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# NEW ZEALAND LISTENER

NOVEMBER 20-26 2021

## Being disabled in NZ

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# SHUT IN & BURNT OUT

Disabled New Zealanders are delighted they will finally get their own ministry next year. But help is needed right now for those who've reached breaking point during the pandemic, argues COLLEEN BROWN. • photographs by ADRIAN MALLOCH

**W**hen the Government announced last month that Auckland students would not be heading back to school, Margaret Chung was beside herself. She posted a message on a social media channel for those with special needs: "Level 3, no school. I'm out. I can't do this." She received 66 comments.

Chung and her husband, Michael, are foster parents to a two-year-old boy and have adopted another three boys, aged 7, 8 and 10. Along with their own adult children, that's a family of 10. Their four boys all have fetal alcohol syndrome (FAS) and the oldest three have recently been diagnosed with attention deficit hyperactivity disorder (ADHD).

"I wrote two posts, both done in anger, crying while I texted," Chung recalls. After weeks of being cooped up at home, she had had enough. "All the time you are judged. Because the boys don't look disabled, everywhere we go people give me advice on how to control them. I'm almost empty. Children with ADHD are on the go continuously. All they want is me."

One of her boys told her he was suicidal. "He wanted to be in a dark, quiet place. I had to reassure him that sometimes we all feel a bit lost and that we need to talk to each other when we feel down."

Chung took two days out, thought about

what to do next and concluded that the family had disconnected from each other. It was up to her to sort it out.

She refers to her wider whānau as her village. But her village has also been locked down during the Covid-19 pandemic, and with her husband working, it is up to her to structure the day. So she created a 28-day mega-chart, detailing every minute of the day, from menus, puzzle time, talk time, to playtime in the local park.

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**"It is like being in a ballerina music box. When people wind the key, up you pop."**

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With four extremely competitive, hyper-active boys, a two-hour stint of running and playing is critical for everyone's sanity.

"One of my boys has stopped talking, one eats all the time, and one is suicidal. My village isn't there. You can talk to people, but you still feel alone. It is like being in a ballerina music box. When people wind the key, up you pop, [to] give others help and support. Then I'm back in the box, shut in, alone."

Chung simply doesn't have time to feel sorry for herself and has to act as her own counsellor. "I can sit here in a hole and cry about the things I cannot change, but as I

told myself, I am better than that."

The pandemic and the lockdowns have been hard for many people, but they have been especially hard for those with disabilities who often rely on others for day-to-day help in their lives.

In Auckland in particular, many feel abandoned. They already felt the stigma of being seen as "other". They are often exhausted, and some are suffering from mental-health issues.

It's a shocking thing to say, but the question some parents of disabled children have been asking themselves recently is, "Would I regret not having my child vaccinated if they died from Covid?"

Locked away, fearful of venturing into the wider community, with rising mental health needs, no carers, no respite, no whānau and tiny bubbles existing in isolation, members of the disability sector are at breaking point.

## CONSTANTLY ON ALERT

Kat Thomas knows all about not breaking down, and not giving in. Over the years, she has become fierce and firm when advocating for her daughter, Ella, who has cerebral palsy. But she also recognises the importance of building relationships with others she needs to deal with.

Thomas has shared custody of her two

Cry for help: Margaret Chung with husband Michael and their adopted boys who have high needs.



children, eight-year-old Ella and five-year-old Frankie. "I can't ever lose my temper. You never win if you lose it," she says. "I'm burnt out. It's hard to enjoy your children when every little detail has to be managed. I have to plan every minute of every day. It's a constant grind."

She believes few people understand how challenging her life is. "They have no idea of the number of parks I cannot access; the hairdressers who, when cutting Ella's hair, look sideways at her shunt. I am constantly on high alert and exhausted. My

## Some parents have been asking: "Would I regret not having my child vaccinated if they died from Covid?"

circle of friends is small. My whole life has narrowed."

Thomas sleeps with Ella, who has seizures and has to be turned during the night. Sometimes she has had to call on Frankie to help her. "If the seizure is prolonged, I need intervention. I have the call for the ambulance on pause while I count the minutes. I'm always assessing the situation; my brain is in overload; possible actions flicker through it constantly. Do I leave her to open the gates for the ambulance? Is now the time? Can I wait another minute? Ella's life or death is in my hands again and again."

### DISCHARGED TO LOCKDOWN

Ella has stoically endured 29 operations. Her last hip operation required Thomas to stay with her in hospital for two months. She was discharged on August 17 – the day New Zealand went into lockdown – with no food in the house, little money and no home support.

Thomas managed to get money for food through a trust, which enabled the family to survive. But she feels she is always having to negotiate her way forward.

"My children deserve much more than this. I need to be with both of them. It is rare for Frankie to have time with me alone. I have to manage my own energy levels. If I take the children to the park, do I have the energy then to do the bath, dinner, [and the] book-and-bed routine?"

Prudence Walker, chief executive of the Disabled Persons Assembly, lives with the effects of previous brain trauma. She has

Every little detail: Kat Thomas and daughter Ella, 8.

impeccable credentials for her position and is part of Tātou Whaikaha, a group co-ordinating the Government's ongoing response to the pandemic. Nevertheless, she has to regularly confront assumptions made about her intelligence, physical capabilities and leadership abilities.

One issue disabled people have faced during Covid is not being able to wear face masks for medical reasons, Walker says. "The mandatory face-covering policy has seen horrific comments directed at disabled people. Often, people have requested an exemption due to traumatic events in their lives. The lack of compassion in the community from business and services is mind-blowing"

Another concern is the delay in getting vaccinations to disabled people. In March, the disability sector felt reassured when it was told it would be included in the vaccination of vulnerable groups from May, she says. By June, it was starting to become concerned. With mixed messaging, a lack of data and a lack of vaccination sites capable of accommodating disabled people, the sense of not being valued grew.

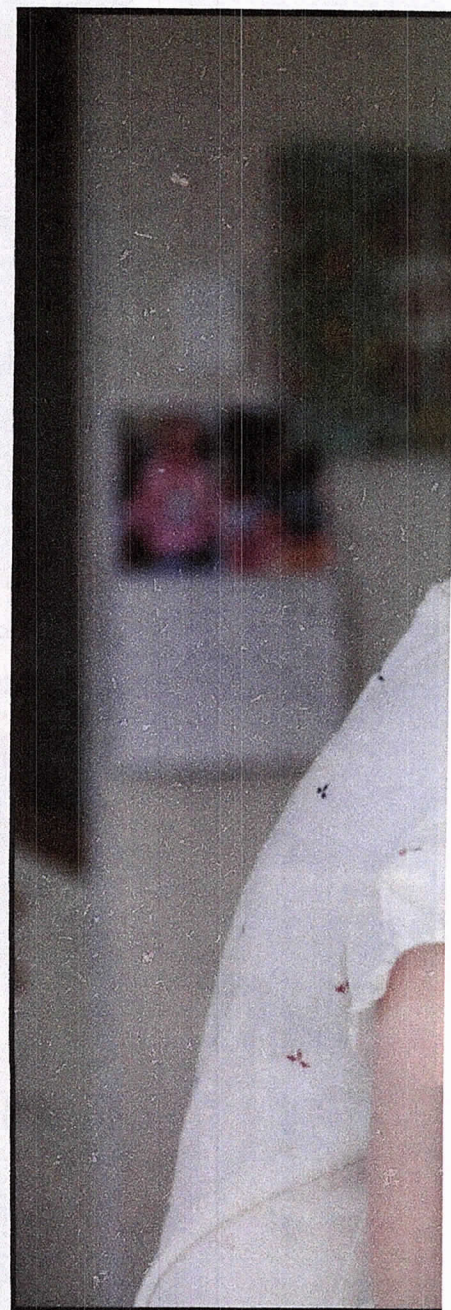
"At the start of the Covid response, the disability sector highlighted all these issues, but the equity issues remain the same," Walker says. "If you want to achieve equity, why not start with the most marginalised groups first? Non-marginalised people will vaccinate anyway."

She has also been disappointed by the poor quality of much of the information surrounding the campaign. "When pages of information are sent out by officials for us to disseminate through the sector, you think, 'Who wants to read this?' In order for it to be generally accessible, we often have to rewrite it."

### "AN IDEOLOGY OF DEFICIT"

Walker believes one of the problems is that officials are distanced from the community. "There is very little cultural competence in government in relation to disabled people. It makes it so much harder when we are trying to give input to the process to enable them to do the work. Systemically, they don't understand. The ideology is one of deficit. It is the medical model over and over again."

Mike Potter is chief executive of Disability Connect, husband to an essential health worker and the father of two daughters. He lives with a spinal injury and understands the medical model intimately. It's a model



where an individual is seen as existing outside society's norms and in need of being "fixed", he says.

"The medical model informs public

## "Can I wait another minute? Ella's life or death is in my hands again and again."

service interactions with the disability community. It reinforces the view that health professionals are the experts – they know best."



Potter's experiences so far with government agencies have not been reassuring. "They talk about being consultative, but when the government representatives talk for most of the meeting and disability representatives get one opportunity to speak, that's not consultation - that's ticking boxes. It undervalues the people involved."

### NEEDING A BREAK

"Information" and "accessibility" are words uppermost in the mind of Lisa Martin, director of the Complex Care Group, which works with families who are caring for children with very high and complicated needs. She also cares for son Kurt, who is autistic, and supports a husband who is an essential

worker on shifts.

She has worked harder during the pandemic than ever before, and the families she deals with are frustrated and anxious. "The burden of care has fallen right back on parents, pushing them to the extreme," she says.

The announcement last month that the Government is to create a new Ministry for Disabled People (see page 26) has obviously been welcomed by the sector, she says. But for many, it is unlikely to make much difference to their lives anytime soon.

"People are really hurting and are desperate for support," says Martin. "Families need a break in order to recharge so they can continue providing support to their disabled family member. It is crucial to

resilience. Humans are social animals and disabled people naturally have a need for social contact, too - on their own terms and in a way that suits them. All this has been

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**"The lack of compassion in the community from business and services is mind-blowing."**

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disrupted."

Often, families just want someone to listen to them, she says. And helping them understand the vaccination process has not

ADRIAN MALLON

# Major reform on its way

The Government has some big promises to deliver on for disabled people, writes COLLEEN BROWN.

**L**ate last month, the Government announced a suite of policy changes for the disability sector. Health Minister Andrew Little and Disability Issues Minister Carmel Sepuloni described the changes as transformational.

"We believe these changes send a very clear signal that there needs to be an ongoing commitment over successive governments in order to sustain better outcomes for disabled people," they said in a media release.

A Ministry for Disabled People will be established, the Enabling Good Lives programme will be implemented nationally, and legislation on accessibility will be presented to Parliament.

The disability sector had been asking for this type of reform for many years, and such was the level of anticipation that about 47,000 people tuned into the announcement via a

Zoom link hosted by Attitude Live. The community had been abuzz for weeks about what the announcement would contain, and it was not disappointed.

However, the establishment of the new ministry (the name of which is yet to be finalised) by next July is going to take considerable planning. The cabinet paper outlines the new ministry's extensive remit. Already, doubts are surfacing within the sector about whether one ministry will ever be able to accomplish such an array of obligations, and whether its budget will match expectations.

Its proposed governance structure also warrants examination. Sepuloni already has an advisory group reporting

to her that determines the action plan arising from the New Zealand Disability Strategy. However, there is currently no representation on it from parent groups representing the most vulnerable disabled people in the country.

**T**he Enabling Good Lives pilot programme already operates in the Christchurch, Waikato, and Mid-Central regions. A national rollout has been welcomed, especially by

Aucklanders who have watched with envy as other parts of the country have been selected to trial this innovative programme over the past decade.

But it, too, will need consultation, clear communication, sound relationship-building and focus, along with a realistic budget. It will provide an opportunity for those disabled people "lost" in the system to be given resources to live their

lives with dignity.

The accessibility legislation possibly conjures up visions of barriers to physically impaired people. In fact, the barriers disabled people face are far more extensive than just the physical ones. They exist in forms of communication, attitudes, employment and housing – in fact, in all areas of life.

The vision of the New Zealand Disability Strategy is "a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen". The wider disability community is looking forward to working constructively nationwide to make this vision become a reality.



Sending a signal: Carmel Sepuloni

been easy.

"Being able to get appropriate information to make an informed decision about getting a vaccination is critical. We have to consider what will happen to any existing impairments if we vaccinate. Luckily, there are now some very good resources available to assist in this process, but they took months to be developed."

## ARROGANT ASSUMPTIONS

All three disability sector leaders agree that if they are struggling to get clear information, it must be even harder for those with fewer resources.

**"Humans are social animals and disabled people naturally have a need for social contact, too."**

Potter believes part of the problem is what he perceives as arrogance from people who are not disabled. When disabled people seek medical treatment or equipment, for example, it is often assumed they don't work and should fit in with others.

It's well known that the health sector is under-resourced, but the lack of knowledge of disability leads to people being stigmatised, he says.

"We can all acknowledge that the wider disability community has particular needs. Resourcing our communities to deliver disability services is a better way to achieve inclusion than relying on a simplistic medical model."

Prudence Walker is optimistic that lessons will be learnt from the pandemic, but believes the new ministry faces enormous challenges in making fundamental changes to the system.

"This is personal for us. It isn't just a job. This is us, our friends, our community – this pandemic strikes differently. We need to look out for and after each other." ■

*Colleen Brown (Ngāi Tahu) is a parent of four adult children, one of whom, Travers, has Down syndrome. She has advocated and written about the experiences of families with disabled children for many years. She lives in South Auckland and serves on the Counties Manukau District Health Board and chairs Disability Connect.*