehabilitation service on outcomes for individuals with a neurological condition

Ruth N. Barker[a,b], Cindy J. Sealey[a,b], Michelle L. Polley[b], Merehau C. Mervin[c] and Tracy Comans[c,d]

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ORIGINAL ARTICLE

Experiences of the return to work process after stroke while participating in a person-centred rehabilitation programme

Annika Öst Nilsson[a,b], Gunilla Eriksson[a,c], Ulla Johansson[a,b] and Therese Hellman[d]

[a]Department of Neurobiology, Care Sciences and Society, Division of Occupational Therapy, Karolinska Institutet, Huddinge, Sweden; [b]Centre for Research & Development, Uppsala University/Region Gävleborg, Gävle, Sweden; [c]Department of Neuroscience, Rehabilitation Medicine, Uppsala University, Uppsala, Sweden; [d]Unit of Intervention and Implementation Research for Worker Health, Karolinska Institutet, Solna, Sweden

Strong rhetoric in brain injury rehabilitation models of service delivery…

What One Rehabilitation Service Offers

One Rehabilitation Service offers brain injury services at the client's home and local community. We provide therapy in the home to optimise learning and transfer of skills. As an interdisciplinary team, we use a client-centred model and provide goal directed therapy. We understand that everyone has different circumstances and that no two people are the same. That's why we tailor rehabilitation programs around your goal and needs.

Hampstead Rehabilitation Centre

Inpatient, outpatient and community based services all work together to provide a mix of services in a client centred model, placing the needs of the individual, their family, carers and significant others at the centre of the care.

abi Rehabilitation Specialists

ABI is committed to providing a person centered service and environment that is characterised by respect and choice.

Professional commitment to person-centred models of practice….

An Introduction to Occupational Therapy Practice in Australia

Key Purpose

"Occupational therapy is a client-centred health profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement.

Physiotherapy Board of Australia

For registered health practitioners

CODE OF CONDUCT

1.2 Professional values and qualities

Good practice is centred on patients or clients. It involves practitioners understanding that each patient or client is unique and working in partnership with patients or clients, adapting what they do to address the needs and reasonable expectations of each person. This includes cultural awareness: being aware of their own culture and beliefs and respectful of the beliefs and cultures of others, and recognising that these cultural differences may impact on the practitioner–patient/client relationship and on the delivery of services. Good practice also includes being aware that differences such as gender, sexuality, age, belief systems and other anti-discrimination grounds in relevant legislation may influence care needs, and avoiding discrimination on the basis of these differences.

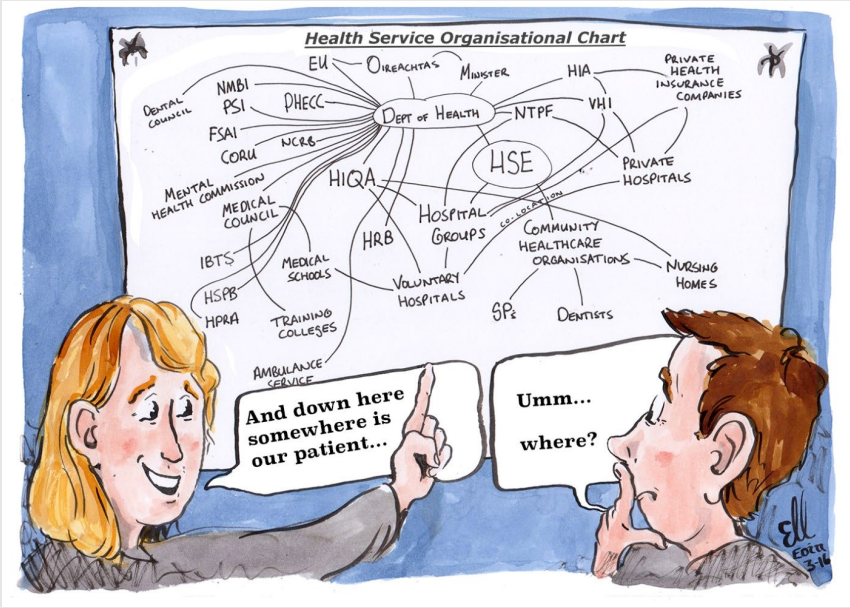
But, it is argued that person-centred practice is still in its ascendency…

- Lack of definitional clarity
- Underestimate complexity of implementing in practice
- Are limited in our critical engagement with the concept and practice of person-centredness
- Rhetoric ≠ Reality?

Whalley Hammell, (2013, 2015); Dewing & McCormack (2017)

#1: Systems, structures and professional cultures

- Unsupportive structures and processes (Dewing & McCormack, 2017)
  - In part due to the dominance of the biomedical model
- Discrepancy between system, service and/or clinician goals and individual goals/motives (Levack et al., 2011)
- Organisational cultures (McCormack & McCance, 2017)



As Faith said…. ‘there is a person inside the patient and a person inside the practitioner’

“Person-centredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development”

(McCormack & McCance, 2017)

#2: Expertise, power and control

- Power dynamics inherent in the clinician/client encounter (Whalley Hammell, 2015)
- Tendency towards paternalism (Soundy et al., 2010; Mudge et al., 2014)
- Struggle to let go of control (Jones et al., 2013; Norris & Kilbride, 2014; Mudge et al., 2014, 2015)

‘‘Predominantly because of the fact that they’re in a medical environment, so you know that sort of paternalistic view of sort of like therapist knows, doctor knows everything kind of thing. So you’re being done to ...I used to ... I used to very much believe that I had all the answers as a clinical specialist. I also should have all the answers as well to a certain extent’’

Norris & Kilbride (2014), p.34

#3: Professionalism and professional boundaries

- Constrained by rigid attention to professional boundaries (Austin et al., 2006)
  - Potential to limit ways of working that might be characteristic of person-centredness
  - E.g. humanness, authenticity, mutuality, reciprocity, sharing of self?
- What is professionalism?
  - E.g. a “friend but not a friend”

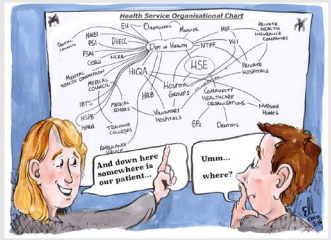
#4: Choice, autonomy, and shared decision-making

- The rise of “citizen-oriented, participative approaches to health care” (Todres et al., 2007)
- Active involvement as synonymous with person-centred care (Whalley Hammell, 2013)
- Empowerment as activation strategy (van Hal et al., 2012)
- Need to be wary of assumptions in person-centred practice (Naldemirci et al., 2018)

“[The ‘right’ client is] basically someone who is cognitively intact, has very good judgement, probably already has some pretty good insight into how they’re functioning within their environment. I guess along with that is some-one who has pretty good problem-solving skills already.”

Wilkins et al. (2001), p.77

#5: Frameworks, guidelines and tick-boxes



#1: Systems, structures and professional cultures

#2: Expertise, power and control

#3: Professionalism and professional boundaries

#4: Choice, autonomy, and shared decision-making

#5: Frameworks, guidelines and tick-boxes

CONDITIONAL PERSON-CENTRED PRACTICE?

We are person-centred but….

IT IS IMPORTANT PEOPLE ARE REALISTIC
"She did have a lot of goals around her mobility which were really difficult though, for the physio to manage, because there wasn't realistic things that she wanted to be doing."
(Occupational therapist)

THERE ARE RULES TO FOLLOW
"I tried to walk to the toilet on my own and the Nurse came and told me off, castigated me. She said 'did you realise, if you fell, the amount of reporting I have to do? So, don't ever try and walk to the toilet on your own again'"
(Person with stroke)

WE HAVE A JOB TO DO
"Some of the questions are very sensitive, so at times you are like 'I don't know if this is actually the right time for me to ask this?' But, that's… you know, how we do our first visit."
(Speech and Language therapist)

WE MAKE ASSUMPTIONS
"He has got a lot going on in his head sort of brain injury wise […] he's not going to want a bar of this." (Physiotherapist)

We are person-centred but….

IT IS IMPORTANT PEOPLE ARE REALISTIC

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SOMETIMES PEOPLE ARE JUST NOT GOOD PATIENTS

"Well generally if they refuse therapy, like say I put them on my timetable twice a week for three weeks and they refuse, you know, 80% of the sessions, or someone brings them down for two sessions but then they don't come for the rest or something like that [then] I'll take them off because I'm really, really busy and I can't waste an hour trying to get someone out of bed each time."
(Speech and Language therapist)

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THERE ARE RULES TO FOLLOW

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WE WANT TO AVOID OPENING A CAN OF WORMS

"I was a bit concerned about how my client would actually respond for the simple reason that he had a lot of social things going on in his life, and I just wondered whether it un-earthed stuff…"
(Physiotherapist)

WE MAKE ASSUMPTIONS

"He has got a lot going on in his head sort of brain injury wise […] he's not going to want a bar of this." (Physiotherapist)

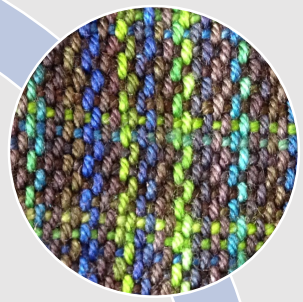
But, it’s complex!

- What person-centredness looks like as a way of working can vary from person to person
- A need to move away from fixed assumptions about what person-centred practice is?
- To a more reflexive, nuanced way of working that asks the question:
  - How do they need me to work? (Bright, 2015)
  - ….or how do ‘I meet them where they are at’? (Caleb Rixon, ASSBI 2018)
- How might a different way of thinking about person-centredness help us to embed it in a more fundamental way?

How do the voices of our participants inform us about person-centredness?
(Lead: Gareth Terry)

- A secondary analysis using existing qualitative data sets
- Aiming to explore how person-centred practice is constructed in the talk of client participants
- Eligible projects explored perspectives and experiences of ways of working in rehabilitation
- 12 projects met criteria => 3 projects purposefully selected
- Data included:
  - 40 interviews and 3 focus groups with clients, carers, or family members
  - 2 interviews and 6 focus groups with practitioners

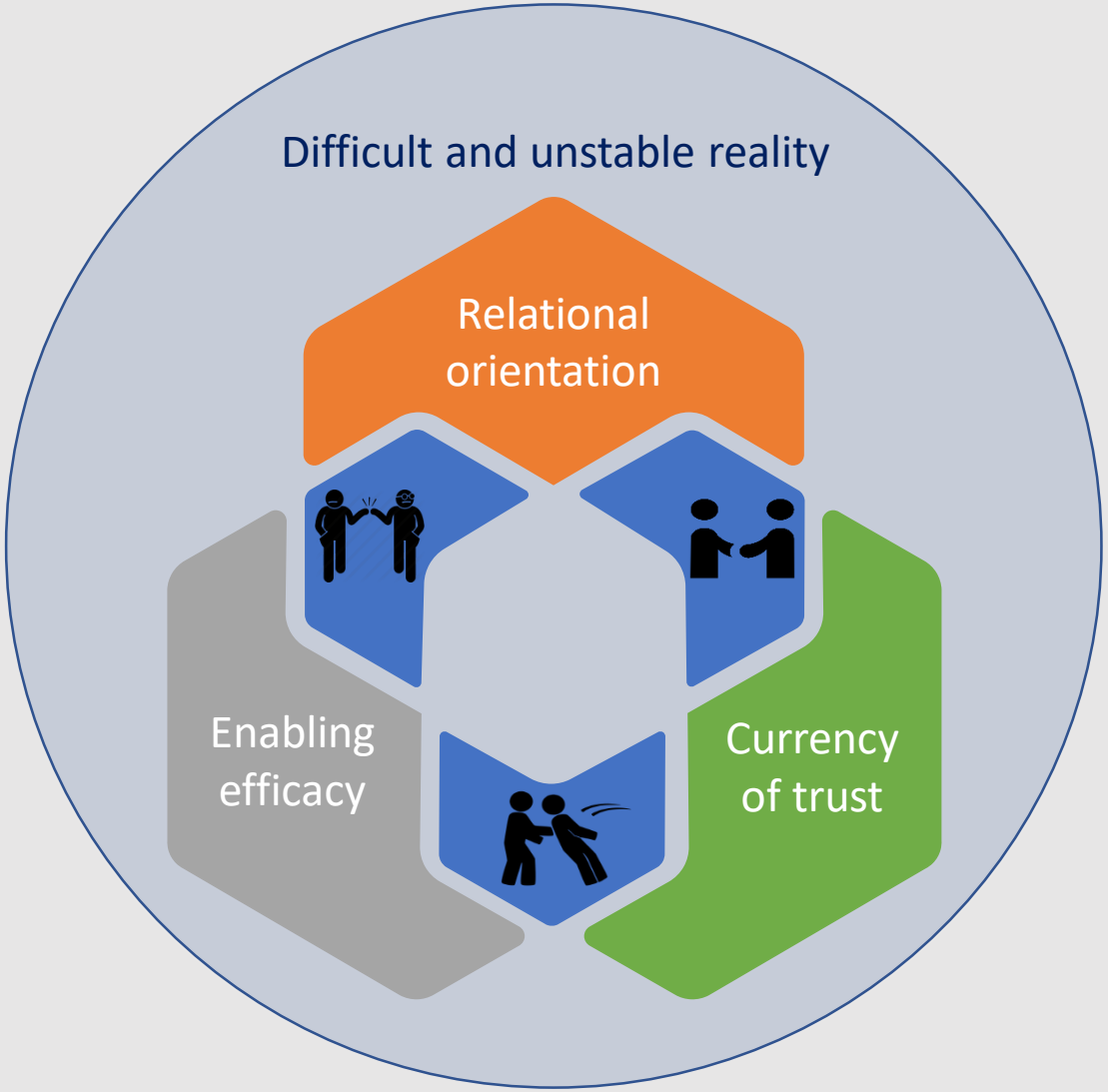
Included projects



Engagement in stroke rehabilitation (Lead: Felicity Bright)

What matters most to the therapeutic relationship in neurorehabilitation (Lead: Nicola Kayes)

Development and implementation of a Living Well Toolkit for people with long term neurological conditions (Lead: Suzie Mudge)


Difficult and unstable reality
Relational orientation
Enabling efficacy
Currency of trust

A difficult and unstable reality

- Context that rehabilitative care occurs within
- Client's lives and identities radically changed
- Entering new, unexplored terrain
- 'Real' world more risky, troubling, and unfamiliar for clients

"Certainly the dealing with the shock and change and challenge of… Perhaps the low point for me, in that first 3 weeks anyway, was going through a phase when I truly, really wanted to die. It was a conscious and rational choice. I choose to die. Death is the best option" (Person w stroke)

Relational orientation to care

- Connectivity and therapeutic relationship as the basis of rehabilitation
- Knowing them, their unique context and what matters most to them
  - ‘Need to start in the middle and know them for who they are’ Jacinta Douglas, ASSBI 2018
- Reciprocity in sharing of self
- Learning how to work together
- Broad philosophy of what constitutes rehabilitation work and how, when and where it occurs

Just being able to relate to that person. Maybe you’ve got to share your life a bit you know to have had, actually had a conversation about yourselves (Person w SCI)

It’s a relationship really and creating that trust, and the feeling valued as a person, that your point of view is important and that the person [therapist] wants to work with you to achieve what you need to do (Person w stroke)

Currency of trust

- Initial leap of faith necessary
  - Competence
- Gaining versus *sustaining* trust
- Vulnerability of trust
  - Takes time, needs to be reinforced, can be lost
- Transferability of trust
- Protective nature of trust

So I think it's important to gain the faith of the person that you are dealing with. You have to prove to them that you know what you are doing (Person w TBI).

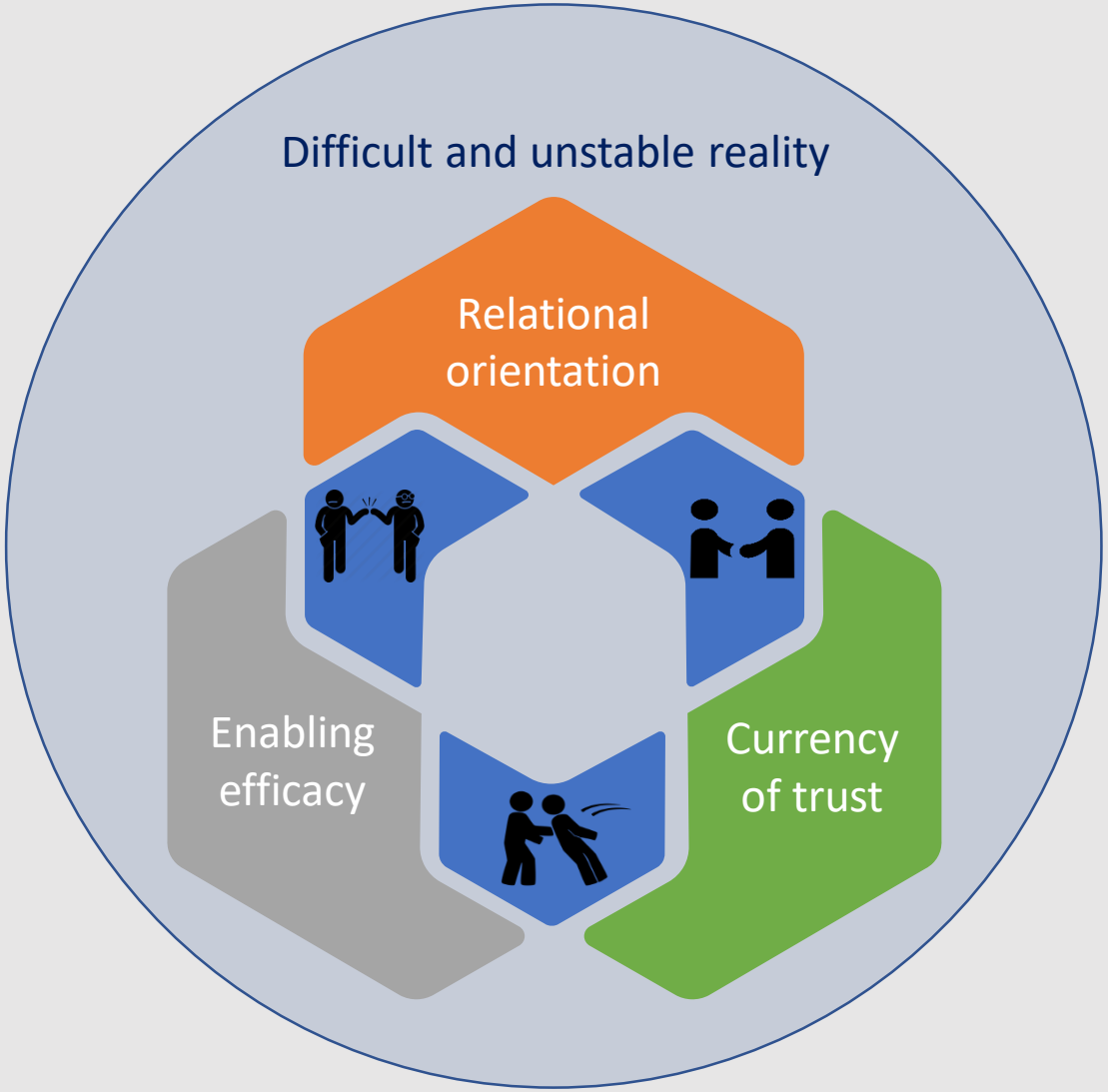
I think you've got to trust that they know what they're doing, that they care about what they are doing, that they are going to do it to the best of their ability, and that they've got your best interests at heart (Person w SCI)

Enabling efficacy

- The role of therapists and significant others as enhancing or enabling capabilities of the client
- Acts as a counter to individualised understandings of ‘self-efficacy’
- A web of supportive personal and therapeutic interdependence as best practice
  - Relational autonomy (Ells et al., 2011)
  - Relation-inferred efficacy (Lent & Lopez, 2002)
- Creating a context for hope and belief in self

You get the feeling you can do the things she teaches you, and she tends to make you believe in yourself a lot more than you normally would (Person w TBI)

I think the therapist and their listening and their flexibility in being able to work with me… if I wasn’t quite feeling there or involved, they had the ability to change it. And that I understood what was required of me in what they were saying. And caring. They have a lot of energy and positive feedback and that spurred me on. This isn’t bad at all. I can do this (Person w SCI)


Difficult and unstable reality
Relational orientation
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To finish…

- Person-centred practice is in its ascendency
- Prescriptive models potentially lead to adoption of practices which become a proxy for person-centred practice
- A need for a more person-centred approach to person-centred practice?
- A more nuanced, reflexive, and responsive way of working that builds connectivity, trust and capability and seeks to understand the psychosocial context in which care is being delivered
- Our participants cited some excellent examples of person-centredness in practice, but this was often in spite of the system

AUT CENTRE FOR
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Acknowledgements

The team at the Centre for Person Centred Research, with special thanks to:
Gareth Terry
Felicity Bright
Christine Cummins
Suzie Mudge
Ann Sezier
Paula Kersten
Kathryn McPherson

Patients, practitioners and services who have engaged in our research over many years
Our funders – Health Research Council of NZ, AUT