

Emergency planning and response

People with intellectual disability reported that their lives had been detrimentally impacted by COVID-19. They also felt that their rights had been pushed to the margins. Rather than opening up new opportunities for connection and inclusion, many people with intellectual disabilities are finding that the reliance on video conferencing technologies such as Zoom was creating a new barrier to inclusion.

Wayne is in his 50s.

He said the pandemic had isolated him.

Wayne said he found it difficult to use technology for online communications. 'It's very difficult when there's so many people talking at once. It makes it hard for us to be involved,' he said.

As a consequence, Wayne was forced to decline numerous invitations to participate in online forums and conferences.

'I don't like it,' he said.

Penny said that the lives of people with intellectual disability had gone backwards during the pandemic.

She said service providers and support workers had unilaterally denied the rights of people with intellectual disability by not letting them travel or have visitors — going against public health advice.

'Even when people were allowed to travel or see people, the support workers were keeping people with intellectual disability segregated,' she said.

In addition to segregation, Penny said she started seeing new bumper stickers during the pandemic that read: 'I'm a support worker. That's my superpower. What's yours?'

She found those bumper stickers disrespectful.

'It's sort of downgrading to the person with a disability,' Penny said. 'It [COVID] is making them [support workers] more powerful than the client. I think that's something that's coming out of corona[virus]. They were going backwards a bit to being more institutionalised and support agencies were having more control.'

Family members were alarmed by the lack of transparency during COVID-19 lockdowns. Many felt like their relatives with disability were at the mercy of support workers.

Angela advocates for Carly, a 50-year-old relative with a disability who lives in a group home.

During the first wave of the COVID-19, Carly's group home went into lockdown for two months and closed to outside visitors and service providers. During the lockdown news broke of the alleged manslaughter of Adelaide woman Ann-Marie Smith by her support worker.

'I was worried she was at risk,' Angela said. 'She was ringing all the time; she was anxious as hell.'

Normally, Angela, who lives several hours from the group home, would receive telephone calls from Carly once-a-month. During the lockdown, she said Carly called her twice a week – a significant increase in calls that she said suggested a heightened state of anxiety. This worried Angela because she knew that Carly, who is physically frail, lost weight when anxious, but she was unable to see her relative on a video call.

Angela said:

'They didn't even offer to set up Skype or anything. They just put it on the speaker phone and then she had a support worker there all the time, so I couldn't ask any questions about what the support workers were doing. ... I didn't even see her. I couldn't see if she was losing weight.'

Wendy said that, during the COVID-19 lockdown, her adult daughter Kate was left on her own for 48 hours without any support worker.

'The whole thing is that no one takes responsibility if there's not a parent or a family member that's around that's going to be following up and making sure it happens for that person,' she said. 'Look, and you know COVID was terrible because all [she] did was sit in her room and watch TV or be on her iPad for two months.'

Advocates said the national response to the COVID-19 pandemic was revealing. It revealed that the health and wellbeing of people with disability was often an afterthought. It revealed that there is an urgent need for strong, proactive oversight of the care of people with intellectual disability, particularly residents of group homes or in the care of a single service provider. And it revealed that – contrary to claims that reform takes time – the system was able to change practices and policies quickly.

Brian said:

'My biggest fear remains, what's happening due to lockdown in supported accommodation? You know, whether there's a whole lot of unacknowledged, unreported violence occurring because people are just really frustrated. ... We've had lots of reports of service providers taking very inflexible approaches to things like whether there should be any visitors and very inflexible approaches as to whether people should be, you know, getting out on community access. ...

'What we've constantly been advocating is that support providers need to be taking a balanced individual approach ... rather than you know what I think has been happening too often, you know, just head office at the service provider saying, "Right, group homes are locked down. No visitors. No outings," or whatever. ... That sort of suppression of people's rights and normal lives ... should happen in a balanced way.'

During the first lockdown, the Speak Out Association of Tasmania became alarmed at the lack of accessible information for people with intellectual disabilities.

Speak Out started a live feed on its Facebook page at 5.30PM every night, interpreting the latest information and rules for people with disabilities, as well as answering questions. Seemingly overnight, the number of active users on Speak Out's Facebook page increased by more than 1,000 per cent.

One advocate, said:

'We also found that the public health hotline had no idea about the disability sector and how it ran.'

Speak Out contacted the State Government to offer advice. For instance, the Government changed its language because Speak Out told it that words like 'lockdown' and 'social distance' were often misunderstood and frightened people with *intellectual* disability.

Belatedly, Speak Out was granted \$15,000 to fund its COVID-19 Facebook live feed. The live feed gave the advocates additional insight into how the pandemic was impacting people with disabilities.

The advocate said:

'People who lived independently but received some in-home support, they became institutionalised because their providers were saying no. ... One of them said, "We can't come and get you and take you to the supermarket. You'll have to walk to the supermarket and the support worker will meet you there.'"

The person with a disability had a significant vision impairment and could not walk to the shops unaided.

The advocate said:

'She became more institutionalised because she had no way of getting out. ... There were a whole heap of standards that were applied to people with disability that weren't applied to the rest of the community. ... The public health regulations were saying one thing and yet the providers were imposing aged-care standards on group homes ... It just made people far more vulnerable.'

During the first wave of the COVID-19, a 30-year-old woman with a disability called Abbey contacted Speak Out.

Abbey was terrified. She had been told by a family member that she was not allowed to leave her house because of the pandemic and that she would receive a \$16,000 fine if she did leave her house.

Abbey told Speak Out that she thought she could leave her house. The reason she thought she was allowed to leave her house was that Speak Out had been streaming live updates on its Facebook page every night, interpreting the latest COVID-19 information and rules for people with intellectual disabilities.

Speak Out told Abbey she was right. Advocates then took Abbey to a local police station. At the station, a police officer told Abbey she could go to the supermarket and have two visitors to her house. He then warned her that some police interpreted the pandemic rules differently.

‘She was still terrified,’ a Speak Out advocate said.

Two days later, Abbey had a reason to be terrified.

A woman identifying herself as a police detective called Abbey and told her she was not allowed to leave her home. The detective told Abbey the police were watching her and could arrest her if they wanted.

When Speak Out heard of the phone call, the issue was raised with the Anti-Discrimination Commissioner, Equal Opportunity Tasmania. In the end, a senior police officer came to Abbey’s house and explained that she was right, and no one wanted to arrest her, and that some police were over-zealous.

Speak Out said Abbey still had not recovered from ‘this trauma that they put her through.’

The police detective who made the threatening phone call has never been identified.

Another advocate, Lillian, said:

‘Interestingly, they [the NDIA] could respond and change things quickly — couldn’t they? — to respond to COVID[-19], so it’s like, okay, so you could put, like, a blanket thing out saying everybody can get an iPad if you don’t have one for tele-health or video conferencing. ... There are ways that they can actually make, you know, changes — even, you know, sending people a draft of their [NDIS] plan before actually signing off on it. ... [Or] having some accommodation, some dwellings for want of a better word, just for transitional [stays] so, you know, this person is in crisis. ... But there just isn’t.’

Case Study: From lockdown to homeless

This is the story of how the coronavirus-related hard lockdown of a public housing tower in Melbourne forced a young woman with an intellectual disability to be physically restrained by police, made an involuntary patient at a hospital, become briefly homeless and reliant on charity to survive.

Celine is 25. She has an intellectual disability and mental health issues and lives in a public housing tower in Flemington.

Celine is a participant in the NDIS, receiving more than 40-hours support a week for disability and mental-health related needs.

On Saturday, 4 July 2020, the Victorian Government announced the immediate lockdown of her public housing tower. Many tower residents — including Celine — did not know of the lockdown until Victoria Police arrived to secure the perimeter. Celine, who has had negative interactions with the justice system, became extremely distressed when she saw the police.

By Saturday night, Celine had suicidal thoughts. Her support worker spoke to Celine on the phone and became concerned that she might attempt to overdose on her medication. Over the weekend, the support worker received conflicting advice from Victoria Police — receiving police advice via telephone that no-one could enter the tower and receiving police requests from Victoria Police members at the scene to enter the tower and confiscate Celine's medication. The support worker told Victoria Police that they should call a Crisis Assessment and Treatment Team (CATT). In the end, Celine remained alone in her apartment on Saturday and Sunday. During this time, she received minimal help from her support coordinator, but around-the-clock phone assistance from her disability support provider.

On Monday, Celine called VALID asking for advocacy support. She also called the State Member for Melbourne, Ellen Sandell and Triple-0. By this time, Celine was running out of food, medication, cigarettes and pet food for her cat. She was also making threats to harm herself and others with a knife, gun or needle. VALID advocated for a physical wellbeing check and wrote a briefing email for Ms Sandell, which was forwarded to the office of the Victorian Premier, Daniel Andrews.

At lunchtime Monday, Celine called VALID and said she had taken her pills. 'She sounded sleepy and groggy over the phone,' a VALID advocate said.

At 3.30PM Monday, Celine was permitted to leave the building. VALID called Flemington police station and requested that Celine be met by a mental health worker when she exited the elevator because she was scared of Victoria Police.

Celine was met by Victoria Police when she exited the elevator and became extremely agitated. Several members of Victoria Police tied her to a gurney with straps and she was taken to the Royal Melbourne Hospital (RMH) as an involuntary psychiatric patient. 'She was very traumatised because the police had to manhandle her,' the VALID advocate said.

At the RMH, a psychiatrist assessed Celine and reassigned her as a voluntary patient. At VALID's request, the Office of the Public Advocate (OPA) intervened — asking the hospital to keep Celine as a patient until VALID could organise alternative accommodation through the NDIS the following day.

On Monday night, the RMH's head doctor agreed to OPA's request, but after a staff shift change the hospital discharged Celine at 7AM Tuesday morning. That meant Celine was effectively homeless, without food, money, medication or a change of clothes.

Celine walked the streets, then caught a train to St Albans, spending the day with a friend who is a known user of crystal methamphetamine (or ice). Celine was concerned that Victoria Police were following her; VALID was concerned she might use ice.

By Tuesday lunchtime, the advocate had arranged for the NDIS to approve funding for alternative accommodation and a serviced apartment was rented in Maribyrnong.

Celine's friend drove her to the serviced apartment on Tuesday afternoon. By this time, she had not had her medication since Sunday. She was unable to access crisis payments from Centrelink or the Victorian Government for two weeks. During those two weeks, she relied on charity vouchers from Ozanam House and the St Vincent de Paul Society for food and clothes.

On the Thursday, Celine went to a Centrelink office with a support worker to ask for a crisis payment but was ejected from the office and banned for six months because Centrelink erroneously believed she should still be in the tower lockdown in Flemington. 'They didn't give her a chance to explain,' the VALID advocate said.

Celine stayed in the serviced apartment for three weeks, then returned to her Flemington flat.

The case of Celine underlines the complexity of the systems navigated by people with disabilities. Celine has an intellectual disability, but — to reach a place of safety — had to juggle relations with a wide range of people and organisations, including two service providers, the Department of Health and Human Services, Victoria Police, the OPA, Ozanam House, the St Vincent de Paul Society, Centrelink, a State Member of Parliament, the RMH and the NDIS. Many of those organisations have limited understanding of the needs of people with intellectual disability.

As no single Government agency took charge of the situation, Celine was forced to navigate this complex, multilayered system with the support of VALID.

Celine is now looking for a new support coordinator and is pursuing complaints against Victoria Police through the Ombudsman and to the Victorian Equal Opportunity and Human Rights Commission.