AUT PERSON CENTRED REHABILITATION RESEARCH CENTRE

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Practical learnings from a trial of peer support after brain injury

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Our research

- A randomised pragmatic waitlist trial with process evaluation
- Designed with implementation in mind from the outset
- Seeking to provide:
  - definitive evidence of the benefits of peer support after brain injury
  - services and funders with a framework that can underpin future implementation of peer support in Aotearoa







BMJ Open

Making sense of recovery after traumatic brain injury through a peer mentoring intervention: a qualitative exploration

Feasibility study

Full trial


Our first mentor training
Auckland, February 2020

Service Framework

Outcomes data

Primary outome: Participation
Secondary outcomes: Satisfaction with life, health status, hope, well-being, self-efficacy
Data points: Baseline, during, immediately post intervention, three months follow up

Process data

Mentee and mentor recruitment
Training and support
Service coordinator interviews
Service coordinator and mentor notes and reflections
Intervention delivery data



Indepth case analysis of mentee-mentor pair

Outcome, demographic and injury-related data
Interviews with mentees, whānau, and mentors
Service coordinator and mentor notes and reflections

Mentor experiences

Mentor recruitment data
Interviews with mentors
Mentor debriefing sessions
Service coordinator and mentor notes and reflections

In this session – our practical learnings







Our peer support intervention



Learning as we went

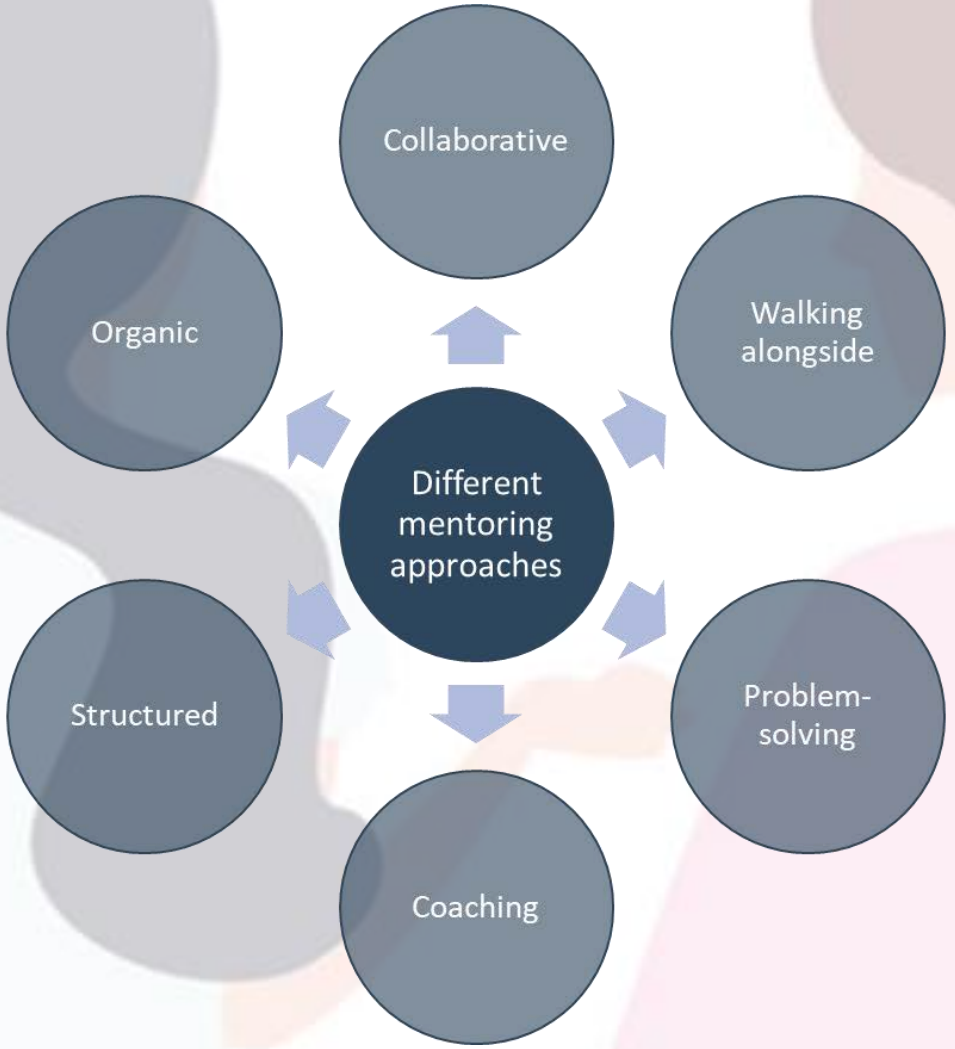
Intervention component	Feasibility design	Feasibility findings	Trial design
Mentor-mentee pairing	Matching on key characteristics e.g. ethnicity, gender, age	Logistically challenging Shared experience trumps matching on characteristics	Pair according to mentee personal preference and mentor availability/location
Intervention timing	Recruited in inpatient setting Peer support commence immediately post-discharge.	Post-discharge chaotic Loss to follow-up Scheduling difficult	Recruit mentees up to six months post-injury Flexibility to engage at a time that works best for them
Intervention length	Six sessions over three months	Time to develop trusting relationship Difficult to maintain pace and tailor to unique needs and context	Eight sessions over six months
Whānau involvement	Mentees could invite whānau participation	Whānau involvement limited Potential to constrain sharing	Whānau involvement informed by mentee 1:1 b/w mentor/whānau

Tailoring peer support using a modular approach



Session 1	Getting to know something about your buddy's interests; Getting to know something about your buddy's concerns
Session 2	Sharing injury and recovery experiences
Session 3	Exploring hopes for doing things that matter
Session 4	Exploring what is getting in the way of doing things that matter; Planning an activity together
Session 5	Doing an activity together
Session 6	Reflecting on what went well and what didn't go that well
Session 7	Planning where to next
Session 8	Reflecting on what went well & what didn't; Ending the relationship thinking about where to next

Allowing room for different approaches



Retaining key ingredients

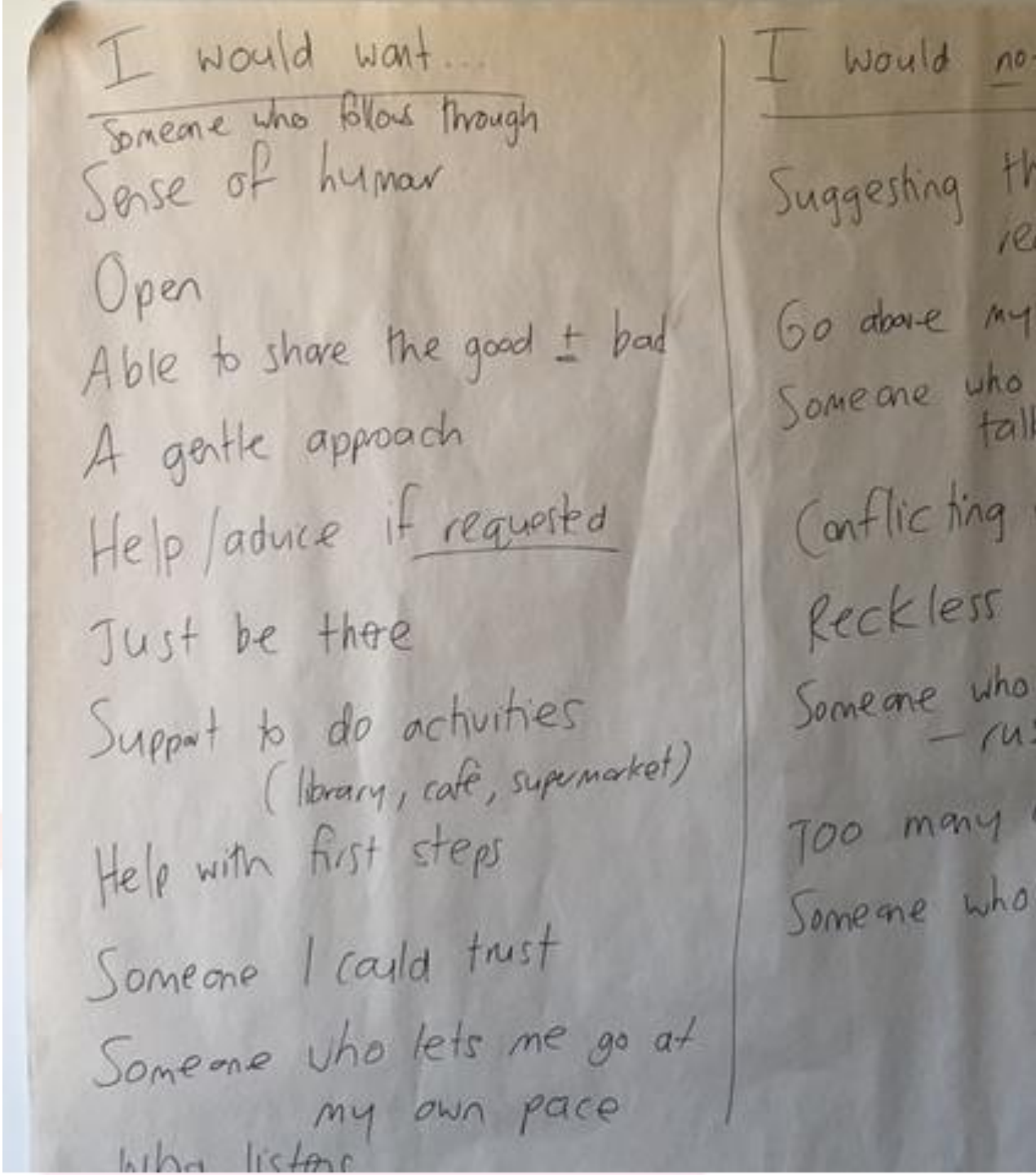
1. Lived and shared experience
2. A connection with purpose
3. Connecting through doing

Deborah (mentee): Just having somebody that you didn't have to pretend with. You didn't have to pretend that you were normal. And just understood exactly what it was like for you. (Mentee)

Marian (mentor): I never just waltzed in thinking […] we will just see what happens. I definitely prepared for each meeting with her. First thinking about what we would do and then I would always in my mind have topics that I wanted to ask her about or bring up or specific questions that I thought would get her thinking.

Peer training and support

- Value and legitimise lived experience in mentor
- Build confidence in existing skills and knowledge
- Integrated material derived in training sessions into peer support manual
- Group debriefing with mentors to share ideas and problem solve together



Modifying training to respond to needs and context

- Two days
- In person
- New mentors
- Topics
  - Sharing your story
  - A primer on TBI
  - What is a mentor?
  - Peer mentoring programme
  - Making connections
  - Managing mentoring relationships



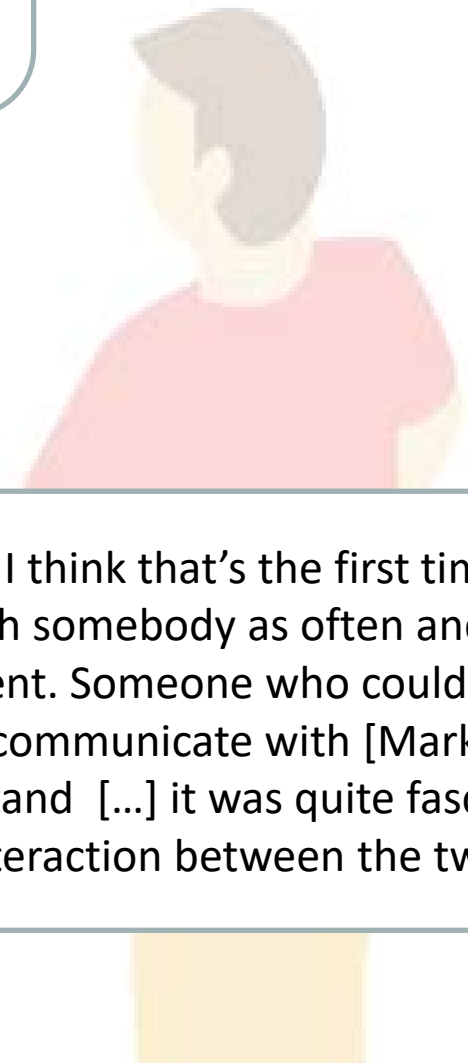
- Two sessions
- Online
- New and experienced mentors
- Similar topics but integrating learning from past experiences (of training and mentoring)

Experiences of peer support



Tom (Mentor): I think most recently [it is] what has helped me in getting this job in New Plymouth, which I'm very excited for. It's a job as a hearing therapist trainee. […] The things that actually got me the job, I think, would've been this and it would've been all the stuff like working in the community, in people's homes, sort of thing. Interacting with all sorts of different people.





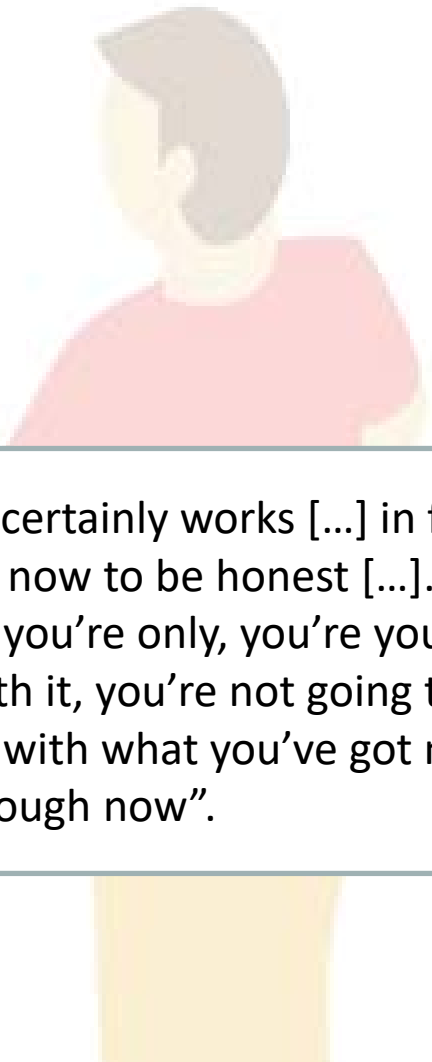
Sheree (Mentees mum): I think that's the first time that [Mark] has interacted with somebody as often and […] to that depth since his accident. Someone who could actually understand and perhaps communicate with [Mark] in the way [Mark] could understand […] it was quite fascinating just to watch that interaction between the two.

Caren (mentor): And just the confidence building and to know that I've still got some skills from my previous life, kind of blew me away I think, and just how efficient and effective I was. […] My experience and my strength and like, being able to share that with somebody was just like, and for them to be so absorbent and it to have such a miracle effect was just so woah, like seriously.

Deborah (mentee): She used to talk about just having to make a new life and stepping over the line and saying "Okay, this is my new life and I'm gonna go with it"… and I was definitely not in that space when I met her. I was still struggling to get back to my normal life. But, after being with her […] I have actually started a new life […] I feel as though I'm forging a new path, yep […] She never pushed it. She never ever said you should do this or should do that. She just talked and just listened.

Ben (mentor): Having done it and felt like I completed it too and made a difference […] I actually feel good about it. I am getting a bit emotional, but it has been huge for me in my recovery. Even like… it sort of gave me a purpose and a sense of purpose, so I certainly felt, […] I felt valued.





Michael (mentee): Yeah, well it certainly works […] in fact, I probably would have left my job by now to be honest […]. Ben was the one who told me… “Hey look, you’re only, you’re you, this is you now – do the best you can with it, you’re not going to be as good as you were before - just run with what you’ve got now and you’re good enough now”.

For mentees

- Normalising ones experiences
- Able to hear advice and guidance that is hard to hear from others
- Getting to grips with changed capacities
- A sense of hope
- Supporting work and relationships

For mentors

- The experience of TBI is worth something
- Able to make a valued contribution
- Reciprocal benefit – learning from each other
- Insights into skills and capabilities thought lost
- A critical component of ones own recovery

Future service delivery



Let go of the ‘right’ match

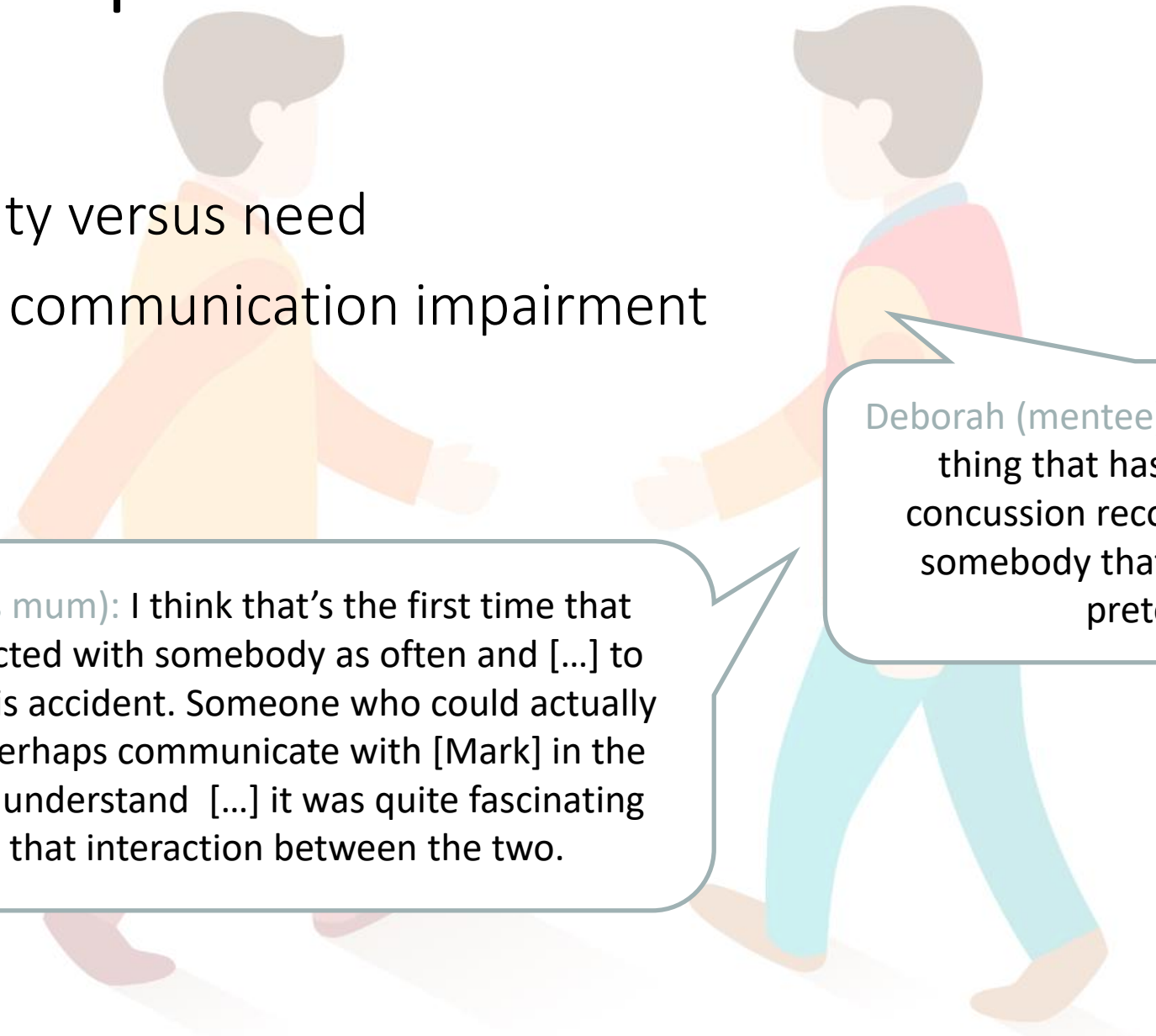
- Shared experience and life stage > injury/demographic characteristics

Deborah (mentee): Like she had memory loss like me now forgetting things. […] we had a lot in common, even though we had different injuries and different backgrounds we could still relate exactly on that level.

Marian (mentor): We were paired really well together because we are at a similar life stage, similar age and could obviously relate about our injury. But I think the reason we got on so well is that yes, we could relate about injury, but we also just happened to be at a similar life stage as well and so we just had so much to talk about and relate to each other about.

Make no assumptions about who can benefit from peer support

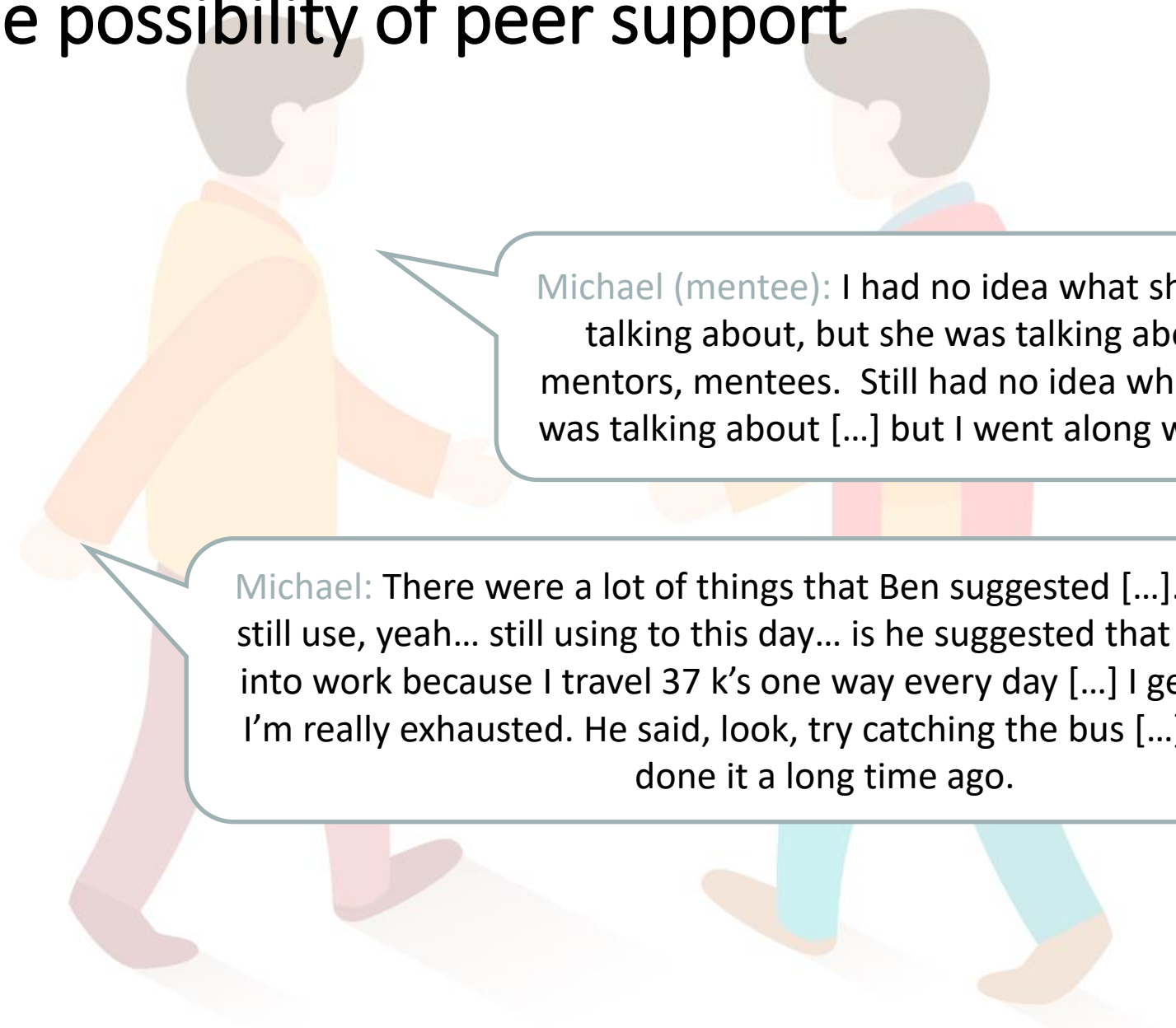
- Injury severity versus need
- People with communication impairment



Deborah (mentee): It's the best kind of a thing that has helped my whole concussion recovery […] Just having somebody that you didn't have to pretend with.

Sheree (Mentees mum): I think that's the first time that [Mark] has interacted with somebody as often and […] to that depth since his accident. Someone who could actually understand and perhaps communicate with [Mark] in the way [Mark] could understand […] it was quite fascinating just to watch that interaction between the two.

Open up the possibility of peer support

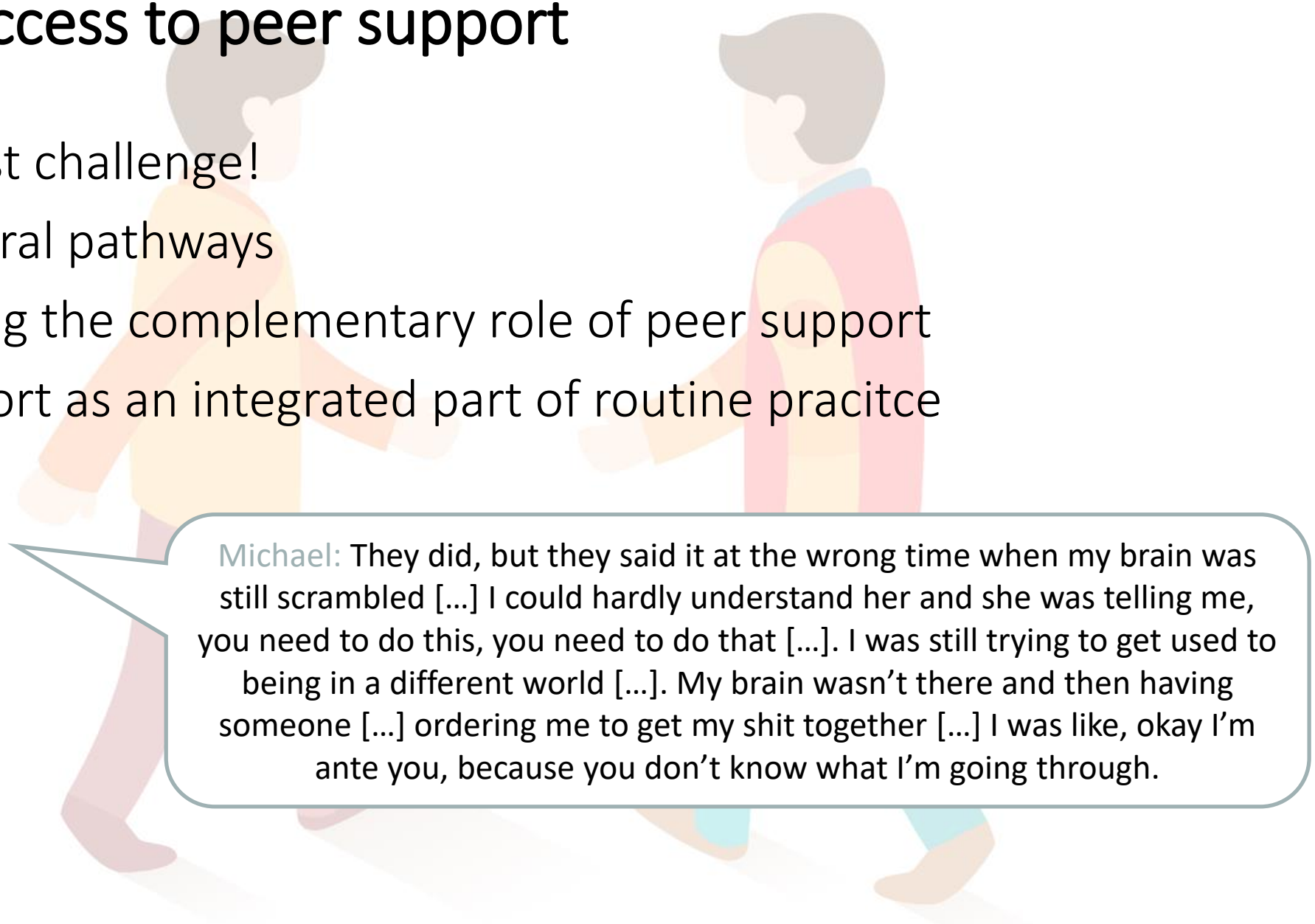


Michael (mentee): I had no idea what she was talking about, but she was talking about mentors, mentees. Still had no idea what she was talking about […] but I went along with it.

Michael: There were a lot of things that Ben suggested […]. The one that I still use, yeah… still using to this day… is he suggested that I catch the bus into work because I travel 37 k's one way every day […] I get to work, and I'm really exhausted. He said, look, try catching the bus […] I should have done it a long time ago.

Optimise access to peer support

- Our biggest challenge!
- Clear referral pathways
- Legitimising the complementary role of peer support
- Peer support as an integrated part of routine pracitce



Michael: They did, but they said it at the wrong time when my brain was still scrambled […] I could hardly understand her and she was telling me, you need to do this, you need to do that […]. I was still trying to get used to being in a different world […]. My brain wasn't there and then having someone […] ordering me to get my shit together […] I was like, okay I'm ante you, because you don't know what I'm going through.



Our peer support intervention

- Flex to respond to people and context
- Maintain key ingredients
- Above all else, legitimse and value lived and shared experience



Experiences of peer support

- Recognise the reciprocol benefit of peer support for mentor and mentee
- Potential to address outcomes currently not well addressed by existing services



Future service delivery

- Make no assumptions
- Value peer support as a key resource for recovery
- Take steps to integrate peer support into routine service provision

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Acknowledgements

- Health Research Council of New Zealand
- Paula Kersten (for her early vision)
- Christine Cummins (Project manager and Auckland service coordinator)
- Greta Smith (Data manager and assessor)
- Deirdre and Kathy (Northland and Tairawhiti service coordinators)
- ABI Rehabilitation and Te Hiku Hauora
- The rest of our very patient project team and steering group: Mark Weatherall, Joanna Fadyl, Christine Howard-Brown, Allison Foster, Braden Te Ao, Hinemoa Elder
- **Mostly importantly…. Our amazing mentors and mentees**



“My experience and my strength, and like being able to share that with somebody was just like… and for them to be so absorbent and [for] it to have such a miracle effect was just so woah, like seriously […]

…wow, I am really doing something really, seriously incredible… extraordinary actually”