

# "Leaving no one behind" : Housing realities of people with multiple and complex disabilities in New Zealand

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Umi Asaka and Associate Prof. Brigit Mirfin-Veitch



**DONALD BEASLEY**  
INSTITUTE



# Background

- Housing for disabled people has been impacted by attitudes and policies
- United Nations Convention on the Rights of Persons with Disabilities:  
Article 19 and 28
- Institutionalisation continues for people with multiple and complex disabilities
- United Nations Guideline on Deinstitutionalisation



# Purpose

- Disabled Persons Led-Monitoring of UNCRPD
- Monitor disabled people's experiences of housing



# Method

- Disability Rights Promotion International (DRPI)
- Ethics: Informed consent
- Perspectives of family, whānau and close supporters
- Semi-structured qualitative interviews
- Thematic analysis
- Narrative and critical disability theory



# Demographics

Age	Number
Mothers of children with complex disabilities younger than 18	3
Mothers of adult children with complex disabilities older than 18	5

Living situation	Number
Living with their family member	6
Living separately from their family member (Group home or Kāinga ora house)	2

Ethnicity	Number
NZ European	6
Pasefika	1
Asian	1



# Theme 1: Physical access

- An absence of accessibility-responsive legislation
- A lack of accessible housing stock
- A lack of consideration given by property developers and builders



# Theme 1: Physical access

“That’s why these rules and policies need to be changed - because these people do not have any compassion.”



# Theme 2: Financial access

- Financial capability to build accessible house
- Financial challenges attached to being a primary carer
- Divide between ACC and MoH



# Theme 2: Financial access

“For us, we’ve had to sink a lot of money into this and we’ve been fortunate that we could do that but we definitely shouldn’t have to do that but if you haven’t got much to start with then it’s not fair. It’s going to make you poorer. I mean having a disabled child means a lot of mothers can’t work and that immediately puts the whole family at a financial disadvantage. So, I think there is a lot of people with disabled family members who probably are lower socio economic but in places that don’t work for them. And I think that should be a priority. Just making sure that people have got decent houses” (DBI, 2020: p.49).



# Theme 3: Support at Home

- High level coordination required
- Recruitment and Training



# Theme 3: Support at Home

“So for our support workers that are on contract, we created our own contract. They’re all independent contractors apart from our regular support team and we were then able to use the language that was important to us.”



# Theme 4: Future planning

- People with multiple and complex disabilities often do not follow the “usual” life trajectory of leaving home at a certain age
- Future housing options felt like “elephant in the room”
- Skills and networks appears to be important



# Theme 4: Future planning

“I really want to know that when I’m not here, [my child] will be, and I think, well I was the [part of disability organisation] prior to last year, and I’m really worried about all the parents that are keeping their kids at home because they don’t trust providers. And I know why they don’t, but I want to try and make a model that they will [trust] [...] I’m really wanting somebody to be able to manage it [my child’s support arrangement] full time if I’m not here, so that’s what we’ve been fighting for.”



# Discussion

- People with multiple and complex disabilities experience multiple systemic barriers to accessible housing
- Some families feel like the only option for their disabled family member is residential services.
- The deinstitutionalisation guidelines provide clear instructions on what governments must do to ensure people with multiple and complex disabilities have access to adequate housing according to the UNCRPD.



# Conclusion

“(b) Develop a comprehensive deinstitutionalisation strategy, with specific timeframes and adequate budgets, to close all residential institutions, including group homes and residential specialist schools to provide community supports for persons with disabilities to live independently in the community“



# Any Questions?

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## ■ **Key Finding 1:**

Many families felt they had little to no choice or control over housing and support at home. Adequate financial resources and knowledge of how to navigate the system increased their sense of choice and control.



# Contact us

- Umi Asaka: [uasaka@donaldbeasley.org.nz](mailto:uasaka@donaldbeasley.org.nz)
- Associate Professor Brigit Mirfin-Veitch: [bmirfin-veitch@donaldbeasley.org.nz](mailto:bmirfin-veitch@donaldbeasley.org.nz)
- Artist credit: Eve McCoy

