People First NZ
Ngā Tāngata Tuatahi

DONALD BEASLEY INSTITUTE

University of Otago
ŌTĀKOU WHAKAIHU WAKA

Supported self management of health and wellbeing:

Where do rights and supported decision-making fit?

Ko wai mātou? Who are we?



We are going to talk about:



1. what we are doing in our research
2. outcomes of the first part of the project
3. what we are doing next.



Taunakitanga Takitini

3 projects about supported self-management of health and wellbeing:

- Māori
- Pasifika
- People with a learning disability

*Long-term health conditions

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Part 1 of the project



In part 1 we explored:

- what health and wellbeing means to people with learning disability
- the kind of support that people want and prefer
- what could help people to manage and make decisions about their health and wellbeing.

6 focus groups



- both islands
- big and small places
- Pākeha, Māori, Pacifika
- different ages
- People First members and non-members

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What health and wellbeing means to people with learning disability

Thoughts about health and wellbeing

“The difference (where I live now) is being safe, and not having abuse”

“It’s good to be out there so you aren’t stuck at home. That makes me feel better”

“Mental health is really important”

“Spending time with my friends makes me feel great”

“I like it when they [family and support services] listen to me”

More thoughts about health and wellbeing

“My home doesn’t work for me and I can’t go to choir because there’s no mobility van”

“People can be harsh. It really affects you”

“I have no say over who I live with, and I have no option to leave.”

“I don’t have enough money to get the stuff I need”

“They [supporters] don’t actually listen to what you are saying”

My Wellbeing

Supported decision-making



Being able to afford things



Emotional support



Spiritual support



Accessing counselling if I need it



Safety and respect in all spaces and not being bullied



Work



Exercise - getting enough and enjoying it



Being in control and making my own choices



Good relationships



Meaningful things going on in my life



Having fun activities or having some alone time



Being able to get outside in nature



My living situation



The right support for me



Physical health



Education and opportunities to learn



Mental health



Diet and food - being able to afford healthy food



Time with animals and pets

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The support that people with learning disability want with their health and wellbeing

What people told us about support

“Doctors get hoha (cross) with me”

“My GP doesn’t really know me”

“I want to have someone I trust to ask for support when I want it”

“I want support with some decisions, but there’s lots I can do on my own”

“I like advice, but I don’t always need help”

“You don’t have to do what they suggest”



Who do I want to support me?

- health professionals – for information and options
- people I trust and know well - to support me with making decisions and managing my health and wellbeing.



Good support involves:

- helping me to understand things
- listening to me
- asking before doing things
- respecting my choices
- supporting me to make / follow my plans

Supported Self-Management



Self-management

Doing it all yourself



Self-management support

Getting a little bit of support



Supported self-management

Getting the right support for you

Independent ⟷ Interdependent



Partner, parents, siblings, family



Friends



Support workers

Supporters must be respectful, not judge, and ensure choice and control

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Ideas for improving how people with learning disability can manage and make decisions about their health and wellbeing

Ways to improve things



1. Education for:
    - people with learning disability
    - Supporters
    - Health professionals
2. Greater use of health passports.

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What we are doing next



In part 2 we:

Co-designed courses for:

- people with learning disability
- close supporters (family, whānau, and supporter workers)
- health professionals



In part 3 we are:

- Trying out and improving the education courses
- Checking what differences the courses make

We are starting the courses soon.

Thank you and questions | Kā mihi me nga pātai



