



**New Zealand disability support network (NZDSN)**

23 March 2022

To: Human Rights Commission

**Re: Inquiry into the Support of Disabled People and Whānau During the  
Omicron Outbreak**

Tena Koutou,

Thank you for the opportunity to participate in the above inquiry. NZDSN is the national peak body that represents over 160 organisations that provide support services to disabled people, mainly through contracts with government. As a membership-based organisation, we lead, and influence changes required to support an inclusive life for disabled people in Aotearoa New Zealand.

Since the beginning of the Omicron outbreak, our members have communicated to us their difficulties in ensuring service continuity. We have also witnessed anecdotal evidence of disruptions in Disability Support Services (DSS). We believe there are critical lessons for the health and disability support system to be learned from the Omicron outbreak. Hence, we support the inquiry, and we are willing to assist and contribute accordingly.

Below are our responses to the questions. We have collected feedback from our members and compromised them in answering each question.

## Questions

### *General questions*

#### **1. What has been the overall experience of the disabled people and whānau in your community or network during this Omicron phase of COVID-19?**

Disabled people and their families and whānau have had a particularly difficult time during the Omicron outbreak, and throughout the entire COVID-19 pandemic. Families have been concerned for their vulnerable disabled person and have found it difficult and frustrating to access disability specific information. Education has been a particularly challenging space. Many people are going without supports they normally receive, and others are needing further supports which are not easily accessed or available.

Overall, people in the disability community are feeling particularly isolated, and are feeling higher than usual levels of anxiety. Many are choosing or feeling compelled to isolate due to concerns for themselves or vulnerable disabled family members. Others are isolated due to disruptions to support provisions, and abrupt and frequent changes to daily activities. Families are finding the social isolation particularly challenging, and report an overall loss of community connectedness.

Many disabled people and whānau have raised concerns about communication issues and lack of timely access to PPE, in-home vaccination, and RAT tests.

Some families in the disability community feel tired after 2 years of minimal Respite opportunities being available – e.g. facility-based Respite has been closed, many community activities stopped, and support workers have been unwell

Ever since the pandemic, people with disabilities have been affected that such labels have led to them feeling embarrassed, created additional barriers, and reduced access to routine health care and rehabilitation. In particular this extended period of uncertainty has caused mental health issues and distress as well.

#### **2. How would you describe the community, network, organisation, or membership that you are considering in your responses?**

Disabled people and their family/whānau, and disability service providers including organisations, carers, and support people.

### *Specific questions*

#### **3. Access to relevant information and advice during the Omicron outbreak:**

##### **a. What do you know about the experiences of disabled people and whānau around accessing information and advice about COVID-19 during the Omicron outbreak?**

Since the beginning of the pandemic, disabled people and their families and whānau have had challenges accessing information that is relevant to their situation. Often any

disability specific information seems to have been an afterthought, or a response to issues and challenges, rather than being provided ahead of time. There is no 'one stop shop' for all COVID-19 related information, and the COVID-19 website does not have enough disability specific information.

The COVID-19 website has become increasingly difficult to use and navigate as the amount of information on the website grows. Many people in our communities have also reported challenges with the accessible phone number.

Overall, people are struggling with the amount of conflicting information. People are receiving different advice from Ministry of Education, Ministry of Health, GP's, Pharmacies and the media.

**b. What has the experience of your network or organisation been of accessing relevant information and advice?**

At NZDSN, we have sometimes received a large number of requests from our members for COVID-19 related information that is tailored to their situation as a disability service provider. Finding this information has been challenging and has often required multiple phone calls to different agencies, and lengthy time spent searching various websites. Often the information that is needed has had to be found and accessed through speaking with multiple sources, rather than being available via sector wide announcements made to everybody.

Some of our members have reported the same issue; they have struggled at times to locate and access relevant information and advice.

**c. How clear, accessible, timely and easy to understand has information and advice been?**

The information has not been timely. And the information that is significant for the disability community seems to be presented in reaction to experiences and issues rather than being considered and imparted ahead of time.

Information has also not been clear across platforms which has led confusion for the disability community resulting in unnecessary additional stress (for instance, mixed advice on accessing PPE and lack of transparent information around RAT kits). There have been multiple instances where information provided to some parts of the disability community was conflicting with information provided by health professionals or information communicated through official media. Frequent changes to messaging, phases, and stages required an ongoing flow of information to be passed on to the disability community.

Easy read and simple English formats have been extremely limited throughout this phase of the outbreak. This has caused issues for disabled people as well as disability service providers.

**d. How has information and advice been tailored towards different groups and organisations (including updates over time)?**

Critical information and advice have never been appropriately and adequately tailored and communicated to disability service providers. Generally, the disability specific COVID-19 information has been reactionary or provided last minute or late. The only exception was information provided to the disability community at the beginning of the vaccine rollout.

#### **4. For people who get COVID-19 during the Omicron outbreak:**

##### **a. What do you know about the experiences of disabled people or someone in their bubble who get COVID-19?**

There has been a considerable impact on disabled people, their family and whānau, and their support workers/carers when someone in the family gets COVID-19. The biggest challenge for our members has been delivering full PPE to COVID-19 positive disabled people to continue their support. In addition, many families and whānau have been isolated at home, sick and unable to look after their family member with the disability. There is little support for people in this situation, especially when people have to reduce their bubbles and continue to provide care (sometimes in the absence of a support worker) meaning ongoing exhaustion for family members.

Families and whānau have also struggled with the inability to be financially prepared. Many of the people in our communities live week to week, and do not have the financial means to stock up on groceries, or the essential supplies needed to get through COVID-19.

Families and whānau have also had challenges with getting disabled family members tested for COVID when there is a positive case in the household. For those who are not able to perform at home RAT tests on their disabled family member we have reports people have waited upwards of three weeks to get an appointment for a test for their disabled family member.

##### **b. What do you know about the experiences of disabled people and whānau in seeking assistance when they or someone in their bubble has tested positive for COVID-19 or needs to isolate?**

Our members told us it has not been clear for disabled people and their family and whānau as to where people can seek assistance when they are isolating with COVID-19. We heard of families who were too unwell (bedridden) with COVID-19 to care for their disabled family member, but they did not know who to contact.

We heard from our members that many families and whānau are unaware they can request assistance with food, it seems in certain areas this is more widely known (Auckland), whereas other areas this is not as widely publicised. In addition, many people in the disability community are also feeling a stigma of testing positive which is impacting the support they have around them – especially local or community-based support.

##### **c. To what extent has assistance met their needs?**

We heard from our members that the assistance has been sufficient for some disabled people and their family and whānau. However, this has not been the case for the majority of the disability community.

### **Government support**

#### **5. Continuity of care:**

##### **a. What do you know about the experiences of disabled people and whānau during the Omicron outbreak, who usually receive services, e.g., funded by the Ministry of Health (DSS/Aged Care supports), ACC and DHBs?**

Many people in the disability community were significantly affected during this outbreak in various ways.

- Disability programmes are being cancelled or significantly reduced so daily routines for many disabled people have changed. In some cases, disabled people are being left with long gaps in their daily routines. For example, many full-day disability programmes are being cut in half, and the number of people attending has been reduced.
- Our members have been dealing with staff shortage for a long time. The Omicron outbreak has exacerbated the problem and many providers struggle to provide quality and timely services to disabled people. Vaccine mandates have also contributed to this issue.

##### **b. What do you know about the communication that disabled people and whānau have had with their support provider about potential service disruption?**

We heard from our members that communication has not been ideal. The information they received from official channels was usually delayed. In addition, sometimes general updates have been long and confusing and not accessible. Some information was not tailored to disabled people and their families and whānau. Our members have tried to openly communicate possible disruptions and share their plans with disabled people and their whānau. However, some support providers have been under significant pressure and did not have enough staff/resources create tailored communication to their clients.

##### **c. Have disabled people and whānau had opportunities to have input into revised plans, due to service disruption? If so, how?**

This has not been universal. Some providers have been able to engage disabled people and their family and whānau in creating a revised plan or providing alternative support.

##### **d. Have disabled people and whānau had services disrupted without any prior communication? If so, how?**

Yes. Some services had to be closed on very short notice due to the staff being infected or having a household member infected with COVID-19.

**e. Are experiences different for disabled people on Individualised Funding or receiving personalised budgets? If so, how?**

The feedback from our members indicates disabled people on Individualised Funding have generally had less disruption to their services. Although there is more flexibility for those on Individualised Funding, it has been difficult to find or replace support workers. In regard to the current more flexible arrangements, there seems to be a considerable amount of confusion as to how long these arrangements will be in place for. Communication around this has been clear.

**N.B., if possible, please say which government services you are referring to in your responses.**

**6. Accessing broader government services (e.g., income support and housing):**

**a. What do you know about what disabled people and whānau experience when seeking assistance with:**

- **Access to essentials (e.g., food, medication, data / access to communications) if self-isolating**
- **Testing (incl. RATS, transport etc)**
- **Access to PPE**
- **Access to vaccination, and accessible information on vaccination**
- **Information about anti-viral medication, if most at risk (e.g., immuno-compromised)**
- **Access to anti-viral medication, if most at risk (e.g., immuno-compromised)**
- **If not connected to any service, where to go for disability assistance (e.g., a person to collect food and bring it inside – not drop at door etc)**

**N.B., if possible, please say which government services you are referring to in your responses.**

Please see below answers based on feedback we received from our members. Overall, disabled people have had significant issues and barriers to access these services; from accessible information about where to go for assistance, to the accessibility of the services. As an example, many community testing centres have a drive-through configuration for distributing RAT kits. These are completely inaccessible for the blind and vision impaired.

**Access to essentials:** Many people in the disability community are unaware they are able to get support with accessing food and other essentials. Some of our members (disability service providers) have had forms for people to fill out regarding access to essentials but the general awareness of support services is low.

**Testing:** Access to tests has been difficult for many disabled people. They were not able to access PCR tests, and there should have been earlier access to RAT tests for the disabled

community. We have heard from disabled people who had to wait in long queues for tests. Initially, people could not pick up tests on behalf of someone else which created issues for disabled people. There have been reports of inconsistency between distribution centres around the number of kits given out; so, some disabled people have had to go back to pick up more tests. The website to order RAT tests is working better, however this should have been actioned sooner. Community pick up centres are not accessible to everyone, they are not open very long hours, and there seems to be confusion regarding collection centres versus testing centres.

**Access to PPE:** Access to has been varied. Some service providers received some PPE in time and were able to distribute those among their clients. So, some disabled people have been provided with PPE, others have had to purchase this themselves.

**Access to vaccination:** For those who require support with getting a vaccination or their family member vaccinated, this has been challenging. Access to getting a vaccination done in their own home for those disabled people who cannot go to a clinic has been particularly difficult. People requesting this service were not followed up with and when they were, had to endure lengthy questioning as to the reasoning for requesting the extra support. We heard from our members that some disabled people gave up on this in the end, choosing not to get vaccinated because the process was so stressful. It is noteworthy that service providers report the first round of vaccination going smoother; information has been good with accessible formats available. Relevant DHBs send teams to various service providers to vaccinate all clients and some staff. Unfortunately, this has not been the case for the second vaccine, and service providers had to take their clients to vaccination centre. This has created a challenge for providers and disabled people.

Our members have reported that if disabled people are not connected to a service, there is not enough information on where to go for assistance.

**7. What do you know about disabled people and whānau experiences of getting assistance from their regular 'go to' places such as Māori providers, Pasifika providers, and GPs? Where have people tried to get assistance – and has it worked?**

Regular "go to" places have been overloaded and many people are not getting the support they require.

*Questions for Māori and Pasifika rōpū and providers*

- 8. Could you please provide any details of any additional Government assistance (including information, funding, other supports) for responding to the Omicron outbreak and meeting the needs of Māori and Pacific people and whānau?**
- 9. Could you please provide any details of how your workload has been impacted by the need to ensure Māori and Pacific peoples have access to vaccination and accessible information on vaccines?**

We did not receive any significant feedback from our members regarding Māori and Pasifika rōpū and providers. It seems that Māori and Pasifika rōpū and providers are experiencing the same issues and difficulties as other disability service providers. However, we recognise there might be specific issues that warrants further investigation.

### ***Final Questions***

**10. Do you think the voices of disabled people and whānau have been included in any planning to date about the Omicron outbreak? If yes, could you tell us how?**

Unfortunately, this has not been the case. Most of the disability information/support has been implemented as an after thought after families and disability organisations demanded response.

Many people in the sector have reported the first round of vaccination was the last time disability had a voice in the COVID-19 pandemic.

**11. Do you have any recommendations for the Government to help address any issues disabled people and their whānau may have experienced during the Omicron outbreak?**

- There should be a comprehensive plan for the disability community during pandemics and humanitarian crises
- Specific and targeted support is required for disabled people to meet their various needs and wants
- Issues of loneliness and depression amongst the disability community needs addressing urgently
- Disability (including family) voice and participation needs to be given meaningful consideration, from the outset and all the way through
- Information needs to be simple, easy to locate and consistent
- Disabled people and their families and whānau should be given flexibility and self-determination in these particular times of stress and uncertainty. Sometimes this means letting go of the 'red tape' in order to ensure people's needs and rights are being met
- Wider access to PPE and RAT tests

**12. Is there anything else you wish to share with us?**

We believe there are three systemic issues for government to address:

1) Data on disabled people and their families and whānau is lacking. Government has had opportunities to improve the data on disabled people and their whānau through this Pandemic.



2) Disabled people and their whānau need a clear simple plan. Government had the opportunity to have a plan generated by disabled people and their family and whānau for disabled people to navigate the pandemic, but chose a different path.

3) Specialist disability unit is required over government agencies and Ministries including Health, DPMC, MBIE, Education, ACC etc . A new Ministry for Disabled People offers hope, but it will need to have more clout than the junior Ministry it is currently positioned as.

**13. Can we contact you to clarify any written information you have provided?**

Yes

**14. Do you give us permission to attribute your comments to your community group, network, organisation or rūpū? If no, we will share your comments anonymously.**

Yes

We thank you again for providing us with the opportunity to contribute to the inquiry. NZDSN is willing to collaborate further on initiatives that improve the health and well-being of the disability community.