

---

# International Day of People with Disability online event

Self-advocates leading in a post-COVID world

*Summary report – 3 December 2021*

---



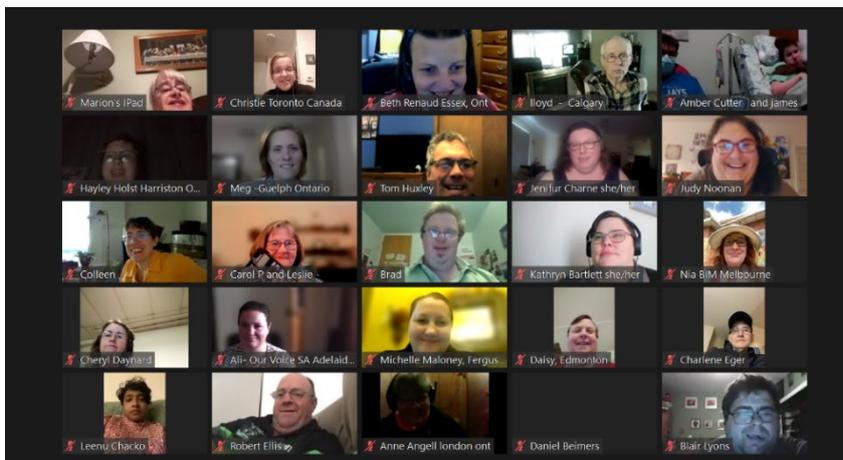


## Self-advocates speaking out

Almost one hundred (100) people with intellectual disability from around Australia, Canada and even America, came together on International Day of People with Disability to talk about how they use their voices to lead in a post-COVID world.

They talked about how they are leaders in their own lives and communities and what is needed from them as leaders in a post-COVID world.

By video link up they talked about their key messages for decision and policy makers to ensure self-advocates continue to use their voices to lead in a post-COVID world.



*“It means a lot to be a leader as I speak up for people with an intellectual disability” forum participant*

## Background

Since 2020 Queenslanders with Disability Network (QDN) Brisbane and Gold Coast Hot Topics Peer Support Groups have been connecting with New Vision Advocates in Ontario, Canada. Meeting monthly on Zoom, the groups talk about things that are important to them, as people with intellectual disability, including the similarities and differences between the countries and how they have been coping with COVID-19.

Following the success of last year's online event, Hot Topics and New Vision Advocates decided to put on another international event to celebrate International Day of People with Disability (IDPWD) on 3 December 2021. This year's theme was leadership and participation of persons with disability towards an inclusive, accessible, and sustainable post-COVID world so this year's topic was "self-advocates leading in a post-COVID world."

## Why is self-advocacy important?

*"I believe there's leaders of all sorts...everyone with a disability and all sorts of different disabilities have a voice. They should be heard by everyone". Forum participant*

## Who helped organize the International Day of People with Disability self-advocate event?

QDN's Brisbane and Gold Coast Topics with Community Living Ontario's New Vision Advocates from Canada.



## Who was part of the forum?

- QDN's Hot Topics – Queensland
- Community Living Ontario's New Vision Advocates Canada
- Valid - Victoria
- Aboriginal and Torres Strait Islander Disability Network Queensland (ATSIDNQ)
- Community Living Association - Queensland
- WWILD - Queensland
- Independent Youth Housing Cooperative - Queensland
- SARU - Victoria
- Our Voice – South Australia
- People First New Zealand
- Loud and Clear – Queensland

## Who couldn't make it on the day?

- Inclusive Research Network, University of Sydney – New South Wales
- Council for Intellectual Disability – New South Wales
- Centre for Disability Studies – New South Wales
- Self-Advocacy Speaking For Ourselves – New South Wales
- Speak Out Advocacy – Tasmania



## What was the self-advocates leading in a post-COVID world 2021 forum all about?

On the 3 December 2021, we had a meeting for self-advocacy groups for people with an intellectual disability from across Australia and Canada – someone from America also joined in!

The purpose of the meeting was for self-advocates from different parts of the world to 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
- how have people been leading in their communities and in their own lives to bring about change
- what is needed from us as leaders in a post-COVID-19 world and how do we get there?
- what we want decision makers to know about what is needed for self-advocates to lead in a post-COVID-19 world



## What did we do at the forum?

### Format of the event

1. Welcome: Michelle Moss QDN and Donna Best, convenor of QDN Brisbane Hot Topics
2. Acknowledgement of country by QDN and ATSIDNQ member Uncle Willie Prince with didgeridoo performance 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.
5. Smaller group discussions in breakout rooms

### Short video presentation

A video compilation was shown showcasing self-advocacy groups from Australia, Canada, New Zealand, and Scotland. These videos shared their stories, showing the power of people coming together and standing together to self-advocate. These videos ensure the voices of self-advocates are heard so their messages are understood by people who make decisions. You can watch the video compilation [here](#) (insert links).

*"I am a citizen too!" People First New Zealand*



## Panel members:

- Peter Eldridge from Brisbane Hot Topics, Queensland
- Michelle Mullane from Brisbane Hot Topics, Queensland
- Robert Ellis from Gold Coast Hot Topics, Queensland
- Paul O’Dea from Community Living Association, Queensland
- Jenifur Charne from Community Living Association, Queensland
- Yvonne Spicer from New Vision Advocates, Ontario, Canada
- Ian Cummins from Our Voice, South Australia
- Nicole Flynn from Staying Connected Network, Ontario, Canada
- Uncle Willie Prince from Aboriginal and Torres Strait Islander Network Queensland
- William Ward-Boas from Valid, Victoria
- Colin Hiscoe from Reinforce, Victoria



## How have we been leading in our lives and communities?

- Helping others and advocating for others in the health system
- Helping people get ready for disasters or emergencies so people with intellectual disability are included
- We run our own housing company and teach other groups what can be done to manage properties so people can have affordable places to live
- Sharing what we know and inviting guest speakers to talk about things we might not know about
- Being involved with various groups and committees
- Speaking up and advocating about issues such as housing, poverty, employment, and disability supports
- Speaking to the government
- Public speaking and presentations to teach people about disability to break down stigma

- Teaching workers and support staff about working with people with intellectual disability
- Educating others about the importance of not excluding people with intellectual disability by demonstrating the benefits of inclusion for all people
- Teach people about Aboriginal culture and what is culturally appropriate
- Communicating with other people who would otherwise be isolated during COVID
- Keeping people updated with information about COVID in a way that they understand
- Reassuring people who might be scared of the COVID vaccine



## What is needed for self-advocates to be leaders?

- We need to respect each other
- To work as a team and put our heads together
- Giving others a helping hand without taking over
- Mentoring people and groups to start their own self-advocacy groups
- Learn from your mistakes
- Staying connected is important especially with other self-advocates
- Keep speaking up about important issues
- Don't be scared to speak up
- Lead by example
- Supporting others to speak up for themselves and have a strong voice
- Listening to other people's stories as everyone has their own story to tell
- Celebrate people's differences
- Constantly talk to people in the community and service provider to educate them about unique needs
- Work with people hand in hand to share experiences so you can

be leaders together

- Building networks to give and share information with people
- Passing on knowledge and skills to other self-advocates
- Talking in plain English and in ways people can understand

*“We need to put our heads together and get on the same page as each other to create our own dreams” Forum participant.*



### **Messages to decision makers:**

- People need to more support. The high cost of housing and food mean people with disability have little money to live on.
- Information should be given in easy English, so it is easier to understand
- Funding is needed for self-advocacy groups
- Self-advocates should be paid for the work they do and provided with training.
- Everyone is equal
- Work alongside with us
- Access to accessible technology is vital and affordable data and education about how to use it
- People need more accessible information about COVID
- COVID has hit people with disability particularly hard and more people with disability should be a part of the ongoing conversation about COVID
- Amplify the voices of people with disability and self-advocates by inviting us to the table
- Don't forget about the people living in rural areas where services and information is harder to access
- Nothing about us without us



## Quotes from participants about being leaders in their own lives and communities:

- I believe there's leaders of all sorts. There are Aboriginals who have a voice; and women have a voice, and everyone with a disability, and all sorts of disabilities have a voice. They should be heard by everyone.
- It is important to for people to have a say about things that are important like the vaccine.
- A leader is a person who leads people to a wisdom. Who doesn't take over but gives someone a helping hand to guide them through different stages of their life.
- A leader has an ability to help but not take over. I help people with banking, budgeting, and the NDIS, and how to get more out of the NDIS.
- I learn a lot from mistakes.
- The work that I do is needed right now as I continually see and hear people who are having a hard time living below the poverty line. So, it's needed to keep speaking up and advocating about these issues.
- I am a trailblazer in my community – breaking down barriers and demonstrating the benefits of inclusion for all people.
- Everybody needs safe housing so organizing a community housing group is a win for everyone in the group.
- For so many years people tell you to keep your mouth shut. Let them open up and hear their stories. Everybody has a different

kind of story in the disability world.

- Leadership means being able to say your ideas and opinions to other self-advocacy groups and trying to bring them along with you and other self-advocates.
- I believe it is really important that we talk in plain English. I, as an elder passing on my skills and knowledge to other self-advocates who can pass on to other self-advocates who can learn about leadership. We need to know our rights to be in a leadership role and a list of all the things we can do. (i.e. United Nations Declaration of Human Rights).
- I hope it (leadership) doesn't change, as why reinvent the wheel. Yes, it's going to be hard. Yes, it's going to be difficult. I can understand that but why do we have to change something when it is already there?
- For self-advocacy groups to continue in a post-COVID world or in a world with COVID I strongly believe for self-advocacy to continue further funding is a must. I repeat, must. You must be able to pay self-advocates. Again, I repeat, pay self-advocates for the work they do. They need to be trained in how to do it.
- I think that even people that know me think I can do this (leadership) standing on my head, and I don't need any training. I think sometimes I just lack the confidence and I like that support with me.
- I would like to connect with other self-advocates around the world but first I would like to connect with self-advocates around Australia. I would like to learn how to do this in Australia and then go international with other self-advocacy groups around the world.
- My dream is for all groups around the world supporting, talking, teaching, training, and all those sorts of things with support and funding. I hope this world is going to be a much, much better world because of self-advocacy groups getting together and

talking and sharing their ideas, skills, and knowledge.

- Mentor others so they can be self-advocates.
- Meetings like this are important as they show us we are not alone.
- If we don't stand up and voice our opinions to get the vaccination, when we want the vaccinations, and it's got to be safe and affordable. And by unifying our voice world-wide to ensure that everyone out there in the community, no matter where they are, have the affordable, accessible and they have the appropriate information, that they have to ensure that they can get the vaccination.
- Stand up and fight for your rights
- I think there's been some fantastic messages and I think the most important one about the connection of people and this connection of an international community of self-advocates.
- Please, please let's continue to work together.

## Closing

In closing Michelle and Donna acknowledged everybody who participated and all their contributions they made; saying we look forward to forging ahead in this post-COVID world and the leadership of you all, to keep making a difference in people's lives every day. So, thank you.