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Self-advocates with Down syndrome research: The lived experiences of COVID-19 lockdowns in Aotearoa New Zealand

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Abstract

Background: Individuals with Down syndrome are particularly vulnerable to COVID-19 because they are recognised as significantly immunocompromised. Yet their voices regarding their lived experiences of pandemic lockdowns have not been sought or heard.

Aim: This study aims to describe the lived experiences of people with Down syndrome during the pandemic lockdowns in Aotearoa New Zealand to add evidence in order to inform systemic advocacy.

Method: A mixed-methods approach positioned within an inclusive research paradigm was used, in which a group of self-advocates with Down syndrome co-designed a structured interview schedule and conducted 40 face-to-face interviews. Key themes were identified by using content analysis.

Results: Despite the difficulties associated with lockdowns and participants not receiving their usual supports and having to make significant adjustments, they remained positive, adapted well, and demonstrated a high level of resilience and adaptability.

Conclusions: The findings add to the limited research on the lived experiences of people with Down syndrome during pandemic lockdowns. This research has given them a voice to contribute to policy, government initiatives, and service providers; particularly on issues around support during lockdown and staying connected with others.

KEYWORDS
COVID-19, Down syndrome, inclusive research, lockdown, self-advocates

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VACCARINO ET AL.

1 | INTRODUCTION

Early in 2020, the novel coronavirus SARS-CoV-2, or COVID-19, was spreading rapidly across the globe. Millions were infected and the everyday lifestyles of most people were significantly affected. This global pandemic has impacted on the way we socialise, how we interact with others, and how and where we work. Isolation, masks, physical and social distancing, limited or no access to essential services, and fear, amongst others, have become typical realities in a COVID-19-gripped world. These are extremely challenging times for everyone, however, disabled people are at a greater risk of contracting COVID-19 (United Nations, 2020). The World Report on Disability (WHO, 2011, p. xi) states, 'more than one billion people in the world live with some form of disability' and this pandemic could affect these individuals disproportionately and put them at risk of increased illness and mortality, particularly people with Down syndrome (Clift et al., 2021; Malle et al., 2021). Therefore, research on COVID-19-related matters should include the voices of people with Down syndrome.

Navas et al. (2021) point out that there are not many research studies that capture the perspectives of disabled people on how the pandemic has impacted on their lives. Our study adds value and fills this research gap by providing insight into the perspectives and experiences of people with Down syndrome during lockdowns in order to add evidence to inform systemic advocacy. It also embraces the 'Nothing About Us, Without Us' motto of the disability rights movement throughout the world. People with intellectual disabilities seldom have the opportunity to voice their experiences and opinions on aspects that directly impact their lives. We believe this is one of the few papers that addresses a pandemic-related issue from the perspectives of people with Down syndrome where their voices contribute to a deeper understanding of the impacts of COVID-19, adds quality data and evidence to the limited research available, provides an overview of how these findings have contributed to changes, and offers recommendations.

When the questions for this research were formulated, the focus was on six key topics, namely (1) access to information, (2) emotional experiences, (3) living conditions during lockdown, (4) access to support, (5) employment, and (6) staying connected with others. The first four topics align with what has been identified as critical by other researchers (e.g., Courtenay & Perera, 2020; Embregts et al., 2022; Hughes & Anderson, 2022; Navas et al., 2021). The research question is: What were the experiences of individuals with Down syndrome during the various lockdown phases of the COVID-19 pandemic in Aotearoa New Zealand?

The World Health Organisation stated that COVID-19 has been accompanied by a huge infodemic, or overabundance of information (PAHO & WHO, 2020). People have become overwhelmed by this abundance of information in media, and this has accentuated the lack of accessible information for people with learning disabilities. Armitage and Nellums (2020) discuss that learning disabled people may experience inequities when accessing public health messaging, and stress that communication should be made available in plain language and across accessible formats. In New Zealand, information on COVID-19, designed to be accessible, is available on the Government's website (Unite Against COVID-19, 2020) and the Ministry of Health's webpage (2020). People with learning disabilities may also rely on others to keep them informed. In Navas et al.'s (2021) study, 582 individuals with intellectual disability in Spain responded to an online survey. Participants either answered the survey independently (40.9%) or received support from another person (23.2%) or had a family member or professional administer the survey to the participant (35.9%). Navas et al. (2021) found that 89.5% of these participants had received information about COVID-19, and 81% of these participants found it easy to understand. The source of this information was mainly from their disability organisations or their professionals (46.5%), from the media (45.3%), and from families (35.5%). In Drum et al.'s (2020) study of adults with disabilities, respondents reported their most important sources of information were relatives, television, and the Internet.

During lockdown, social relations were limited to closest family members or flatmates while contact with friends was prohibited. This led to individuals feeling isolated and lonely. In Embregts et al.'s (2022) study, six individuals with an intellectual disability were interviewed via video conferencing facilities during lockdown. These participants' primary concern was that they were missing their social contacts and were not able to be with their family and friends. Similarly, participants with intellectual disabilities in Navas et al.'s (2021) study highlighted that the most noted consequence of lockdown for them was the impact on their social relationships.

Amongst the significant changes that have taken place due to the outbreak of the pandemic are living arrangements. Families had adult children who had previously left home, returning to their parental home, and others moving to provide support and/or care for a family member, and older relatives moving in with younger relatives (Evandrou et al., 2021).

Government restrictions during lockdowns impacted on the provision of support services and social care for disabled people (Armitage & Nellums, 2020). Disabled people may not have been able to receive the support they needed to ensure their general wellbeing, independence, and self-determination, due to their carers being ill or quarantined. Rumrill et al. (2021) highlight that one of the stressors for disabled people during a pandemic is the reduced or no access to formal and natural supports. Frequently, service providers had to adjust how they offered support and tried to do as much as possible remotely through phone or video calls. In many cases, disabled people tend to live in the community and receive support from paid carers or from their family members. Navas et al. (2021) highlight that individuals who were living in specific settings such as residential care had fewer natural supports such as family and friends, whereas those who were living with family relied heavily on their family support. Without assistance such as transport, for example, many disabled people living in the community experienced difficulties leaving their homes to buy basic goods such as food (Jesus et al., 2021).

With the pandemic, disabled people have been 'disproportionally removed from the labor force' (Rumrill et al., 2021, p. 2), with many

losing their jobs or having their hours significantly reduced. Findings from Global Disability Inclusion (2020) highlight that 38% of disabled people had been laid off or had to shut down their business. Emerson et al.'s (2021) study indicated that disabled people were more likely than their non-disabled peers to be working reduced hours and experience more financial stress. In several parts of the world, people have had to work from home during lockdowns, requiring adaptation to new modes of working. With certain professions, there has been a shift from office buildings to home offices (Gallacher & Hossain, 2020). However, many disabled people work in the service, retail, food preparation, and manufacturing sectors (Maroto & Pettinicchio, 2014) where working from home was not an option. For disabled people who could move their work to home, there were additional barriers such as lack of technological and in-person support. Rumrill et al. (2021) highlight that often it can be difficult to arrange the technology required for disabled people to work at home, as specialised equipment and software may not be available for a home office (Maroto et al., 2021).

Government restrictions included limited freedom of movement, and a lack of social inclusion (Brooks et al., 2020), including interpersonal relationships, social roles, and participation in the community (Abbott & McConkey, 2006; Simplican et al., 2015). For some people, having restrictions on their usual activities, self-isolation, and physical distancing can intensify their stress levels because their routines have changed (Courtenay & Perera, 2020). Limited or no face-to-face contact with friends could lead to individuals feeling isolated and even emotionally distressed (Brooks et al., 2020). A resounding positive in this age of communication technologies is being able to connect virtually with family, friends, and colleagues around the globe, and this was evidently the case during lockdowns. Juvonen et al.'s (2021) study highlights the psychological benefits of connecting with others electronically. However, digital inequalities exist and not everyone is able to connect virtually. Insufficient digital skills can intensify social inequalities and exclusion of disabled people (Cho & Kim, 2021). The swift shift to the virtual world during COVID-19 may have further widened the digital inequality for learning disabled people.

2 | METHOD

A mixed-methods approach positioned within an inclusive research paradigm was employed in this study, in which a group of self-advocates with Down syndrome were co-designers and co-researchers. Walmsley (2001) coined the term inclusive research to refer to research in which people with learning disabilities—who may have merely been seen as subjects of research—are research collaborators in the research design, data collection, analysis and dissemination of research findings (Walmsley & Johnson, 2003). Six of the co-authors in this article are STRIVE members of the New Zealand Down Syndrome Association (NZDSA). STRIVE is a team of self-advocates with Down syndrome who are the self-advocacy leadership and advisory group of the NZDSA. They are also national ambassadors and advocates for people with Down syndrome.

Walmsley (2004) points out that just like academic researchers, individuals with intellectual disabilities require training and support to engage in research. The STRIVE members had previously undergone intensive training over a period of time to be co-researchers (Inglis & Cook, 2011). This training was designed and conducted by the first two authors, Franco and Zandra, and included amongst other things, an explanation of what research is, different research methods, how to conduct interviews, the importance of consent, and understanding research ethics.

2.1 | Clarifying research roles

A key aspect of inclusive research is to clarify the roles of the co-researchers involved in the research process. Ward and Trigler (2001, p. 58) state that 'role clarification at the beginning of the process, identifying areas of expertise, and establishing guidelines for the team process will mediate power and control issues'. The following describes the co-researchers' involvement at different stages of our research process:

2.1.1 | Determine research questions

During a Zoom meeting with the second author, the STRIVE members expressed an interest in conducting some research, as they had appreciated being co-researchers in another project. The members wanted to find out how other people with Down syndrome had coped with lockdowns. This interest became the research question for this paper: What were the experiences of individuals with Down syndrome during the various lockdown phases of the COVID-19 pandemic in Aotearoa New Zealand? One of the characteristics and principles underpinning inclusive research highlighted by Walmsley and Johnson (2003, p. 64) is that 'the research problem must be one that is owned (not necessarily initiated) by disabled people'. With our project, it was the STRIVE members who initiated this research. The STRIVE members brainstormed possible questions that they would like to ask; all these questions were collected and circulated amongst all the co-researchers. At another Zoom meeting, the entire team jointly decided which questions we were going to include. Based on these questions, the first author organised the questions into six key topics. This was circulated to all co-researchers, discussed via a Zoom meeting, and finalised. As Strnadová et al. (2014) highlight, inclusive research places emphasis on the fact that it must be the people with learning disabilities themselves who conduct the research on issues that are important to them, and this is the case with this research project.

2.1.2 | Design approach and method

This study utilised a descriptive mixed-methods approach, which combines elements of both qualitative and quantitative research to

answer the research question. A qualitative design was used to provide a better understanding of the lived experiences of people with Down syndrome during the various lockdowns. A quantitative design was used to collect numerical data, and multiple answer, or check-all-that-apply answers. The first author presented this mixed-methods design to the team. As this research team had previously conducted research using the same mixed-methods design, we agreed to use the same design.

2.1.3 | Prepare research instruments

From a previous research study, STRIVE had conducted face-to-face interviews using an interview schedule of structured questions, and the team decided to use the same instrument for this study as well (See Appendix for the interview schedule).

2.1.4 | Identify and recruit participants

After lockdowns when it was safe to interact with others, STRIVE members recruited people with Down syndrome nationally through Special Olympics sports, dance groups, social and leisure clubs, and through regional Down Syndrome Associations. They organised a specific venue and time that was suitable to both interviewer and interviewee.

2.1.5 | Collect data

Before the data were collected, a small pilot study was conducted, after which a few amendments were made. After the pilot study, STRIVE members conducted 36 interviews, however there were four participants who were interested in being part of this research but could not be interviewed face-to-face, so the interview schedule was posted to them. Participants were provided a gift voucher for their participation. STRIVE members followed the interview schedule very closely and wrote the participants' responses on the interview schedule. A total of 40 participants took part in this study, comprising 20 females and 20 males, ranging in age between 18 and 41, with an average age of 27. To maintain anonymity, each participant was coded with a sequential number. This number is used in Section 3 after a direct quote from one of the participants. The authors believe it is important for the voices of the participants to be relayed in the format they were expressed, and not interpreted by the authors. The completed interview schedules were posted to the first author who input the data into SPSS, a statistical software suite.

Often in qualitative research, the researcher collects the data as well as analyses the data, and this could lead to researcher bias. Researcher bias can be reduced by a method known as member checking, which is asking the research participants to check and confirm that the information they have provided to the interviewer is correct (Birt et al., 2016). Member checking is used in validating,

verifying, or assessing the trustworthiness of results (Doyle, 2007). After each interview, STRIVE members asked their participants to check that the information they had written on the interview schedule was correct, thus validating and verifying its trustworthiness. In addition, STRIVE members were only involved in the preliminary analysis of data, which would reduce any researcher bias.

2.1.6 | Analyse data, draw conclusions

At a workshop, STRIVE members received further training on how to analyse the data, and then had an opportunity to analyse some of the data. The members worked on the demographic data. With the quantitative data, they calculated the check-all-that-apply answers that the participants had provided. With some of the qualitative data, the members conducted a preliminary content analysis by looking for recurring themes and words. Very preliminary conclusions were drawn. At this workshop, the STRIVE members were supported by the first, second and last authors. As Walmsley (2004, p. 66) points out, 'most people with learning difficulties need support to lead fulfilling lives, including participation in research'. Support was provided as and when required. A more in-depth content analysis (Krippendorff, 2019) was undertaken by the first and second authors, who also provided the final conclusions.

2.1.7 | Produce a report

After the initial analysis of data by the STRIVE members, the first and second authors analysed the data further, and produced the article and prepared it for submission. Throughout the research process, regular Zoom meetings were held with the team so that joint decisions could be taken.

2.1.8 | Disseminate the report and findings

Some of the findings from this research project have already been disseminated, for example, at the World Down Syndrome Congress. Additional dissemination and impact of these findings are listed at the end of Section 3.

2.1.9 | Advocate and mobilise for impact

The findings of this research have already been used for systemic advocacy and this has included providing a response to the *Inquiry into the Support of Disabled People and Whānau During Omicron*, launched by the Disability Commissioner (Baker & King, 2022). In addition, the findings from this research offered the foundation to provide feedback in the fortnightly COVID-19 Disability Sector Leadership Group meetings and Disability Sector Leaders' Group meetings hosted by the Ministry of Health in New Zealand. The findings also informed the

way that the New Zealand Down Syndrome Association disseminated information to its members and how it delivered support.

2.2 | Team reflexivity

Reflexivity refers to 'the continuous process of self-reflection that researchers engage in to generate awareness about their actions, feelings and perceptions' (Darawsheh, 2014, p. 561). Although reflexivity is often portrayed as an individual task, Barry et al. (1999) propose using reflexivity as a team activity which can improve 'the rigor and quality of the research' (p. 26) resulting in more robust research. In addition, working as a team makes the researchers feel less isolated and they can also provide each other with emotional support. Our team had regular discussions about the research process, particularly when conducting interviews. We reflected on difficulties experienced, and if one member mentioned a particular difficulty, for example, others were able to assist with possible solutions, or mentioned that they had also experienced similar difficulties. We were able to discuss this as a team.

3 | FINDINGS AND DISCUSSION

The findings and a discussion of the key topics are presented below using the following themes: access to information, emotional experiences, living conditions during lockdown, access to support, employment, and staying connected with others.

3.1 | Access to information

Participants in our study received most of their information about COVID-19 from their family (77.5%), then television (75%), and the internet (45%). These sources of information concur with Drum et al.'s (2020) findings. Receiving information and understanding it are very different, so our participants were asked what their understanding of COVID-19 was. There was a variety of responses, but overall, they indicate a solid understanding. Below is a sample of responses:

1. Some people will get sick and some people will die from it too (9).
2. It is like when you develop some symptoms: it can be a cold, chest infection, a dry throat, a runny nose, or if you have a headache. COVID-19 is a deadly virus which can kill, which has happened over in China and a lot of people have died from it (17).
3. Virus that attacks the lung system, can make a person who comes in contact with COVID very sick and unable to breathe properly (28).
4. Makes you sick, heaps of people died (35).

From the above sample of the participants' understanding of what COVID-19 is, it appears that they have gained access to information which is accessible to them. This could mean that they accessed the

information themselves, or a family member could have assisted them to 'translate' the information into a more accessible format. In fact, 77.5% received information from their family. The main point is that the participants understood what the virus was. In its Policy Brief, one of the United Nations' (2020) four overarching areas of action relating to the impact of COVID-19 on disabled people is to ensure accessibility of information.

3.2 | Emotional experiences

For our participants, not being able to see their friends was very difficult and this was the most noted consequence of lockdown. In addition, some participants who lived independently missed seeing their parents and family. One participant said 'I had to go my parents' house. I lost my independence. I missed my flatmates' (36), whilst another participant who had also moved back to their parents' home, said that 'it was hard saying goodbye' (37) to their flatmates. Our participants also missed sports activities like athletics training, tenpin bowling, Special Olympics, performing arts, and leisure activities such as going out with family and friends, and doing the 'Good Friday pilgrim walk through our city' (37). These findings align with findings by Embregts et al. (2022) and Navas et al. (2021).

One participant summed up what many were feeling 'I just couldn't get out and do my own thing' (17). Many participants felt restricted, and 'Locked in our bubble, not being able to get out in the community' (28) with some saying they did not like being at home, or 'Being stuck at home not doing anything' (17). Some participants said they 'felt down' (4), 'felt hopeless' (9), were 'upset' (12), or 'really angry, sad and annoyed' (37). A participant in high school said, 'I cried and cried, I was very sad' (38) that they could not go to school, but had to stay at home and do school online. Another participant said it was difficult 'Seeing my nephew from the window and we could not touch him' (37).

Despite these upsetting feelings that most people throughout the world experienced at some stage during lockdown, there were many positives as well. Many embraced being at home with their family and engaged in a range of activities, including making 'a very cool video for lockdown' and making 'coloured crosses at Easter and putting them at the window' (37). Favourite activities at home included watching television, playing on their phone and iPad, watching DVDs, watching movies, Netflix, and playing their music. Many enjoyed cooking and baking with their families, reading, staying in touch with friends by phone or FaceTime or Zoom, doing exercises and going for walks and bike rides. One participant said, 'my biggest favourite was sleeping in' (20) and this was echoed by many others.

Participants were asked how they coped during lockdown, and responses varied from 'super brilliant' (17) to 'awful' (18). Just over half the participants said they coped well, with one participant saying they coped very well. Others said lockdown was 'not so good, but I coped well' (16), it was 'a bit hard but I did well' (19), it was 'not well at the start but I was okay at the end' (32), and 'managed most of the time' (4). The rest of the participants however struggled a bit and said

they did not always cope that well and found lockdown difficult at times: 'I didn't cope very well, it was emotionally very draining and tiring and I was upset and sad' (7); some felt angry, upset, nervous, scared, confused and 'kind of going out of my head' (10).

One participant went through a tragedy during lockdown. They lived with their flatmate who became ill during lockdown, had to be taken to hospital, and after a few days died. The participant had special permission to visit the flatmate in hospital and say goodbye. This participant said it was very difficult to continue living in the flat which they shared with their flatmate. In addition, during this difficult time the only support they received was from their parents.

The majority of the participants in this study reported adapting well to lockdown, and their accounts included examples of resilience. Although our participants experienced stress during lockdown, as most people did, they generally managed to remain positive and made the best of the situation. For example, most of the participants continued or adapted their daily routines so instead of going to the gym, they walked or did exercises at home. Many remained positive by keeping in touch with their friends, spending time with family, and engaging in creative activities with their families. Generally, resilience is understood as referring to positive adaptation within an adverse or stressful context. In a study by Scheffers et al. (2021), professional carers stated that disabled people's positive thinking was the most recognised source of resilience.

3.3 | Living arrangements during lockdown

During lockdowns, the majority of the participants, 82.5% (N = 33), lived in their usual home, either with their parents or with flatmates, whilst 17.5% (N = 7) did not live in their usual home during lockdown and most moved back to their parental home. Many of those who either continued to live in their parents' home or who had moved back to their parents' home found that their siblings who had been living independently had also returned to their parental home. This aligns with Evandrou et al.'s (2021) research that many families had been brought back together during lockdowns. Participants enjoyed spending time with their siblings during lockdown: 'I liked that my sister returned home' (30), and one participant who had been living independently in the community with flatmates and had returned to her parents' home said, 'I taught my brother to cook, and I also trained him about flatting' (37).

3.4 | Support during lockdown

Many of our participants were living or returned to live in their parental home during lockdown. Thirty-seven participants (92.5%) did not have any support or assistance from providers or caregivers during lockdown, and often family members provided the support required. This aligns with other studies (Armitage & Nellums, 2020; Navas et al., 2021; Rumrill et al., 2021). Statements by participants such as 'I had support from my mum and dad' (17) and 'I needed mum and dad

to help me with everything' (32) and 'Didn't have any support' (8) were echoed by most participants. One also added friends as support: 'I had my mum and her partner to support me and my friends on video call' (11). Only three participants had limited support. One participant said their 'Usual support person came' (10), and another, 'I had my support worker and also my mum and dad' (26), whilst another who lived with their flatmate said, 'Only support from parents. I didn't have support to do my shopping. Support staff did not come, they only called to check, only called once or twice a week, that was very hard' (7). One participant however, added 'Don't need support as I have my wife, mum, dad, and sister' (12).

The United Nations' Policy Brief (2020, p. 6) states that for many disabled people, 'access to support services is essential to lead safe, healthy and independent lives', so zero or very limited support for our participants during lockdown raises concerns, not only in Aotearoa New Zealand, but in most parts of the world where restrictions impacted on the provision and social care for disabled people (Armitage & Nellums, 2020). One can understand that during lockdowns only essential services are available, but is support for disabled people not regarded as essential? It is disturbing that disabled people who live in the community on their own or with flatmates, such as our participant 7, stated that support staff 'only called to check, only called once or twice a week'. Rumrill et al. (2021) highlight that one of the stressors for people with disabilities during a pandemic is the reduced access to formal support. Participant 7 also did not have the support 'to do my shopping', and this aligns with Jesus et al.'s (2021) research where disabled people living in the community experienced difficulties accessing basic goods such as food. For most of our participants, their parents and families took exclusive responsibility for providing support. This aligns with Navas et al.'s (2021) study where disabled individuals living with their families had to rely on their family's support. With parents and families providing all the support, it could lead to family overload (Rose et al., 2020).

One of the two fundamental factors that Navas et al. (2021) emphasise that needs rethinking relates to 'the degree to which service providers support families when the person lives in the family home' (p. 9). They suggest the need for more family-centred practices (Vanderkerken et al., 2020), as these represent a key factor for parental autonomy and wellbeing.

3.5 | Employment

Twenty-five participants (62.5%) in our study had work before lockdown. Work for this group of participants was defined as paid work, voluntary work, or unpaid work experience. Most of these participants work in the service, retail, and food preparation sectors (Maroto & Pettinicchio, 2014), so transferring from their workplace to home during lockdown was impossible. Twenty-two (88%) participants did not work during lockdown, and this aligns with Amor et al.'s (2021) study where the majority of participants were unable to continue working in the same way. Only three participants in our study continued working during lockdown, and in sectors that remained open during lockdown,

such as supermarkets. One said that the difficulty of working was 'keeping clean and keeping a distance' (6). Another participant said they had no difficulties, whilst the third one stated it was 'a bit different, mainly the social distancing' (19). They continued by saying that they went to work as usual a few times a week, but they had to put the trolleys in different places, and they had to wear a mask, which they found very irritating.

Of the 25 participants who had employment before lockdown, 20 (80%) had their jobs after lockdown. This finding is different to other research where many disabled people lost their jobs (Emerson et al., 2021; Global Disability Inclusion, 2020; Rumrill et al., 2021). One of the difficulties and frustrations of lockdown for many of the participants was that they could not actually go to work, with many saying they missed going to work and their work colleagues. People with Down syndrome find it difficult to get paid employment, and often volunteer their time and skills in order to have a sense of belonging in the employment sphere. The New Zealand Government is aware of employment inequalities for disabled people and in its Disability Strategy states it is committed to increase the focus of supporting disabled people into employment (Office for Disability Issues, 2016).

3.6 | Staying connected

As mentioned previously, a crucial component of lockdown that all our participants did not enjoy, was being isolated from their friends and not being able to see them face-to-face. As Baumeister and Leary (1995) highlighted, human beings are motivated by a need to belong, namely, to form and maintain permanent interpersonal connections with others. Being unable to meet with friends face-to-face meant that many participants felt lonely and frustrated as they had to remain confined within a given space. Fortunately, an array of available communication technologies allowed our participants to connect with their friends. Findings from Juvonen et al.'s (2021) study suggested that connecting electronically can facilitate a sense of connectedness and support, provided that this contact is satisfying. This could be a way to cope with isolation and feeling lonely. Connecting with friends could also offer emotional support (Baumeister & Leary, 1995), and this is particularly true during lockdowns. Zaagsma et al. (2020) highlighted that increasing online contact may reduce anxiety caused by uncertainty. Most of the participants in our study embraced technology to stay in touch with family and friends, as well as to attend meetings, for example, with their training coaches and networks and clubs to which they belong. The most frequently used technologies to stay in touch were by texting, followed by phoning, then Zoom, Facebook, FaceTime and email.

Marinova's (2020) article has a bold title: 'Zoom is the king of social connection in this crazy, new world'. Although Zoom existed before the start of the pandemic, it proliferated with global lockdowns. Zoom has been used extensively in workplaces and education sectors, as well as becoming a novel way of connecting with others socially. Thirty three of our forty participants (82.5%) used Zoom

regularly to connect with friends, family and to have meetings, with one saying, 'Love zoom meetings' (6). In fact, many said they enjoyed connecting with others via Zoom, and one participant said, 'I don't like not seeing my friends face to face but I can still do it via Zoom, and you can still see them on your screen' (18). Of these 33 participants who used Zoom, 29 (88%) said that using Zoom was easy. Zoom was used for a range of different activities: 'I could not go to dancing and acting, but I could still do my drama still on Zoom' (18), 'Gym via Zoom' (36), 'Zooming with drummer course at different light theatre company' (8), and 'Church on Zoom' (28).

It is evident that the majority of these participants embraced technology and utilised it to connect and stay connected to friends and family, as well as using Zoom to remain in touch with activities that were important to them. This aligns with other studies highlighting that people with intellectual disabilities with the skills, and/or assistance, and access to technology, use this effectively to connect with significant others (Alfredsson Ågren et al., 2020; Chiner et al., 2017). In addition, in Scheffers et al.'s (2020) review, social connectedness is seen as a key factor to facilitate resilience in people with intellectual disability. It must be mentioned that most of the participants were living in their parental home or had returned to their parental home during lockdowns. In some cases, their parents could have assisted them in accessing technology which would have facilitated them engaging with their friends and other family members.

3.7 | Impact and actions from research findings

The findings from this research have already generated some actions, highlighted below:

1. To address issues of isolation, STRIVE members have introduced the Afternoon Tea Club and the STRIVE Supper Club, where people with Down syndrome can connect with each other via Zoom. These activities have continued beyond the lockdowns.
2. The findings regarding access to information have encouraged the NZDSA to provide COVID-19-related information in more accessible formats for people with Down syndrome. A COVID-19 Bulletin with accessible information is emailed regularly.
3. The findings have assisted the NZDSA to more effectively represent the Down syndrome community when advocating issues around COVID-19 to various Government Ministries and service providers.
4. This research has prompted the NZDSA to conduct research with families and carers to glean their experiences of COVID-19.
5. The findings prompted the NZDSA to produce resources on wellbeing, particularly as people were struggling.
6. Some of the findings have been shared with disability engagement groups that are a conduit to the Ministry of Health. The research findings have informed discussions at various meetings.
7. The first author and a self-advocate presented these findings virtually at the World Down Syndrome Congress in 2021.

3.8 | Limitations and future directions

Although this study provides valuable insights into the lived experiences of people with Down syndrome during the pandemic lockdowns in Aotearoa New Zealand, there are limitations. Firstly, it would have been beneficial to have families of the interviewees involved in the research as well to get a more holistic account of the various lockdowns. Secondly, a more in-depth study with interviewees living independently would have provided more specific information about their living context during lockdowns.

Future research could explore the roles of service providers during lockdowns and what has been put in place to ensure that disabled people will always receive support in the future. Research focusing on digital access and digital inclusion could highlight areas that need to be considered so that all people can remain connected with others. A longitudinal study on the long-term effects and impact of COVID-19 on disabled people, and particularly with Down syndrome, would be beneficial.

4 | CONCLUSION

With more than a billion people living with some form of disability, it is crucial to hear their voices on a global pandemic that affects them and puts them at increased risk. However, there are limited research studies that capture the perspectives and experiences of disabled people. Our study adds significant value and fills a research gap by providing insight into the perspectives and experiences of people with Down syndrome during lockdowns in Aotearoa New Zealand.

Our research supports the following recommendations for Government and/or service providers:

1. Government should look at improving the development of accessible information for people with learning disabilities.
2. Government should aim to close the digital divide between disabled people and people without disabilities; and promote digital inclusion so that all people can remain connected to significant others.
3. Government should facilitate digital access with appropriate accommodations, where required.
4. Government should review supports to disabled people and their families to better meet the needs of this community.
5. Government should continue to support and encourage the employment of disabled people in their communities.
6. Government should ensure that disabled people always receive support, regardless of the situation, and that family-centred practices (Vanderkerken et al., 2020) are implemented for parental autonomy and wellbeing as well as the disabled person's wellbeing.
7. Government should work closely with disabled people, their families, and with organisations that support and work with disabled people.
8. Government should address COVID-19-related issues through a disabled lens, by engaging with disabled people in a participatory

manner to work collaboratively. In this way, disabled people are valorised and recognised as contributing citizens.

What emerged is that it was not the Government's response to COVID-19 nor service delivery by providers, but rather the resilience and adaptability of people with Down syndrome and the strong support network provided by families, that enabled our participants to report mostly positive experiences during lockdowns.

CONFLICT OF INTEREST

No conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

Ethics approval was obtained from the Massey University Human Ethics Committee (MUHEC), Massey University, Palmerston North, Aotearoa New Zealand – ID 4000023644. All participants gave their informed consent prior to participating in this research study.

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APPENDIX

What is coronavirus or COVID-19?

Where did you get information about COVID-19? (choose as many as you like)

Family – Friends – Support buddies – Television – Internet – Newspaper, magazines - Radio.

What was different for you during lockdown?

What did you like about lockdown?

What did you NOT like about lockdown?

What did you do during lockdown?

What activities did you miss?

Overall, how did you cope with lockdowns?

How did you feel during lockdowns?

Happy – Sad – Scared – Lonely - Upset.

During lockdown were you living in a different place than your usual place?

Where were you living during lockdown?

Who were you living with during lockdown?

Who did your grocery shopping during lockdown?

Where were you living after lockdown?

What support did you need during lockdown?

Did you have support during lockdown.

If yes, what support did you have during lockdown? (e.g., home help, shopping, etc.)

Did you have a job before lockdown?

If yes, did you work during lockdown?

If you did work, what were some difficulties working during lockdown?

Did you still have a job after lockdown?

How did you stay in touch with your family and friends? (choose as many as you like).

Phone – Text – Facebook – WhatsApp – Email – Facetime – Zoom.

Did you use zoom for meetings or activities?

If yes, did you find zoom easy to use?

What were some things you did after lockdown?