

## **Nothing about us without us**

With over 2000 members and supporters, the Queenslanders with Disability Network (QDN) is an organisation of, for, and with people with disability. QDN's motto is "nothing about us without us."

In 2019, QDN joined with a research team led by Associate Professor Michelle Villeneuve at The University of Sydney to co-design a peerled approach to increasing awareness about disaster risks and supporting tailored emergency preparedness through peer support. Before that, QDN and their members had not been part of emergency preparedness conversations. Two years on, QDN's disability advocates are leaders in DIDRR.

## QDN's state-wide peer groups

QDN has a pool of volunteer peer leaders who convene peer support groups of people with disability in numerous cities and regional towns across Queensland. The networked connections of the peer leaders means that they can bring issues to QDN about the everyday barriers that people with disability experience. QDN uses this information to inform their policy advocacy efforts to remove the barriers to full participation of people with disability in their communities.

All QDN peer leaders are people with disability. Many identify as community leaders and disability advocates, each with different support needs and life circumstances. They have experience leading peer support groups. Twenty-five local peer support groups across Queensland meet monthly. People with disability come along to meet others, learn new things, share information and support each other. When asked why they attend, one group member said, "to share my personal lived experiences and, in return, hear firsthand the personal stories of others. It has been positive for me to hear from other people with disability who have had similar life experiences. Peer support groups make space where I am able to be transparent, open, and honest about my disability." QDN's network of peer support is growing thanks their **Emerging Leaders** Program.

Twice per year, peer leaders meet together in Brisbane for leadership and skills development. These workshops give the peer leaders an opportunity to support each other on their leadership journey as they build their knowledge and skills together. Their leadership mission is "to inform, connect, lead, and influence."



# It all started by bringing the peer leaders together to learn about P-CEP and support each other to make a plan.

In 2019, the peer leaders took up the challenge of advocating for DIDRR. They said yes to formally being part of the Disability Inclusive and Disaster Resilient Queensland project. Little did anyone know that shortly after that meeting, Australia would experience a devastating summer of Bushfires followed by the global COVID-19 pandemic.

First, twenty-five QDN peer leaders developed their own personal emergency plans. Then, these peer leaders engaged their peer support networks to build capability in other people to:

- self-assess risk, preparedness and support needs;
- develop their own individual emergency preparedness plan; and
- share their plans with others in their support network.

We called it the Person-Centred Emergency
Preparedness (P-CEP) Peer Leadership Program.

#### **Co-design was central to program development**

The P-CEP Peer Leadership Program started with two-day training which was co-designed and cofacilitated with three people with disability: Tara, Des and Carol.

Tara, has a physical disability, chronic health conditions and is deaf. With past experience working in the military Tara eagerly applied the P-CEP to develop her own individual emergency preparedness. During the training, Tara led a role play on how to start the conversation about emergency preparedness. Her message to the group was to be careful not to overwhelm your conversation partner because talking about emergency preparedness can be scary. Tara also shared her plan and facilitated group discussion on tips for sheltering in place and evacuating to a place of safety.

Des, a QDN board member with quadriplegia, was involved in a cyclone that left him without power. Unable to get out of bed and without his support providers, Des had to rely on his neighbour for help. Des told his story in a Community Recovery campaign called, "Get to Know Your Neighbour." In that video, Des talks about the importance of relationships and social connectedness - a key

element of the P-CEP. At the P-CEP training, peer leaders watched the video together, then Des led an interactive session where the group generated their own strategies for strengthening their personal networks of support.

Carol is a retired emergency manager who also has lived experience of disability. She had a stroke when she was 27 which left her with hemiplegia. Later, Carol lost her vision and two feet to amputation. Carol shared an emergency manager perspective and encouraged peer leaders to develop realistic expectations about what emergency services can and cannot do in times of disaster. She shared these insights and led a Q & A session to help people self-assess what they can do for themselves and to pre-plan with their family and support networks for the support they will need in an emergency.

Peer leaders participated in interactive learning activities, videos, simulated exercises, role play, and small group discussions. They also heard from Adam Green, Queensland Fire and Emergency Services (QFES), and Vicki Anderson, a Local Council Emergency Manager from Moreton Bay. Connecting with emergency services personnel was valued by the peer leaders who actively engaged in asking questions about the role of emergency services agencies, the support available for people with disability, and where to access information on local hazard risks and warning mechanisms.

Time was dedicated to one-on-one peer-led conversations for participants to develop their own emergency preparedness plans and to practice being a person-centred conversation partner.

Many of the peer leaders reflected that the P-CEP training was "eye opening." Learning together was key to building their confidence to develop their own plans. Peer leaders enabled each other by sharing tips and supporting each other with

suggestions for emergency preparedness planning. Peer leaders who had experienced disasters in their communities provided their insights and support to others during and following the training.

We documented everything we learned and began using the experiences of these peer leaders to coproduce the <u>P-CEP Workbook</u>. The peer leaders tested the workbook on themselves and with their support groups. Their ideas were included in the final Workbook which was made available to everybody in Australia by August 2020.

### Timing is everything

The timing of the initial training with peer leaders (February 2020) coincided with the emerging global pandemic which hastened peer leader engagement with the information to develop their own P-CEP plans. Real-time learning and reflections were enhanced by their lived experiences of accessing information and managing their individual support needs amidst evolving understandings of this health emergency.

The experience of COVID-19 advanced informationsharing between peer leaders and their support networks ahead of our original timelines for implementing P-CEP peer support and mentoring. QDN pivoted quickly from face-to-face meetings to an online format. QDN support included:

- up-skilling peer leaders and their group members to use video-conferencing software;
- developing private social media groups for members to interact and share information; and
- supporting the participation of individuals with limited or no access to devices or data.

Through this process of learning and working together, we developed a second resource – the P-CEP Planning Guide for COVID-19 for people with disability.

COVID-19 has been a challenging time for people with disability. It was critical to have a resource that delivered practical tools and information. It gave Australians with disability a resource to help them to make a plan for their own individual needs and situation during COVID-19 – to stay safe and get the supports they need. This resource has been included in the National Management and Operational Plan for People with Disability as an element of the Australian Health Sector Emergency Response Plan for Novel Coronavirus. It won the Community Award in the 2020 Resilient Australia Awards - Queensland Division and received Highly Commended at the National Award Ceremony held in Canberra in December 2020.

Michelle Moss, Director of Policy and Strategic Engagement QDN's said, "People with disability have been leaders in this work and this has provided a platform to enable people to be empowered, have the information, tools and support they need to play a critical role in developing their own emergency and disaster resilience alongside the people who support them and lead DIDRR with their communities."

#### **Lessons Learned**

- Co-design and co-delivery are the foundation of learning together with people with disability to co-produce tools that people can use to tailor emergency plans to their support needs and situation.
- People with disability have an important role to play in leading change toward DIDRR.
- Peer leadership and peer support is an effective way to help people with disability to know about and use the P-CEP resources to make a plan.

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For more information: www.collaborating4inclusion.org







