

Self-Advocates Building Back Better post COVID-19



Summary Report – Self-advocates building back better forum 3 December 2020

Australian and Canadian Self Advocates Speaking up and speaking out

Almost forty (40) people with intellectual disability from around Australia and Canada came together on International Day of People with Disability to talk about their experiences during 2020 with Covid-19.

They talked about the challenges, the positive things that happened, what needs to stay and what needs to change.



By video link up they talked about their key messages for decision and policy makers to ensure we ‘build back better’ for people with intellectual disability, as we move through Covid-19.



“ covid brought people together - a lot of people checked in on each other ”



Background

During 2020 Queenslanders with Disability Network (QDN) Brisbane and Gold Coast Hot Topics Peer Support Groups connected with New Vision Advocates in Ontario, Canada. Meeting monthly on Zoom, the groups talked about things that are important to them, as people with intellectual disability, including the similarities and differences between Queensland and Ontario, and self-advocacy.

During these meetings, Hot Topics and New Vision Advocates decided to put on an international event to celebrate International Day of People with Disability (IDPWD) on 3 December 2020. This years' theme for the day was Building Back Better so the groups decided to discuss building back post COVID-19 lockdowns.



Why is self-advocacy important?



“Self-advocacy is a movement, an organised force because of discrimination, because people have human rights” quote from participant.

“one of the greatest ideas has been Zoom, everyone got connected”.

Who helped organise the IDPWD Self-Advocates?



QDN Brisbane Hot Topics, QDN Gold Coast Hot Topics and New Vision Advocates Canada
ASID – Australasian Society of Intellectual Disability (ASID) supported event too.

Who was part of the forum?



- QDN Brisbane Hot Topics – Queensland
- QDN Gold Coast Hot Topics – Queensland
- New Vision Advocates – Canada
- Valid - Victoria
- Speak-out Advocacy - Tasmania
- Loud and Clear - Queensland
- Community Living Association - Queensland
- WWILD - Queensland
- Independent Youth Housing Cooperative - Queensland
- SARU - Victoria
- Inclusive Research Network, University of Sydney – New South Wales
- Our Voice – South Australia
- Council for Intellectual Disability – New South Wales



Who couldn't make it on the day?



- People First New Zealand
- Aboriginal and Torres Strait Islander Disability Network of Queensland
- Loud and clear

What was the self-advocates Building Back Better 2020 forum all about?



On the 3 December 2020, we had a meeting for self-advocacy groups for people with an intellectual disability from across Australia and in Canada.

The meeting was held so self-advocates could share information about:

- who each group is and what they are about
- ideas we have as an international community of people with intellectual disability
- what has happened for people with intellectual disability during COVID-19,
- what has been hard,
- what has been new or good, and
- what we want to know, what we want action on so we can build back better after COVID-19 and what works for us.



What did we do at the forum?



At the beginning

1. Welcome: Michelle Moss QDN and Paul O'Dea (National Board Member) on behalf of
2. ASID Acknowledgement of country by QDN member Nick Darby
3. Videos of all the groups sharing who they are and what they do
4. Panel discussion to hear from everyone about what's happened in COVID and what's important for decision makers to know to build back better.



“my important points are, we have rights, so we need to uphold our rights and to get information in the way we understand it”.

What did we do at the forum? (continued)

Short video presentation

To introduce the panel members each group shared a video which showed the group sharing their stories, showing power of people coming together and standing together to self-advocate. [You can see the videos here.](#)



Panel discussion

The panel was invited to reflect on how the world had changed for them in 2020 and how as people with an intellectual disability, they have stood up to advocate for themselves.

COVID-19 - What has been hard?



- Remembering the new rules
- Understanding all the rules
- Feeling afraid in different places like on public transport
- Keeping 1.5 metres apart – social distancing
- When other people don't follow the rules
- Not seeing family and friends
- Not being able to get our services – they closed or stopped
- Not being able to go out
- Not having access to phones, devices and technology



“for people in lockdown, it has been hard not to see people face to face. The isolation has been hard. With COVID-19, it is hard keeping in touch with everybody”.

COVID-19 - What has been hard? (continued)



- People have felt afraid to use public transport
- Not having access to phones, devices and technology
- Not being able to afford data to use
- No phone to access essential services or call friends
- Having to learn different ways of connecting with people with technology
- Having to wash our hands all the time
- Having to continually change
- More domestic violence
- Disability Royal Commission hearings being put on hold
- Services that interpreted the rules in a way that made it different for people with disability in group homes at the beginning of COVID



What have been some positive things from Covid?



- Learning new things and starting new projects to help other people with intellectual disability
- Getting information in a way that we could understand from services we trust. Info about our rights
- Being able to have a voice and let people know what people with intellectual disability need
- Learning how to zoom, meet on line, have ways of connecting with family
- Having a say on important issues like transport and Disability Royal Commission
- Support workers adapted their support and were creative in supporting us
- Taking the things we learnt in the first lock down to help us when it happened again
- Businesses changed the way they did things to help people with disability like NDIA, Coles and Wbolyworths

Even in the middle of the pandemic, people put themselves out there to speak up at the Royal Commission



What we want to know for the future?



- What's going to happen with people's mental health
- What's going to happen to get people to connect together more
- How to get better information in the format that we can understand
- How to make the most of some of the changes we saw when people were in lockdown – even though everyone was at home, the number of incidents in some



What is your hot topic to tell decision-makers?



- I think it is educating decision makers. We have never had anything like this before and it is time that they listen to us
- We need government to help provide IT hardware and lessons on how to use it. It was hard trying to get hold of technology
- To keep changes government and business have made that helped people with disability, like telehealth
- To give people information in a way they can understand
That self-advocacy is important in people's lives
- To keep asking people with intellectual disability for their feedback and listen to us
- To keep supporting, checking on, caring for and respecting each other
- To give people access to devices, data and education to use iT
- To look after people's mental health
- Uphold people's rights
- Get the vaccine





Quotes from participants

What has been hard during covid?



We have seen people using public transport less. People have felt afraid to use it. We didn't know if we would be safe or catch the virus.

We have been doing the right thing and wearing masks on public transport, but some people haven't been doing that. It doesn't just impact the disabled, this choice not to wear masks impacts everyone's health and safety.

Keeping the 1.5m apart, actually really difficult. We have had to help each other to try and remember to keep apart and be aware of COVID. We thought it was only going to hang around for a little while, but its going to be here for a little while yet.

Remember the rules – at work there are pictures and photos up to help us remember and to know how far 1.5m is. The pictures and photos help having information up on doors and walls. Having information in accessible ways has been really good.

Knowing what to do in places where it is really hard to social distance like on transport. Its been hard with lots of people wearing masks.

Washing our hand and rub our hands with the sanitizer all the time.

Getting to the doctor because when we were locked down, we couldn't go anywhere. Had to stay in our house and all that; could not do anything; just sat there.

Not been able to see my wonderful friends and family.

We have had to make so many adjustments, especially through the first lot of lockdown.

Not being able to do face-to-face interaction; since we encourage empowerment for others and people to have their own form of self-advocacy; and for us it is a lot easier in person. It is not impossible online but it is just a lot more difficult.

We have had a lot of challenges here in Melbourne. We have had even the lockdown for six months, when we couldn't go out; and we had to wear masks. And in Melbourne, it was just really dead and quiet. And the trams had changed their times as well. The business people are not back in Melbourne yet. They are still working at home.

We used to go on outings, and we haven't been going out on our outings as well.

The impact on my mob has been hard. Even if they are not Aboriginal, but I know there's been some domestic violence going on.

The Royal Commission has been a bit hard because people haven't been able to go to the hearings.

At the beginning of learning to use zoom it was a bit difficult because I wasn't used to using Zoom.

Not being able to meet up because of the restrictions and Covid-19 has meant we have had to find different ways to do things.

The biggest challenge has been social distancing. Trying to do a lot of activities with social distancing was quite hard to keep active. Especially not able to handshake or hug your opponent when you win a game or "high five" or something like that when you win a game.

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There was one point that if we wanted a drink or something to eat, we had to sit down; and that was quite a real big challenge. A few people got kicked out of the venue because they couldn't keep that.

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Using public transport was hard. It was quite hard to keep social distancing on transport.

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There was over-restricting of people in group homes, and with people with disabilities and families and service providers making up their own rules that were not the same as government restrictions.

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Not being able to sit in the front seat of the taxi.

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Anyone with mobility aids that was slightly large and wouldn't fit in the boots of taxis. We had to go in taxis because public transport was not running.

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What has been positive changes during covid?

People looking at how to make that transport system work not just simply for the abledbodied but for everybody; people like me who have got some mobility problems, people with intellectual disabilities.

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Being forced to learn how to use zoom. Once I got the hang of it (zoom), it got better and better.

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Doing things that normally happen out in the city we have been doing on Zoom. Like, we have programs and stuff that people connect on Zoom. Sometimes we have shows or music and stuff on Zoom.

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One of the greatest ideas has been Zoom, keeping everyone connected.

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We also connect through Messenger too, for those who don't have Zoom. We connect with friends and sometimes with family.

Being able to teach others about Zoom.

Starting the “Staying Connected network“. Self-advocates, support allies and family members from across Canada meet and share resources, experiences and worked together to advocate for change to improve the lives of people with disabilities. We meet throughout the COVID-19 period, we started doing the staff meetings over Zoom; so, people all over the State could still partake in our staff meetings. We had social drinks on Thursday nights so we would have stuff like trivia, staff conversation over Zoom. It was all over Zoom.

Running crochet nights with a lot of members of Valid. So there were ways that Valid staff could still communicate ~~ through the tough time, even though it wasn't in person.

Doing choir online

And then through the second lockdown, we already knew what to expect, except it had a lot more restrictions than the first wave. The fact that we had already been through it once it wasn't as hard the second time.

Still being able to provide our services was great. We just had to adjust to what the community and our State was going through at the time.

The Disability Royal Commission being extended for another 12 months for people with disability to come and tell their stories.

While there has been the lockdown Zoom meetings have been great. Catching up and chatting with people.

Sending out letters to see how everybody is going has been good.

After lockdown, we meet a couple of times face-to-face. We started meeting again...and everybody talk about their experiences. Zoom kept people together.

In our first face-to-face meeting, we have been talking about how everybody has stayed together through COVID and some of the things that they have been doing to stay healthy; not only physically but mentally as well.

It is great having other people from other countries and other States in Australia to have connection with other self-advocacy people in the whole - around the whole of the world.

Our face-to-face meetings have been getting bigger and bigger since lockdown.

Getting a phone call each day from someone was excellent.

Covid-19 brought a lot of people together. A lot of people checked-in on each other.

Woolworths and Coles changed their hours for people with disabilities. Being able to get groceries during earlier opening hours than most other people. Support workers were quite adaptive to people with disability on COVID because they were coming to the house and they were either wearing a mask or hand sanitized before they come and see us.

People were getting more access to technology. They were getting technology through NDIA; and we also got to learn how to communicate on Zoom. Starting own veggie garden and I were able to start our own vegetable garden and do those sort of things.

Speak Out...was streaming every night; and they explained the restrictions in the way that we understood them; keeping us updated.

It was good to have our rights explained what our rights were and what we could do.

Covid has brought our group together. It also helped people from Queensland Department of Health understand the issues people with disability face.

The Royal Commission continued through COVID and that really displays that even though people are going through a pandemic and they can't put themselves forward, but they can still put their rights forward.

Fact that the Royal Commission went strong throughout the whole of COVID-19, it just really displays how strong self-advocacy is and how much they want to put forward other people's human rights.

It's hard to join our groups because we don't have the technology. But through...funding, they have tried to get people to have those connections and laptops.

What is your message to decision makers?

For disability people to respect other people and get respect in return.

Education is important because we have never had anything like this before. It's important that we are heard by decision makers. There is a big impact on people's mental health who have been in isolation for a long time. We need to look after people's mental health.

To support people to find ways to make sure that everyone is doing okay within various groups through covid. To make sure that the government understands the needs of people with disability through covid. The rules change every day so it is hard to know what you are doing from one day to the next.

We need the physical hardware to be able to stay in touch.

Provide the IT hardware and the education to use it. Help to get hold of computers, web cams and microphones would be good. For anyone with intellectual disabilities or physical disabilities, it felt like we were at the bottom of the pack for trying to get hold of any equipment.

Telehealth has been great and we want it to stay. It is a great thing for people with disability. Decision makers need to let people have a voice and get understood in the right way. With planned meetings, decision makers need to know how to read and understand people with disabilities in a better way.

People need to be able to share their knowledge without feeling like they are going to get into trouble with their plans. More transparency.

What's good for one person, should be good for everybody; even though they can't present themselves.

Staying at home we were kept safe. Wearing masks that protects people from the virus worked well. We will wear them until they tell us when not to wear them at all. And people have rights; to stand up and have a say. That's what self-advocacy means; step up for your rights; have a say. You have got to step up and if you don't want anything, just say "no". And you tell them what your rights are.

Continue the communication for people in group homes and housing accommodations because especially in those kinds of environments, it can be quite confronting, and you often can't really communicate with anyone. Encourage group home staff and supervisors to encourage outside of home communication.

For Canada: ...come up with a vaccine. Need to continue to educate others about COVID, to keep people safe. We need to get more people involved with their programs on Zoom; and education for the government. We need to educate others on how to stay safe and how they can be safe in their homes.

We are the vulnerable people, the aged, carers, people with disability. We want to know how the vaccine is going to affect us.