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Co-creating health: supporting people to live well in the context of a neurological condition

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ASSBI, Adelaide, May 2018

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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

Our research in neurorehabilitation?

- Longitudinal experience of recovery
- Goal planning and hope
- Therapeutic relationship and engagement
- Physical activity engagement

Informed by the perspectives of people living with injury or illness

"Certainly the dealing with the shock and change and challenge of perhaps…. the highlight 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 with stroke)

"It's like having a tin can with holes punched in it, no matter how much water you pour into it, it is still pouring out. So even if you pour heaps more water in, it will still pour out, you will never get anywhere."
(Person with MS)

People think oh well you look alright. My sister through there… that's what she said "but you look alright… what's wrong with you?" you know "why aren't you feeling better? But I'm sure you must be a lot better cos you look better" and I'd say "but I'm not . . . I'm absolutely exhausted"
(Person with mild TBI)

Living Life After Traumatic Brain Injury: Phase 1 of a Longitudinal Qualitative Study

Kathryn McPherson, PhD; Joanna Fadyl, PhD; Alice Theadom, PhD; Alexis Channon, PGDip; William Levack, PhD; Nicola Starkey, PhD; Laura Wilkinson-Meyers, PhD; Nicola Kayes, PhD; on behalf of the TBI Experiences Research Group

and hinders recovery and adaptation after disabling traumatic brain injury (TBI) mproving service responsiveness. **Design:** A longitudinal qualitative descriptive **ing:** Community. **Participants:** Forty people with TBI, and 22 significant others, **ain Measures:** Semistructured interviews, analyzed using qualitative description, tance or concern and (b) strategies or actions that people found helpful or that natic brain injury produced a complex set of challenges in *keeping up with life*, and *means for*, and *to*, *me*. This period encompassed a *tangled fit* and *misfit in life* as *brain* ple had to *actively change* some aspects of life and yet *allow other changes* to happen.

The process of adjustment over time following stroke: A longitudinal qualitative study

Alice Theadom [a,b], Sandy Rutherford[a], Bruce Kent[a] and Kathryn McPherson [c] on behalf of the ARCOS IV Group

[a]Person Centred Research Centre, Faculty of Health and Environmental Sciences, Auckland University of Technology North Campus, Auckland, New Zealand; [b]National Institute for Stroke and Applied Neuroscience, Faculty of Health and Environmental Sciences, Auckland Unive North Campus, Auckland, New Zealand; [c]Health Research Council of New Ze Zealand

ABSTRACT

Understanding how people adjust following stroke is essential to c and ensure services are responsive to people's needs. This study people's experiences over the first three years post-stroke and ider or hindered recovery. As part of a longitudinal, qualitative desc people and 27 significant others purposefully selected from a stroke incidence study were interviewed 6, 12, 24 and 36 mo Interviews were audio taped and transcribed verbatim. Participa ongoing process of *shock, disruption, and fear, making sense of needing to fit in with what's offered, finding what works for them ar normal, whilst managing the ups and downs of life*. This process negotiated over time, as people experienced changes in comorbidities and/or wider circumstances. The adjustment proces the three years post-stroke, even for those who perceived that they well. Rehabilitation services need to support patients to make sens navigate the health system, address individual concerns and priori what, when and how much to challenge themselves. Rehabilitatic be revised as circumstances change to facilitate adjustment followi

Recovery and adaptation after traumatic brain injury in New Zealand: Longitudinal qualitative findings over the first two years

Joanna K. Fadyl, Alice Theadom, Alexis Channon & Kathryn M. McPherson

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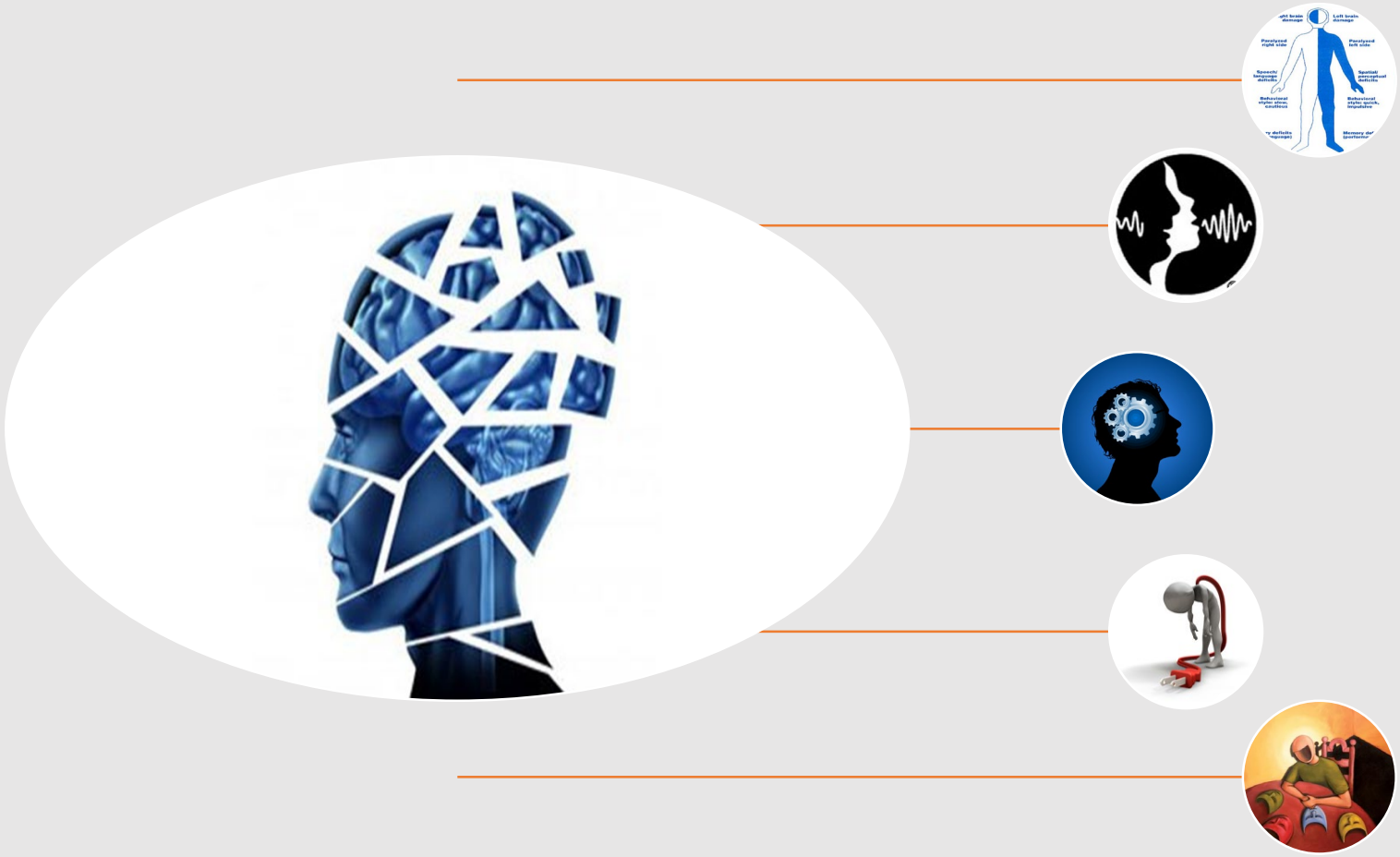
So…

- Existing services do an excellent job of saving lives and supporting safe discharge to the community
- But, neurological injury or illness result in significant ongoing impact for the individual, their family and society e.g. in TBI...
  - In NZ, the lifetime costs of moderate to severe TBI estimated at $27 million and projected to be $33 million by 2020 (Te Ao et al. 2014)
  - Internationally, >70% of people with TBI experience wide-ranging and significant long-term problems that persist for many years (Hoofien et al. 2001; Colantonio et al. 2004; Sendroy-Terrill et al. 2010)

Managing the ongoing impact

- People with neurological injury or illness and their family are largely left to manage the significant, on-going consequences alone
- Resource poor environment = a strong rhetoric of ‘self-management’
- But, sustained engagement in activities to manage the ongoing impact of injury or illness requires:
  - skill and effort
  - ability to regulate ones own cognition, emotion, and behaviour
  - being able to select concrete, manageable goals, which align with a person’s current or desired self-identity

More complex than we might think?



A shift necessary?

Self-management → Co-creating health

- What is the role of health systems, services and providers in supporting people to build skill and capability for long term health and well-being?
- To what extent do our existing systems, processes and ways of working constrain or make possible long term health and well-being?
- How might we work differently at the point of care to optimise long term health and well-being?

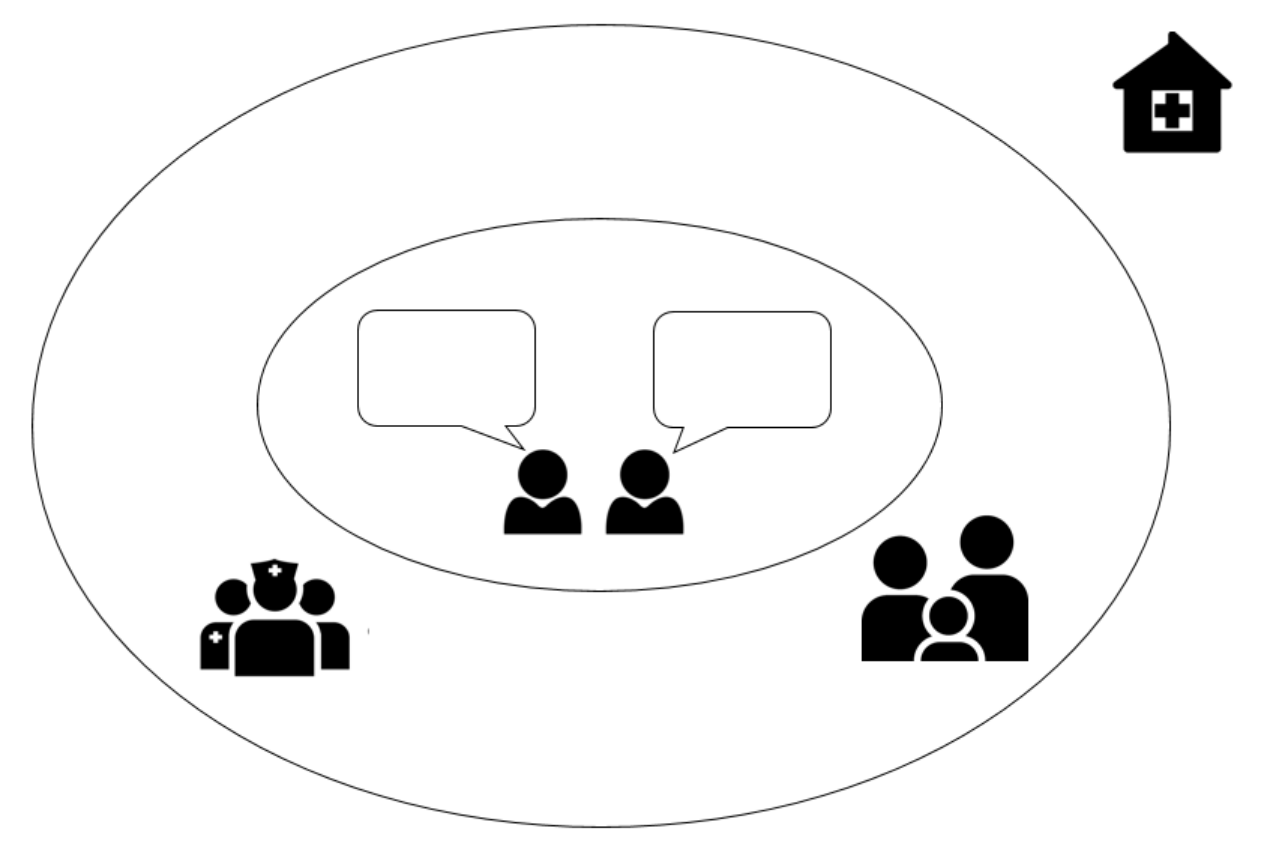
Our aims today?

1. Look critically at existing processes
2. Explore how we could work differently at the point of care to optimise long term health and well-being
3. Discuss what it would take to embed strategies into practice to co-create health for people living with the enduring impact of neurological impairment

To get us started: What is it that we are talking about?

- What does long term health and well-being look like?
- What matters most to individuals living with the consequences of neurological injury or illness?

Reflecting on current systems and processes

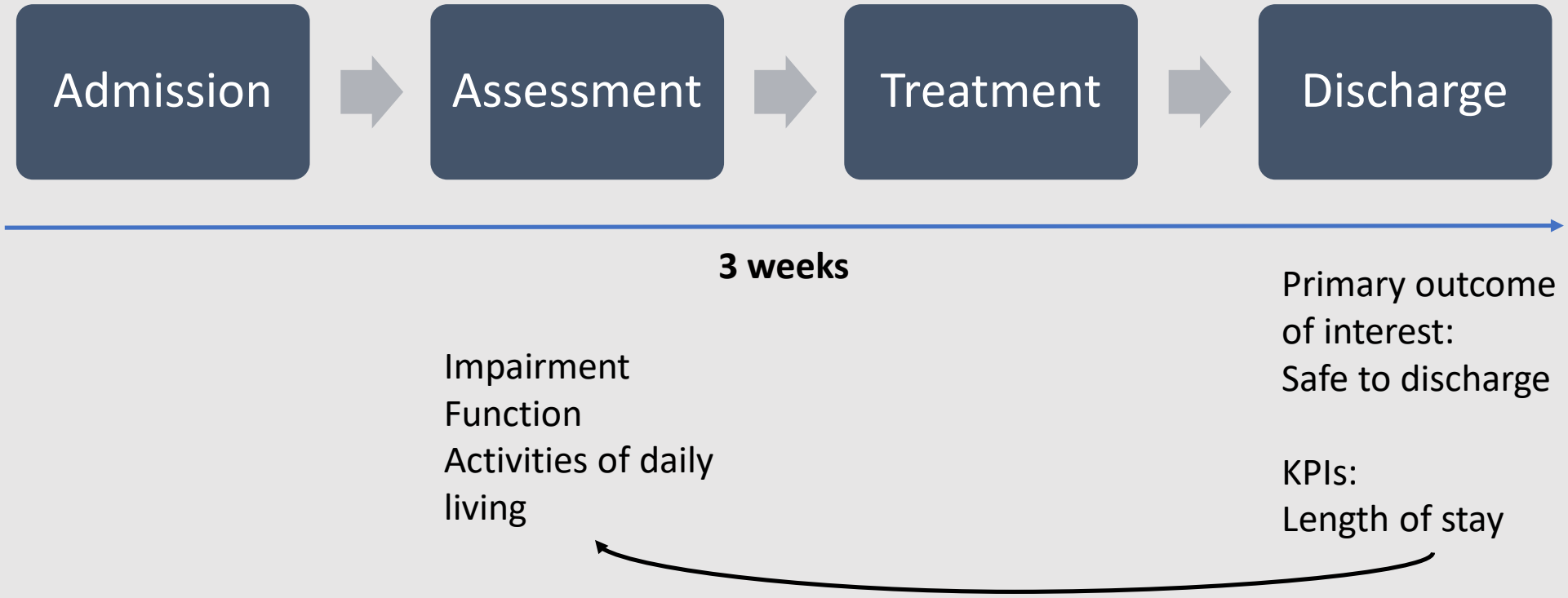


How might our current systems, processes and ways of working constrain or make possible long term health and well-being?

Tipping point #1: Service-drivers can dominate ways of working

Service-specific goals and parameters

- E.g. Assessment treatment and rehab (AT&R) ward



“I remember the first time the therapist at the hospital talked about setting goals I said something about tramping again perhaps swimming perhaps even playing golf again – she said what about getting up in the morning and getting dressed and I thought hell’s teeth we’re on a different page here and my heart sank a bit”

(Person with stroke)

A need to look beyond individual services?



Assessment treatment and rehab (AT&R) ward

Admission → Assessment → Treatment → Discharge



A life time

Primary outcome of interest:
Long term health and well-being

?

KPIs:
Living the life I want to live

A need to reconceptualise neurological injury or illness?

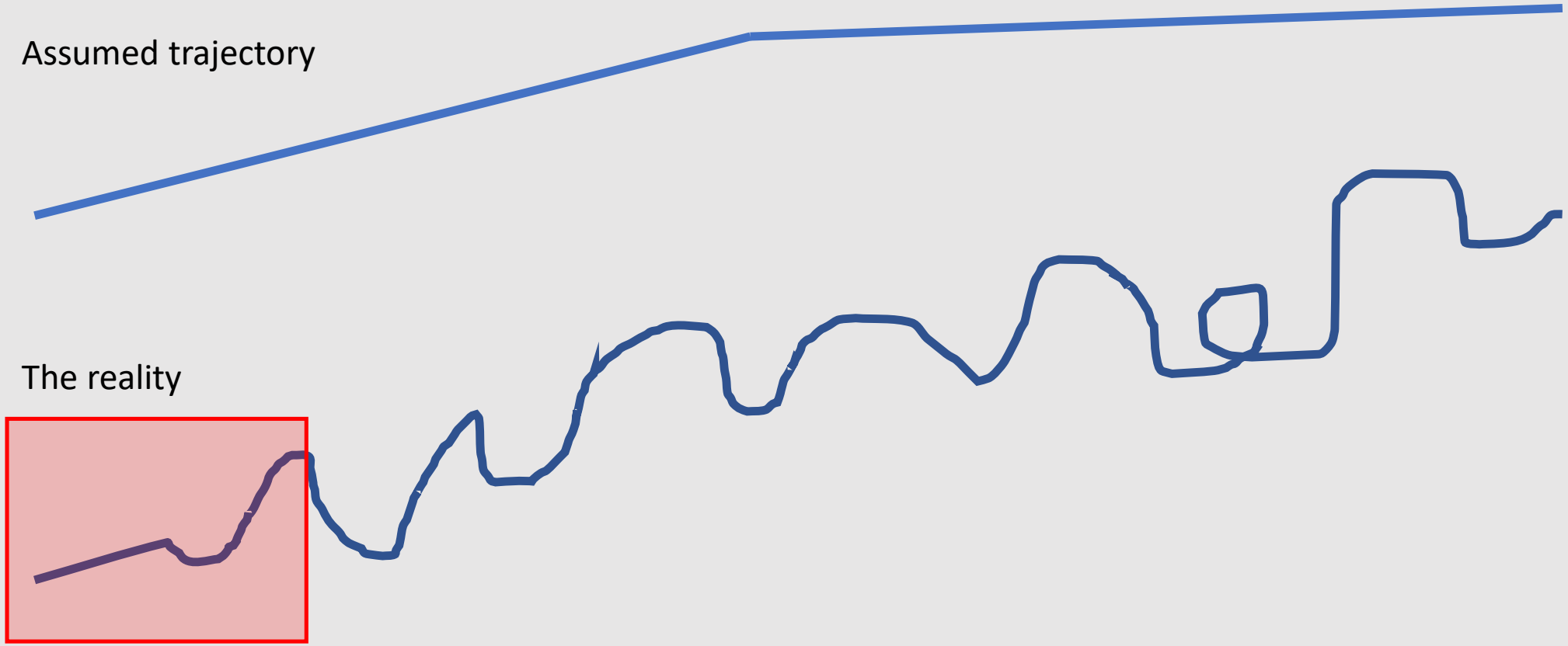
Neurological insult as an ACUTE EVENT

Neurological insult as a LONG TERM CONDITION

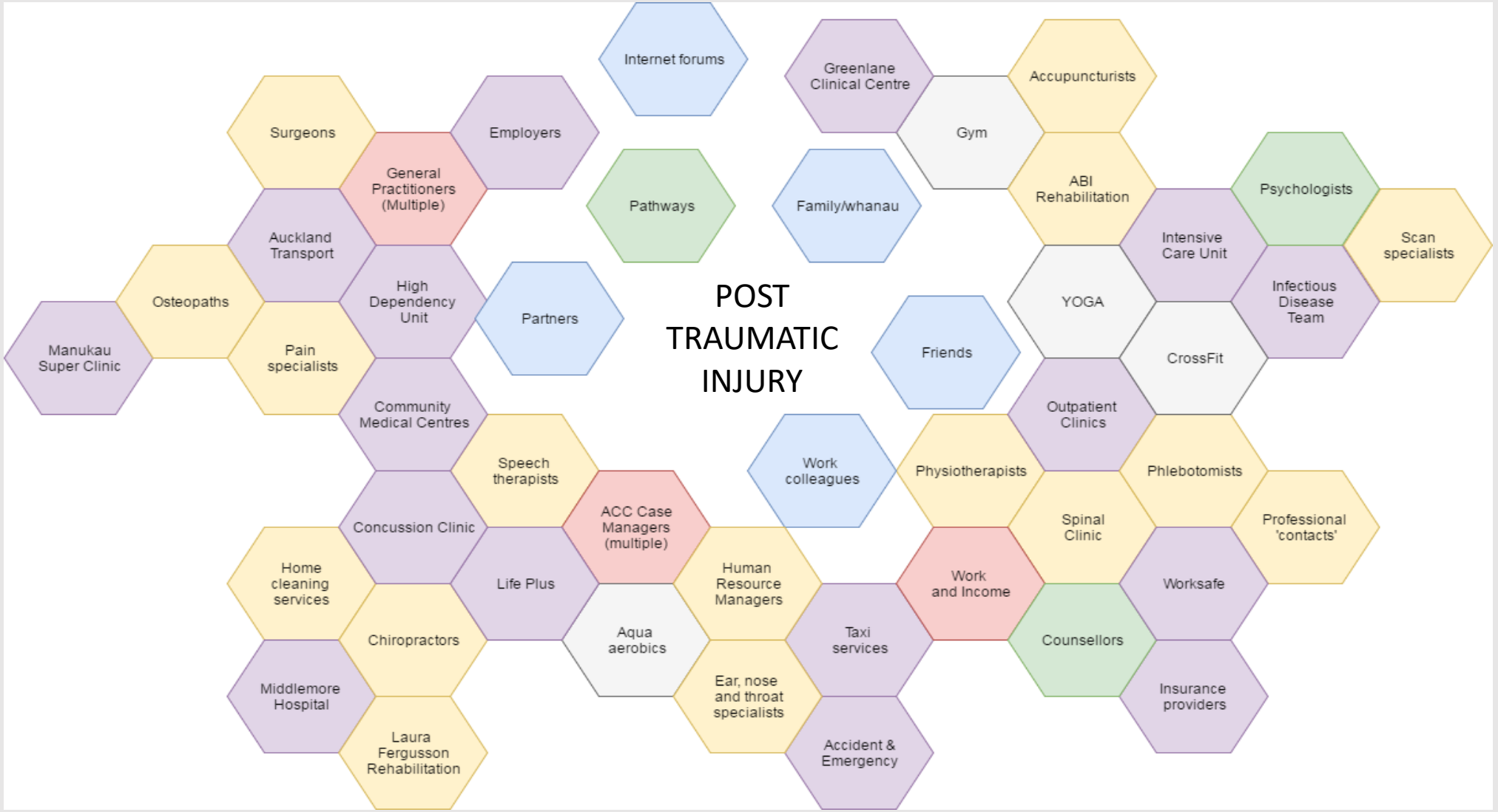
=

?

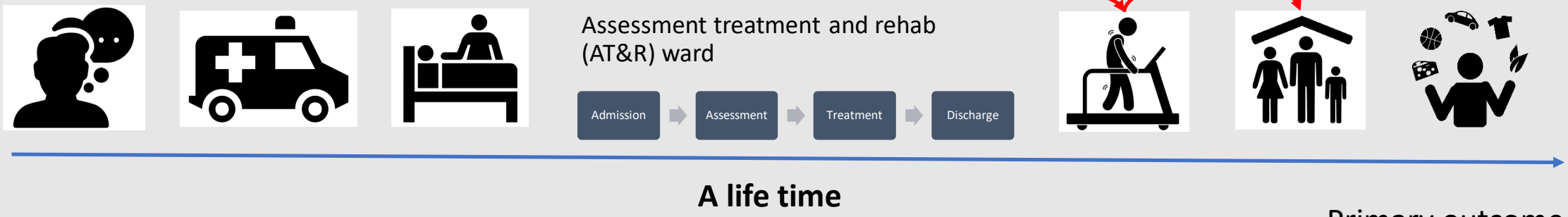
Tipping point #2: Assume a linear trajectory



The rehabilitation landscape



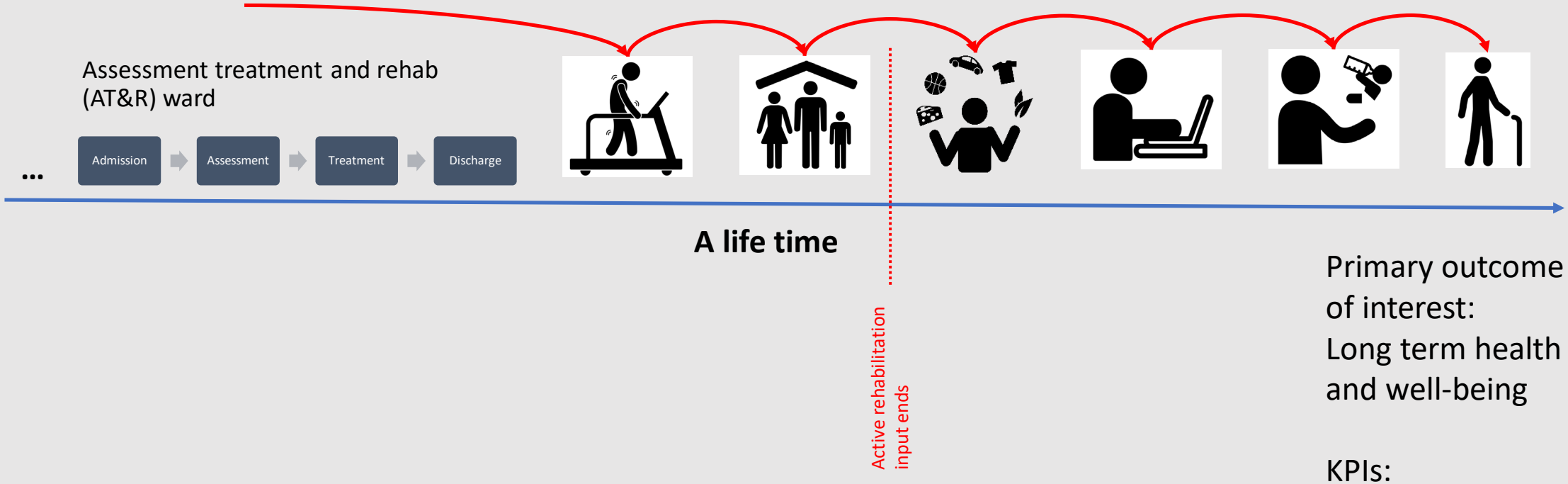
Transition points inherently problematic



Primary outcome of interest:
Long term health and well-being

KPIs:
Living the life I want to live

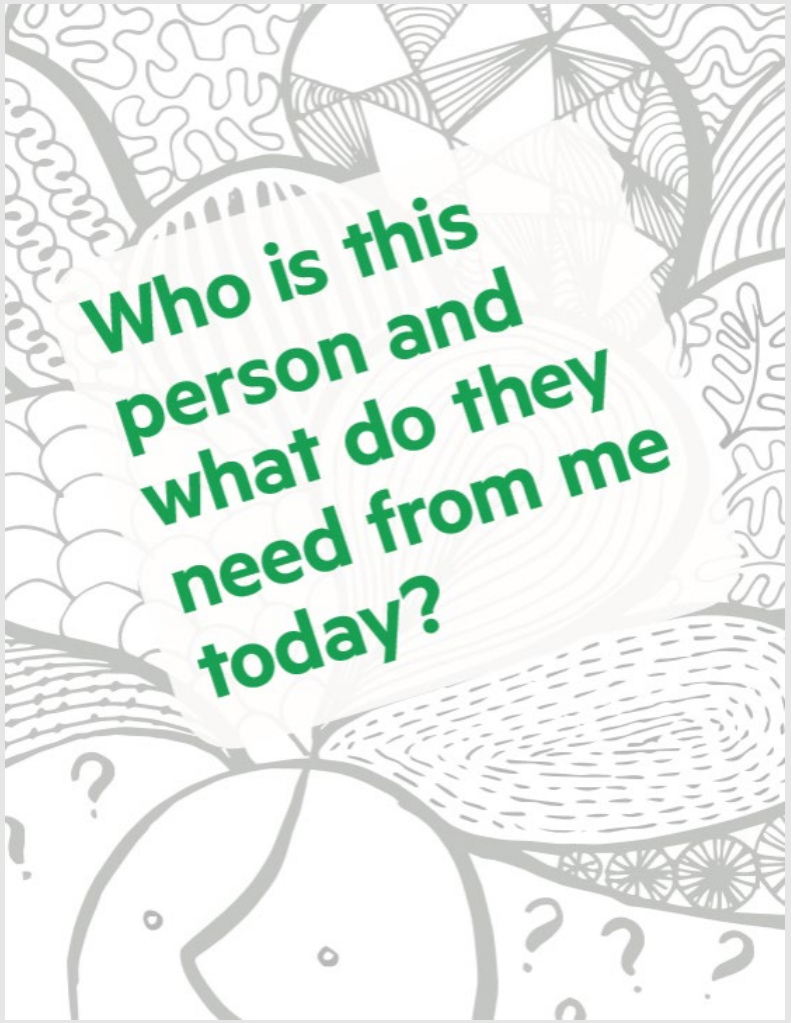
More transition points



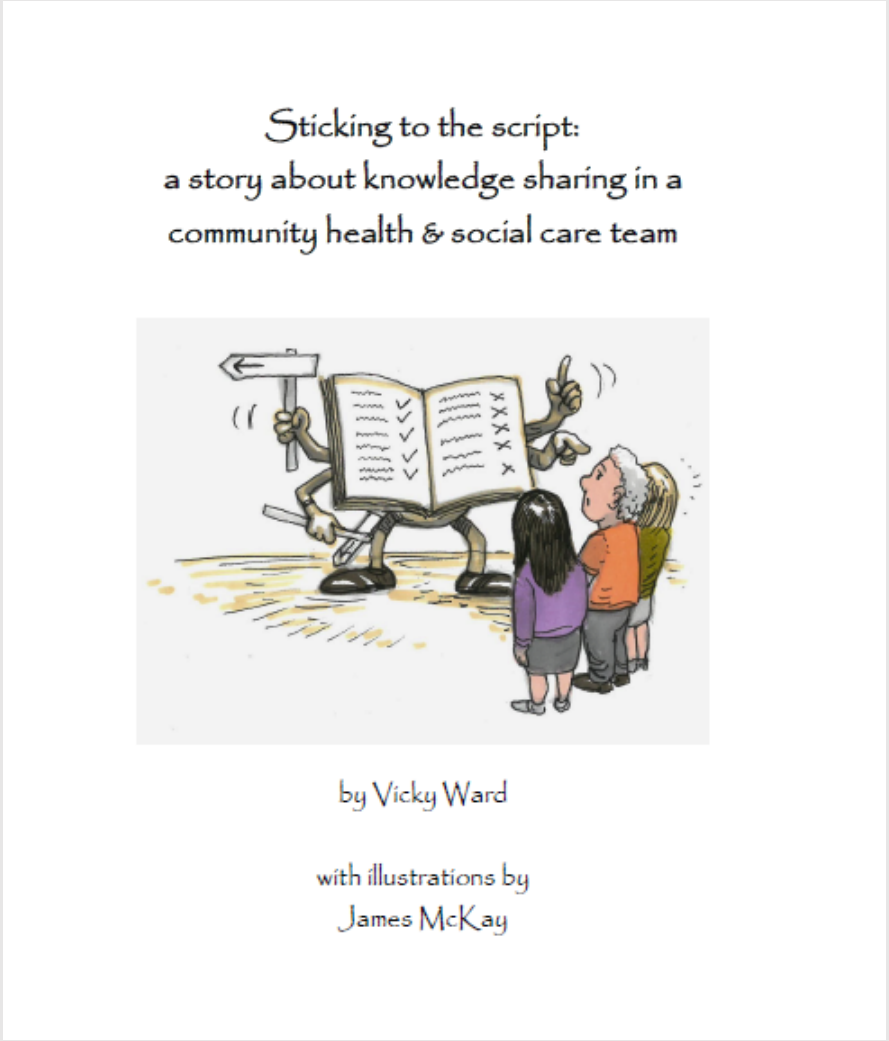
Primary outcome of interest:
Long term health and well-being

KPIs:
Living the life I want to live

A need for flexible, responsive services that can meet people where they are at?



Tipping point #3: Working in silos



http://medhealth.leeds.ac.uk/info/2673/results_and_resources/2343/stories_about_knowledge_sharing

"I know we talked about this… it might be more of a goal setting issue but you know, [other therapist] had lots of different goals that could potentially fit into like where I had my goal. So, I think it's just a matter of getting everybody on board, yeah. So just thinking… I guess from a therapist's point of view of how are we going to divvy up these goals? I think it needs to be very interdisciplinary for that to work. And I think after we had that kind of in-service by you guys, it was kind of, oh okay… […] So I guess yeah, it was just a bit of a challenge fitting in our goals in that way."

(Inpatient post-acute brain injury rehabilitation provider)

A need for transdisciplinary working?

"The antecedents of transdisciplinarity include:

- the involvement of two or more disciplines
- effective and frequent communication that facilitates participants' ability to understand each other and reduces confusion and frustration
- shared purpose and goals that promote synergy among members and guides the focus of the team
- trust and/or respect that allows participants to expose vulnerabilities associated with not knowing, and to seek information about the basics of a specific disciplinary approach"

(Bewer, 2017)

Tipping point #4: Conditional person-centredness

We work in a person-centred way but….

IT IS IMPORTANT PEOPLE ARE REALISTIC
"She did have a lot of goals around her mobility which were really difficult

WE HAVE A JOB TO DO
"Some of the questions are very …itive, so at times you are like 'I …f this is actually the right …k this?' But, that's… …do our first visit."
…age therapist)

WE MAKE ASSUMPTIONS
…s got a lot going on in his …f brain injury wise …ing to want a bar …siotherapist)

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)

…T TO AVOID
…AN OF WORMS
…ncerned about
…would actually
…e simple reason
…t of social things
… life, and I just
…her it un-earthed
…f…"
…erapist)
…al beha…
…siotherapist)

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)

A need to recognise personhood and foster hope?

- “There needs to be connectivity”
- A need to acknowledge and have faith in the expertise individuals and their families bring to the encounter – harnessing that may be fundamental to future health and well-being
- People need to contextualise their rehab in terms of things that matter to them – ‘recovery anchors’
- Hope - a critical resource for recovery
- Experiencing a sense of success and progress towards what matters most is important
- People are skilled in recalibrating and adjusting hopes over time

Tipping point #5: Dominant focus on impairment and function

What do we risk missing?

- Multimorbidity
- Emotional/psychological trauma
- Self-regulatory capacity
- Psychosocial context

A need to shift from managing the condition well to managing well with the condition?

We need to talk about purpose: a critical interpretive synthesis of health and social care professionals' approaches to self-management support for people with long-term conditions

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Abstract

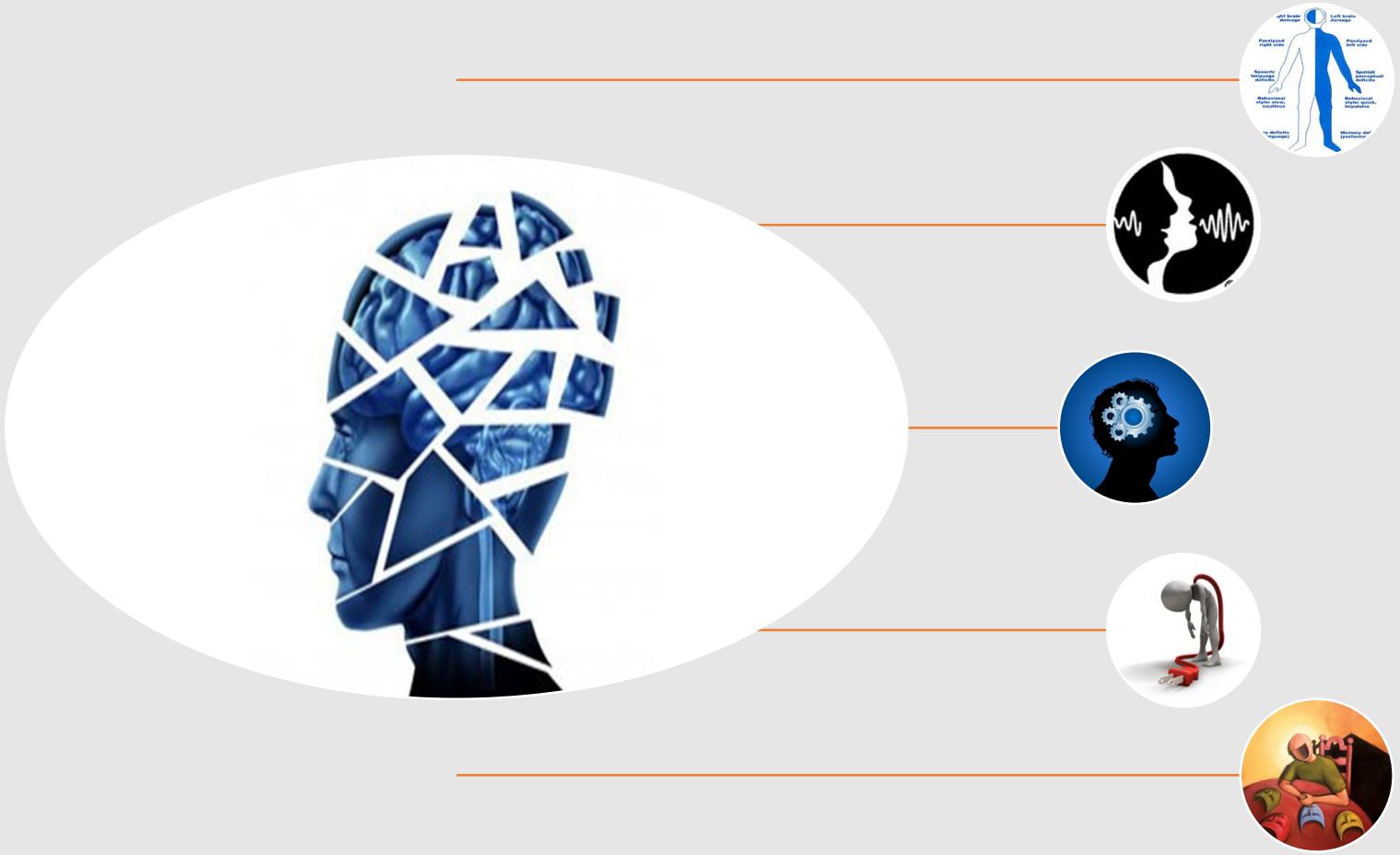
Background Health policies internationally advocate 'support for self-management', but it is not clear how the promise of the concept can be fulfilled.

Objective To synthesize research into professional practitioners' perspectives, practices and experiences to help inform a reconceptualization of support for self-management.

Design Critical interpretive synthesis using systematic searches of literature published 2000–2014.

Findings We summarized key insights from 164 relevant papers in an annotated bibliography. The literature illustrates striking variations in approaches to support for self-management and interpretations of associated concepts. We focused particularly on the somewhat neglected question of the *purpose* of support. We suggest that this can

A need to build skills and capability to manage health and well-being into the future?

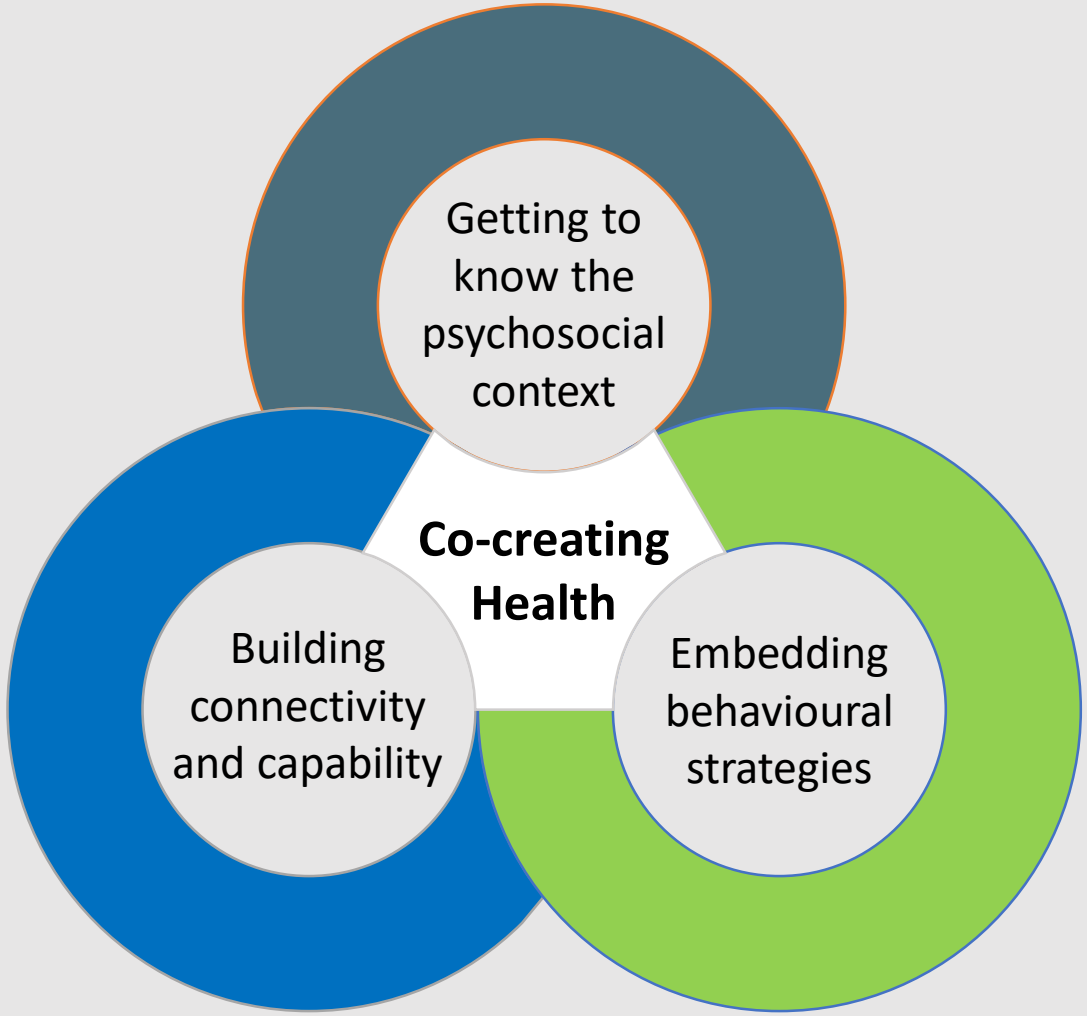


So, to co-create health we need….

- … to look beyond individual services?
- … to reconceptualise neurological injury or illness as a long term condition?
- … for flexible, responsive services that can meet people where they are at?
- … for transdisciplinary working?
- … to recognise personhood and foster hope?
- … to shift from managing the condition well to managing well with the condition?
- … to build skills and capability to manage health and well-being into the future?

Let’s co-create health - imagining a possible future…

Some of our thinking:
A framework for co-creating health?



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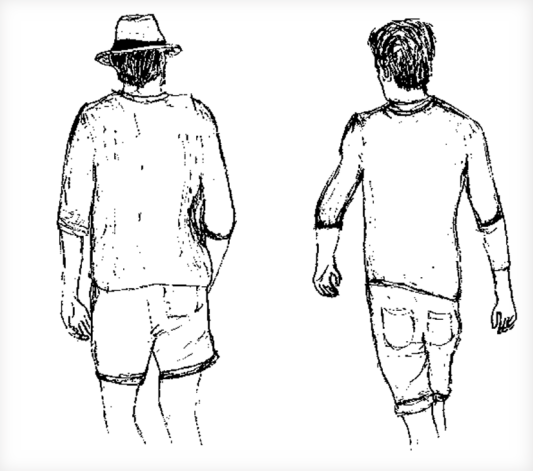
Some examples of how we are trying to do this in our work



Identifying Meaningful goals

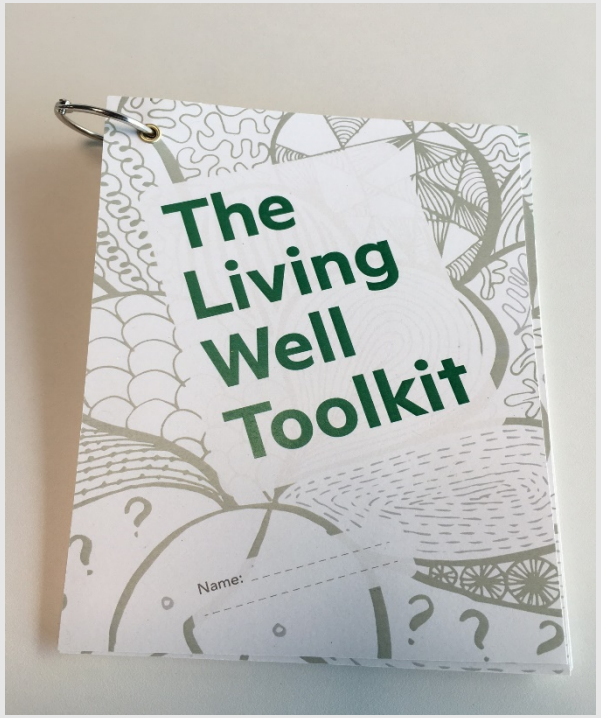
Anchor concrete actions, goals, tasks of therapy to what is meaningful

Planning to support implementation of intentions into action

The Living Well Toolkit

Suzie Mudge, Nicola Kayes, Ann Sezier, Deborah Payne, Paula Kersten, Kathryn McPherson, et al.

Who is this person and what do they need from me today?

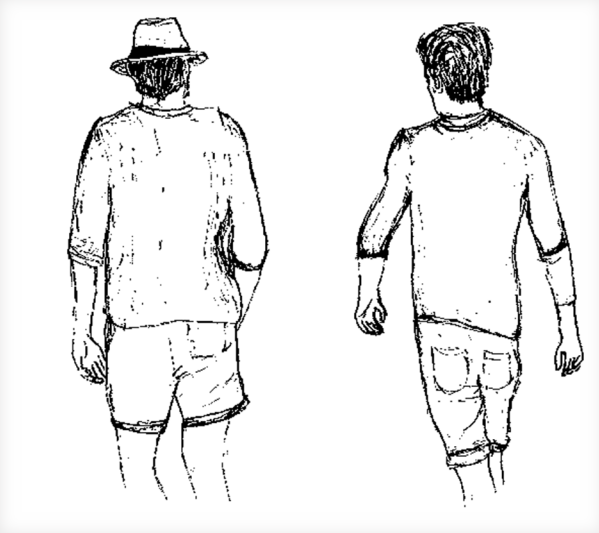


https://www.youtube.com/watch?v=vmx5U4DXIj8

Peer mentoring for people with TBI

Paula Kersten, Christine Cummins, Nicola Kayes, Richard Seemann, Allison Foster, et al.

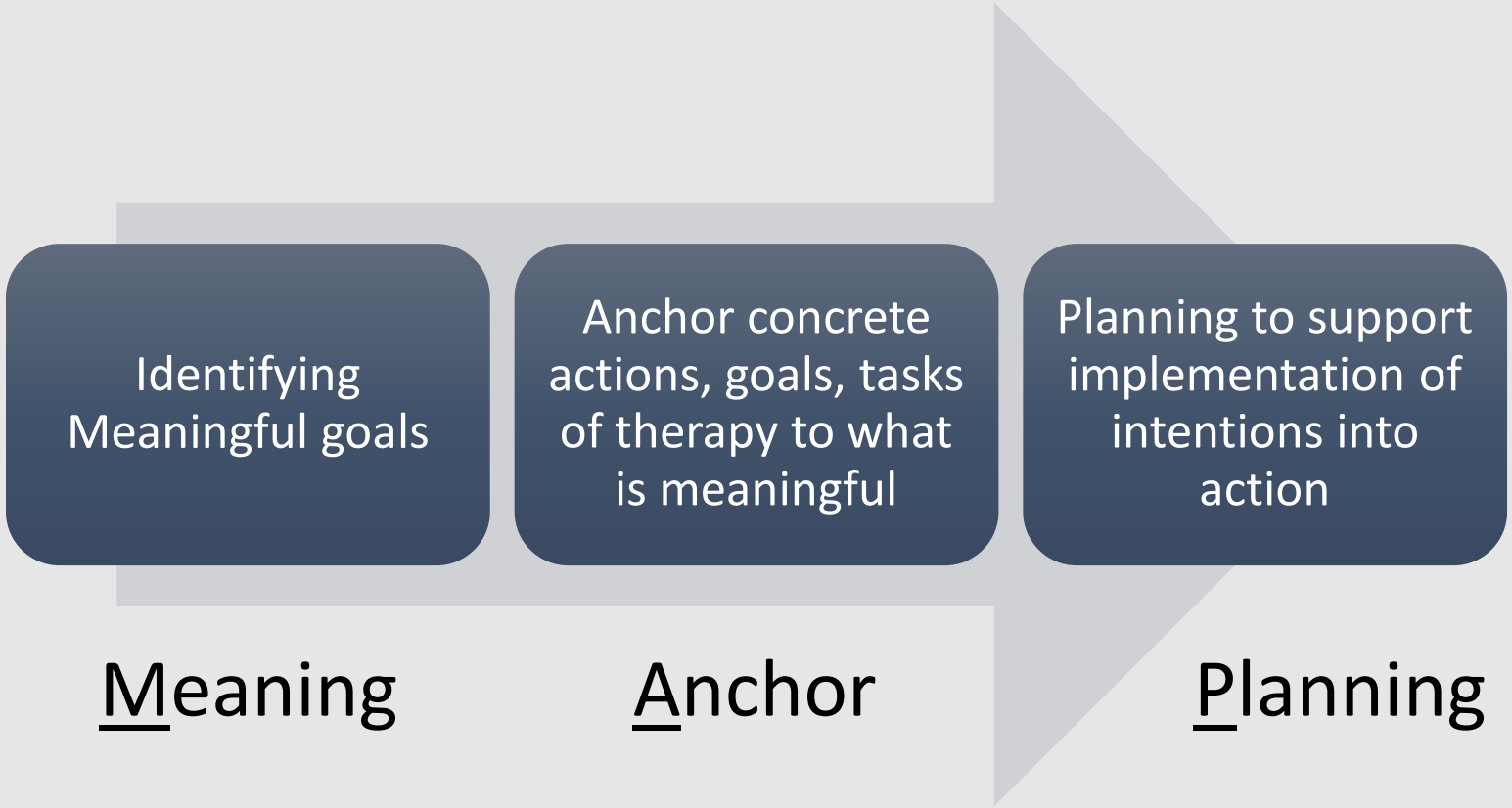
“Because he had been through it. … Because he had lived it and physically trained in that field by being run over on his bike. I am just new at this… He was like a brain injury guru”



“It helps you feel like you are understood, and you are not the only person going through this trouble, but there have been other people who have gone through similar things, who are able to show you a glimpse of hope that life gets better”

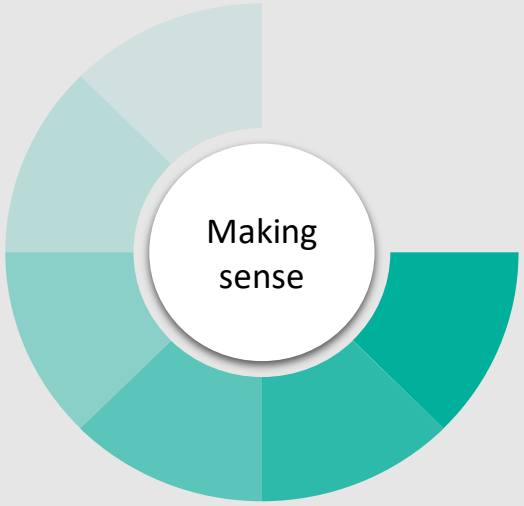
Goals, Health and Engagement - MAP

Nicola Kayes, Kathryn McPherson, Paula Kersten, Felicity Bright



So, lots of great ideas…

But, we know making change is….



CONDITIONS
Perceived value/need
Service structures
Knowledge broker

INTER/ACTIONS
Gathering information
Contextualising knowledge
Finding fit

CONSEQUENCES/ CONDITIONS
Consolidating
Developing coherence
Seeing the possibility

CONDITIONS
Knowledge broker
Simple/intuitive
Perceived expectations

INTER/ACTIONS
Looking for opportunities
Testing the water
Slipping it in

CONSEQUENCES/ CONDITIONS
Developing Capability
Recognising value
Tailoring

CONDITIONS
Reflecting on practice
Seeing results

INTER/ACTIONS
Gaining confidence
Experiencing success
Embedding into practice

CONSEQUENCES/ CONDITIONS
Feeling empowered
Feeling good
Making a difference

....complex...

…and there are multiple possible tipping points

“Although clinicians embrace a holistic approach to healthcare, what they do is still very discipline specific, and what they do is dealing with the here and now. Like your needs today. Like, ‘my needs today’ is very much what clinicians deal with on a day by day, on a session to session basis. That’s what I deal with really. And so… stepping back and looking at the bigger picture and equipping people for dealing with when they leave rehab or kind of taking care of their general health. Although, I intellectually think that is important, I can’t… when do I do it? Because there is always a my needs today that is more urgent and pressing for me to deal with and […] I think that’s the dilemma most clinicians find themselves in […] and I’m part of the responsibility, but not all of the responsibility […] does it feel like it’s a physios role? Or a psychologists role? Or… although its everybody’s role, but that can get clunky in itself”

(Physiotherapist and Senior Research Fellow)

Thinking about your practice

- I think….
- I feel….
- I wish….
- I am going to….
- I need….

In summary: to co-create health we need….

- … to look beyond individual services?
- … to reconceptualise neurological injury or illness as a long term condition?
- … for flexible, responsive services that can meet people where they are at?
- … for transdisciplinary working?
- … to recognise personhood and foster hope?
- … to shift from managing the condition well to managing well with the condition?
- … to build skills and capability to manage health and well-being into the future?

The challenge

- To do this well we need to
  - Reconsider what constitutes a good outcome; and
  - Put structural supports in place
- We need to harness the expertise, strengths and skills of people living with neurological injury and illness and their families
- Highlights the importance of valuing other core skills and processes e.g.
  - Therapeutic relationship
  - Goal planning
  - Teamwork
  - Behavioural adaptation
- More explicit emphasis on these core skills and processes has the potential to optimise the impact of neurorehabilitation

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