

# 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 people 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”

“One of the greatest ideas has been Zoom, keeping everyone 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 and what we want action on so we can build back better after COVID-19 and do more of 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 ASID
2. 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.

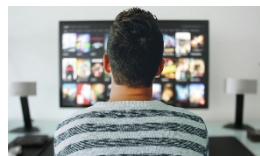


**I guess my important points go to: we have rights, so we need to uphold our rights, and to give us information in the way we understand**

# What did we do at the forum? (continued)

## Short video presentation

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



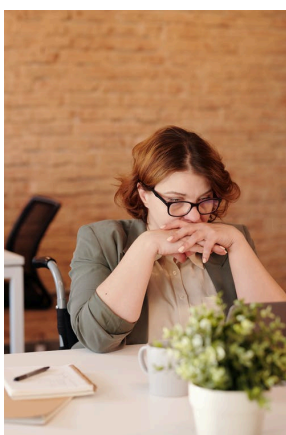
## Panel discussion

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 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's hard keeping in touch with

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



- People have felt afraid to use public transport. People have felt afraid to use it
- Not having access to phones, devices and technology
- Not being able to afford data to use
- Phones 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 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 started 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
- Zoom has been great. 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 got extended
- Support workers adapted their support and were creative in supporting us. New ways of getting supports
- 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, woollies

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?
- "people need better information in the format that they can understand".
- "understand some of the different changes we saw when people were in lockdown – even though everyone was at home, the amount of incidents in some group homes dropped"



# What is your hot topic to tell decision-makers?



- I think it's education. We have never had anything like this before. And it's time that they listen to us
- Government to help provide IT hardware and how to use it. It was hard trying to get hold of technology
- Keep changes government and business have made that helped people with disability, like telehealth
- They just announced tele-health is staying and that is a great thing for people with disability
- Give people information in a way they can understand Self-advocacy is important in people's lives
- Keep asking people with intellectual disability for their feedback and listen to us
- Keep supporting, checking on, caring for and respecting each other
- Give people access to devices, data and education to use it
- 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.

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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.

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Its been really hard to keep 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.

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Its been hard to 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.

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Its been hard to know 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.

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Its been hard to wash our hand and rub our hands with the sanitiser all the time.

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It's been hard to go to the doctor and my ; because when we were locked down, we couldn't go anywhere. Had to stay in our house and all that; couldn't do anything; just sat there. Couldn't do anything.

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Not been able to see my wonderful friends and family.

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We have had to make that adjustment, so we can adjust to that kind of scenario in a sense; because it's just been a continuous adjustment, especially through the first lot of lockdown.

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I think the biggest impact has definitely been taking away the face-to-face interaction; since we encourage empowerment for others and people to have their own form of self-advocacy; and for us, encourage that, it's a lot easier in person. It's not impossible online but it's just a lot more difficult.

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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 in all this; and we had to wear masks and that. And in Melbourne, it was just really dead and quiet. And the trams had changed their times as well; because they are still in Melbourne. The business people are not back in Melbourne yet. They are still working at home.

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I am in a home for people under 50; and we used to go on outings and we haven't been going out on our outings as well.

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Impact on my mob, there's been a lot of - like, even if they are not Aboriginal, but I know there's been some domestic violence going on.

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Royal Commission, that's been a bit hard because people haven't been able to go to the hearings because I have done my Royal Commission.

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

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Well, we haven't been coming because of the restrictions of self-advocacy; we had to wait until they told us when it was on. I am the treasurer of self-advocacy and I feel...we haven't come because of the restrictions; and we haven't meet up since - we haven't meet up at all with the self-advocacy while the COVID was on.

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I think the most big challenge has been social distancing. I play a lot of competition pool; so I am inside pool halls and stuff like that; and the 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.

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.

My thing was public transport as well. It was quite hard to keep social distancing on transport.

There was overrestricting 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.

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

Anyone with mobility aids that was slightly large and wouldn't fit in the boots of taxis, those aids were put on the driver's side back seat; and if it was slightly large, well, your space on the passenger-side was greatly reduced. So that was a real problem.

## What has been positive changes during covid?

Positive impact working on how to make that transport system work not just simply for the abled bodied but for everybody; people like me who have got some mobility problems, people with intellectual disabilities.

But then once I got the hang of it (zoom), it got better and better

Well, we have been doing things on Zoom. Like, we have programs and stuff that people connect on Zoom; like the process they do in person, they have done it on Zoom. Like, sometimes we have shows (?) sometimes on Zoom and music and stuff on Zoom. So things that normally happens out in the city, we do it on the Zoom.

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

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

Well, some people didn't know anything about Zoom, so we explained to them what Zoom does. We said, "It is sort of like Messenger, when you see everybody on the screen." But then when we started, we teach them how to do things. So we told them, "It is easy, once you get the hang of it".

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We have started the "Staying Connected network". Self-advocates, support allies and family members from across Canada meet and share resources, experiences and work 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. But we still communicated with one other through meeting dinner together and talking and playing games on Thursday nights.

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On Wednesday nights, xxx ran the 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.

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Doing choir online

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And then through the second lockdown, we sort of already knew what to expect, except it had a lot more restrictions than the first wave. The fact that we went through it in the first time and then we had it happen again, it didn't mean it sucked any less. But we knew what was coming.

I think we were still able to provide our service; just having to adjust to what the community and our State was going through at the time.

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(Disability Royal Commission) they are going to extend it for another 12 months for people with disability to come and tell their stories, on the ones who brought up in institutions and the ones who have been through the domestic violence and all that as well.

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So while it's been the lockdown, I have been having these Zoom meetings, like I am having today, and that; and catching up with a lot of people on Zoom as well. And I am free as a bird as well; been through domestic violence, myself; and I got my own unit and that and I am very happy now.

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Sent out letters, seeing how everybody is going and all that

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And we have been doing a lot of Zoom meetings over the computer.

Yes, we have been doing that. After lockdown, we meet a couple of times, where we start meeting again...and everybody talk about their stuff, bring everybody back together. Talking about what COVID means to everybody.

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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.

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And 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.

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

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Getting a phone call each day from someone

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But the good part about COVID was: it's brought a lot of people together. A lot of people checked-in on each other.

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And Woolworths and Coles brought out their - for people with disabilities, they can get their groceries shopped a little bit earlier than most other people. I think 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 sanitised before they come and see us. So they were quite adapted to our abilities as well.

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The good things were people were getting more access to technology, as everyone else has said during the meeting. They were getting technology through NDIA; and we also got to learn how to communicate on Zoom; and I guess for me, just personally, one of the good things was, I was ~~ able to start our own veggie garden; my husband, Peter, and I were able to start our own vegetable garden. And those sort of things. So we were able to do those. Yep.

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I guess understanding the government - oh, sorry. Speak Out...was streaming every night; and they explained the restrictions in the way that we understood them; keeping us updated.

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They also explained what our rights were ~~ and what we could do.

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I think it has brought our group together. Also, I think we educated the man from the Queensland Department of Health on COVID. I think our Hot Topics group educated him on the issues about COVID for people with intellectual disability; and he still wants to come and talk to the group about it. We asked questions about COVID and having an intimate relationship

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Royal Commission; and people continued that 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; and it doesn't necessarily mean that they have to be there in person to do it.

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

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With the people I know, right now it's hard to join our groups and stuff because you don't have the technology. But through...funding, they have tried to get people to have those connections; laptops and stuff like that. So that's one thing about the rights, that they tried for people with disabilities.

## What is your message to decision makers?

For disability people to respect other people and respecting back.

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I just think it's education; because we have never had anything like this before. And I think it's time that they listen to us; because some of the people we deal with have just come out of lockdown. They have been away for, say, nine months; they are just coming out. And if they go back into lockdown, I think their mental health is going to be really bad.

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I guess to try and make sure that everyone is doing okay within our groups throughout this whole situation; and to make sure that the government are doing the right things by us and by other people as well; and to make sure that this kind of thing never happens again; which could or may - may not happen but who knows. Yes, because the rules change every day. So it's kind of hard to know what you are doing from one day to the next.

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

Provide the IT hardware and the education to use it. Because with COVID-19, it was every man for themselves; trying to get hold of computers, web cams, microphones. All the stuff that's needed to stay in touch. For anyone with intellectual disabilities or physical disabilities, you were basically at the bottom of the pack for trying to get hold of anything.

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As they just announced that Telehealth is staying, which is a great thing for people with disability; and that's in a good way. They need to let people have a voice and get understood in the right way. And I think with planned meetings, and things like that, they need to know how to read and understand people with disabilities in a better way.

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Yes, and know more; be able to share their knowledge. People be able to share their knowledge without getting, uhm, what would you say, uhm, in trouble with their plans and stuff like that; because there's just too many secrets

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

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When COVID was on, they cancelled everything; and they weren't allowed to go out. All we had to do was stay in the house, where we are; and we kept safe; and we are having masks that protects the virus. 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.

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I think it's to continue the communication for people in group homes and housing accommodations; because I feel like especially in those kind of environments, it can be quite confronting and you can't really communicate with anyone except for your own company. So I would say maybe encourage ~~ group home staff and supervisors to encourage outside of home communication. That would be my one recommendation.

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For Canada: ...come up with a vaccine. Need to continue to educate others about COVID, to keep people safe. Well, I guess what needs to happen: we need to get more people involved with their programs on Zoom; and educate for the government, we need to educate others on how to stay safe and how they can be safe in their homes; be safe with this virus going around and stay well. We need to educate more on that.

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We are talking about vaccine, one in Victoria alright; that we are the vulnerable people, the aged, carers, people with disability are vulnerable people. How is it going to affect us in a way, like anybody else and all that? That's going to be hard. And we don't know how it's going to affect people with disabilities in a way, anyway.