

Flourishing throughout the lifespan: exploring what works (and doesn't work) to optimise health

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Burwood Academy of
Independent Living (BAIL)
Research that matters by people who care!



WHAT WE DID:

RESEARCH QUESTION

What works (and doesn't work) to optimise health for disabled people, and those with long term health conditions, to flourish throughout their life span?

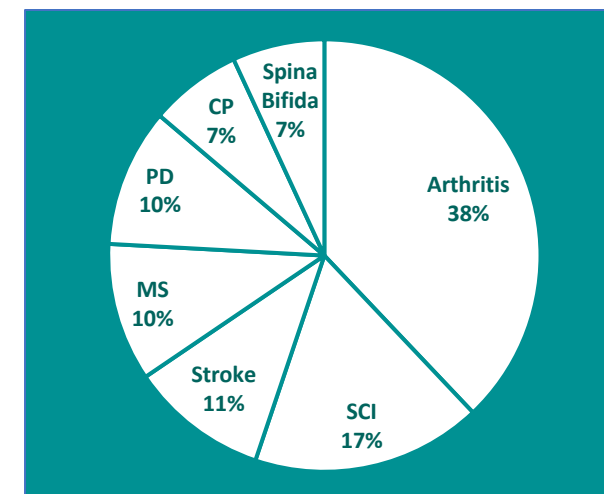
We **interviewed 30 people** with a range of long-term health conditions including arthritis, spinal cord injury (SCI), stroke, multiple sclerosis (MS), Parkinson's Disease (PD), cerebral palsy (CP) and spina bifida.

We intentionally included people who had acquired their health conditions at birth, during childhood and adolescence, and in adulthood.

The age of participants ranged from **20 - 65 years.**

People reported a wide range of functional limitations and experiences of disability.

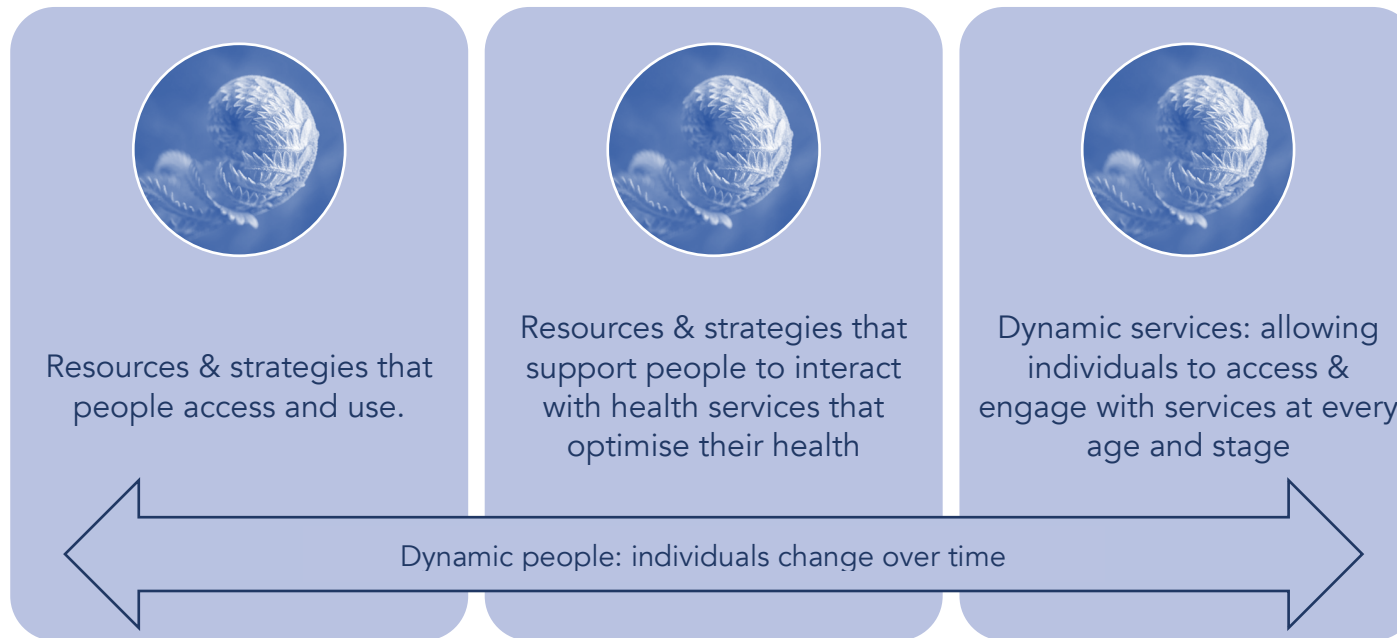
We conducted two **feedback workshops** with 10 of the participants.



We have used qualitative methods to analyse the interview transcripts. We have been particularly interested to explore what internally-derived (i.e., personal characteristics and strategies) or externally-provided (i.e., environmental contexts, types of interactions, processes) resources work to support people to live well and flourish across the lifespan. Given the timing of the interviews – which took place during the COVID-19 lockdown restrictions of 2020, we have also been able to explore how this impacted on people's ability to maintain their health. We used the feedback workshops as a way of checking our findings, and to explore next steps with participants.

BAIL gratefully acknowledges funding support provided by the NZ Rehabilitation Association (NZRA), the Canterbury Arthritis Supporters Trust (CAST) & the MSD Community Awareness and Preparedness Grant Fund

WHAT WE FOUND:



RESOURCES & STRATEGIES THAT SUPPORT PEOPLE TO ACCESS & INTERACT WITH SERVICES SO THAT THEIR NEEDS & ASPIRATIONS ARE MET

- Accessing information
- Navigational support
- Consistency – they know me and my story
- Listened to and respected for my knowledge
- Enacting personal choice and autonomy
- Co-constructing plans

DYNAMIC PEOPLE: INDIVIDUALS CHANGE OVER TIME

- Acceptance and identity-development over time
- Shifting priorities over time
- Emerging expression of health condition on body and experiences over time
- Emerging 'expert' status over time

DYNAMIC SERVICES: INDIVIDUALS CAN ACCESS & ENGAGE WITH SERVICES AT EVERY AGE & STAGE

- Services need to meet my needs across the lifespan
- Services need to meet my needs even when my impairments are 'invisible'
- Services need to meet my needs even when my impairments emerge gradually over time
- Services need to meet my needs even when my health condition fluctuates
- Services need to see me as whole person

RESOURCES & STRATEGIES THAT PEOPLE USE OF ACCESS TO SUPPORT FLOURISHING

- Community and connection with peers
- Community and connection with friends and family
- Contributing
- Personal attributes (e.g. perseverance, reframing, kindness to self)
- Environmental considerations (e.g. technology, transportation)
- Financial security ensures choices and options

WHAT WE AIM TO DO NEXT:

RESEARCH APPLICATIONS THAT HAVE BUILT ON THIS WORK:

Flourishing together: including tāngata whaikaha in health policy development – HRC Emerging Research First Grant (under review)

Involving disabled people in health-related policy development: Exploring what has worked, how and why in Ōtautahi/Christchurch – Lotteries (declined); CRMF Art Auction (in process)

OTHER IDEAS:

How to best **co-construct management plans with GPs** (e.g., medication, self-management of symptoms, liaison between primary and secondary care providers, access to equipment and environmental supports).

What environmental factors best support people to participate in meaningful activities and life roles? For example, accessibility features, policies and processes, financial security options, housing, technology, attitudes.

Navigating health services – what works best to support people with long-term, complex and dynamic health conditions?

ALIGNING WORK THAT IS ALREADY HAPPENING:

Staying on Track: designing a peer-led self-management programme for people with newly acquired SCI and their whānau

Early vocational rehabilitation following acquired neurological health conditions (EVocS study)

Co-designing pain services for people with SCI.

Building psychosocial and cultural resources for living with age-related neurological impairment.

If you would like more information and/or would like to offer your ideas and suggestions, please contact me.

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