Research Project Impact Case Study

Pandemic preparedness
and learning disability

Key researchers
[1]**Assoc Prof Brigit Mirfin-Veitch,** [1]**Dr Robbie Francis Watene,** [1]**Dr Kelly Tikao,**
[1]**Jacinta Tevaga,** [1]**Dr Solmaz Nazari,** [1]**Julia Young**

[1]Donald Beasley Institute, Dunedin, New Zealand

Research activities

Since our submission to Te Niwha, we have progressed our research and conducted the following research activities:

- An integrative literature review of academic and grey literature, using both Google Scholar and Academic Search Complete (EBSCO host). The literature was then thematically analysed to identify key themes
- Interviewing five people with a learning disability with different living situations during the COVID-19 pandemic
- Interviewing two family members/support persons for people with a learning disability
- Interviewing two health and disability service providers
- Data analysis
- Identifying key themes
- Developing people's stories and case studies

With the completion of the above research activities, the next step in our project is the co-production of a framework for ensuring that people with a learning disability are informed about, and inform, future infectious disease and pandemic response planning.

Findings

To date, our findings have provided insight into:

- The experiences of people with a learning disability during the COVID-19 pandemic
- The impact of different living situations on the experiences of people with a learning disability during the COVID-19 pandemic
- The impact of the COVID-19 response on people with a learning disability
- Critical factors to ensure future infectious disease and pandemic planning are responsive to and accessible for people with a learning disability

Results

Our findings indicated that the experiences of people with a learning disability during the COVID-19 pandemic were characterised by uncertainty, isolation, and a lack of accessible information. Our participants told us they did not know why they needed to go into lockdown, what was happening, and why there were restrictions on what they could do and where they could go.

Different living situations played a significant role in the experiences of people with a learning disability during the COVID-19 pandemic. Those who lived on their own felt they had fallen through cracks, as they did not receive any support during the COVID-19 pandemic and lockdowns. While those living in residential settings faced additional restrictions, they had a small community within their bubbles, which helped them feel less isolated. People with a learning disability who lived with their families and whānau talked about the importance of connectedness and receiving support from their family, which they saw as instrumental in assisting them to get through the COVID-19 pandemic and lockdowns.

Participants told us that the COVID-19 response did not take into account people with a learning disability. There was little accessible communication, and no provision for people with additional access needs, who could not use technology, and those who could not navigate the overwhelming information and guidelines. Confusing guidelines, rapid shifts and constant changes created additional challenges for people with a learning disability. They reported that national and local learning disability advocacy organisations helped them navigate the pandemic. These organisations provided trusted advice and advocacy that was not available via any other organisation or mechanism.

Participants told us that disabled people should have been at the decision-making table to ensure the response and guidelines were appropriate for disabled people. They would like to see disabled people play a significant role in planning and preparedness for future responses to infectious diseases and pandemics.