Person-Centred Emergency Preparedness Actions by People with Disability

What is the issue?

Personal emergency preparedness is the most important thing anyone can do to prepare for and respond effectively to disasters triggered by natural hazards and other emergencies (e.g., house fire; pandemic). However, emergency planning places high demands on people with disability, particularly for those who rely on others to support their safety and well-being in emergencies. Until recently, a significant barrier to personal preparedness was that planning tools, designed for the general population, were insufficient for people with disability who need to tailor emergency preparedness to their individual support needs and situation.

The Person-Centred Emergency Preparedness (P-CEP) framework and process tool was developed to address the barriers. It was developed through co-design process involving multiple stakeholders, including people with disability, their support networks, and emergency personnel. The P-CEP outlines four steps to increase emergency preparedness The four steps bring people together with the services that support them and emergency personnel to enable planning through person-centred conversations. The P-CEP has developed into a toolkit incorporating a suite of resources, videos, case studies that are freely available and accessible online. A P-CEP Workbook provides information, resources and guidance to support planning through a series of conversations.

We have the tools. Now we need to find ways to make sure that people with disability know about the tools and can use them to develop their personal emergency preparedness – so they know how they will act together with their support network when disasters strike.

What did we do?

Queenslanders with Disability Network (QDN) has built a pool of volunteer peer leaders who convene peer support groups in numerous cities and regional towns across Queensland. All peer leaders are people with disability, each with different support needs and life circumstances. Many identify as community leaders and disability advocates.

Local peer support groups provide regular (e.g., monthly) opportunities for people with diverse disability to come together as equals to connect, engage and support each other. Peer group convenors initiate planning for each group, coordinate activities, and mobilise peer group events that are both informative and inclusive.

In this project, researchers from The University of Sydney partnered with QDN to develop their role and capacity to lead change toward more inclusive approaches to disaster risk reduction. We drew on QDN's existing peer support model and networks of peer support to develop capability in the peer group convenors to increase their personal emergency preparedness and then to raise awareness and increase access of their group members to emergency preparedness information, people, and resources.

Research Aims

We wanted to understand the contribution of the Peer Leadership Program to enabling the peer group convenors (peer leaders) and the people they supported to develop personal emergency preparedness plans tailored to their support needs and situation.

Our aims were to:

- describe the preparedness actions that people reported taking because of their participation in the P-CEP program;
- identify things that interfere with preparedness planning for people with disability; and
- understand the barriers and facilitators to enabling emergency preparedness in others.

We interviewed 37 people with disability who participated in the P-CEP Peer Leadership Program.

- 21 were QDN peer group convenors
- 16 were people with disability who received P-CEP mentoring through peer support

We used reflexive thematic analysis to identify themes in the interview data. Findings were used to support improvement to the design of the P-CEP Peer Leadership program and to help develop a P-CEP education program and evaluation strategies.

What did we learn?

We learned about the actions that people with disability took to prepare.

Preparedness Actions

1. Identifying sources of support (e.g., family, friends, neighbours, support workers)
2. Communicating with support people about their needs and emergency plans.
3. Identifying sources of information during an emergency and making sure this information easy to access (e.g., putting emergency contacts in phone; keeping emergency numbers on fridge magnet)
4. Making plans for evacuation, including exiting the building and planning where to go.
5. Preparing sources of power for specialised equipment and communication systems
6. Preparing supplies, for staying at home or evacuating, including food and water, medications and prescriptions, first aid kits, portable equipment (e.g., bed raisers), radios, supplies for animals, and important documents and valuables.
7. Communicating health-related needs to others, (e.g., blood type, medications, health conditions). Forms of communication included electronic and printed documents, bracelets and Apps.
8. Making this information visible and available to others, while maintaining some level of privacy.
9. Preparing for the emotional impact of disaster to cope better during an emergency.
10. Advocating for needs by talking with others and getting support when there are gaps in preparedness that increase risk during an emergency.

We learned about the things that make it harder for people with disability to prepare for and respond effectively in an emergency. Participants anticipated things that could become a problem for them in an emergency. For some people the impact of these problems could be significant.

Anticipated Problems

Difficulty evacuating

- Managing stairs with a mobility impairment
- Only having one accessible exit
- Vision impairments affecting navigation around obstacles
- Evacuating from unfamiliar environments (e.g., if emergency happens when in the community or on holiday)

Inaccessible evacuation centres

- Inaccessibility of the building or facilities (e.g., toilets)
- Lack of specialised equipment at an evacuation centre (e.g., hoist; adjustable bed)
- Lack of access, availability or funding for alternative accommodation that meets personal support needs
- Lack of knowledge of emergency personnel and volunteers at evacuation centres about how to help people with disability
- Concerns about evacuating with assistance animals and pets

Needing power for specialised equipment

- Mains electricity needed to power different types of specialised equipment may not available. This could impact access to equipment (e.g., electric wheelchairs; pressure mattresses; hearing aids and communication aids) needed for their health, safety and well-being; and increase dependence on others who might not be available to help.

Preparing emergency supplies

- Inability to secure adequate supplies of medications (e.g., controlled medication; cost; not having sufficient prescriptions)
- Emotional challenges with eating stockpiled food
- Maintaining fresh stockpiles of food
- Ability to carry emergency supplies during an evacuation
- Cost of supplies/to prepare a kit

Lack of personal support

- Needing physical assistance from others and that support not being available
- Not having family, friends, or neighbours who can help
- Not being able to rely on a formal (paid) service provider in an emergency
- Authorities not aware of the individual or their support needs and not having a plan for how to help

Availability of accessible transport

- Not being able to drive and relying on others who may not be available to help
- Reliance on public transport or scarce wheelchair accessible taxis that may not be functioning in an emergency.
- Not being able to replenish supplies, access services, or seek support without effective transportation

Getting and giving information

- Getting accurate information about unfolding emergency situations
- Being able to explain to emergency personnel what their needs are or to ask for help (e.g., for people who are deaf or non-verbal)
- Understanding emergency information and knowing what to do (e.g., low literacy)

Privacy

- Concerns with sharing medical information or details about their personal support needs that makes them feel more vulnerable to abuse from others

Protecting property

- Not being able to prepare or protect property and/or not having help to do so
- Navigating when the environment is inaccessible (e.g., fallen trees; debris)

> **We learned about strategies that helped peer group convenors to enable preparedness with their peers.**

Peer support strategies that enabled preparedness in others

1. Discussing emergency scenarios and sharing ideas about how to manage risk through peer-to-peer support helped people to think about ways to manage in an emergency.
2. Learning from people with similar support needs and hearing from diverse perspectives of people with different support needs provided more strategies for preparedness planning.
3. Following up group meetings with individual support and mentoring helped to keep participants accountable and on track with tailoring their preparedness planning.
4. Using the P-CEP Workbook helped to give structure to the emergency planning conversation.
5. Using the P-CEP framework or capability wheel provided a visual anchor to ensure that all eight areas of were covered.
6. Stimulating discussion by providing some initial ideas or inspiration supported brainstorming of strategies to manage support needs in emergencies.
7. Enabling individuals to take ownership of their plan helped to facilitate individual choice and control as part of the emergency planning conversation.
8. Being willing to share personal experiences and examples of their own journey toward increased preparedness and being open to learning new things from their peers made preparedness planning seem more manageable and the process relatable.
9. Having high expectations of their peers and being a positive and supportive guide was motivating and inspiring for others to make an emergency plan.
10. Reaching out and following up with people individually helped people who needed more support to take preparedness steps.

What do our findings mean?

- Experience of managing every day with a disability enhances capability to prepare for emergencies.
- Preparedness is more effective when it is individualised and tailored. The P-CEP framework helps people with disability to consider their capabilities and needs holistically.
- People with disability may need support to prepare for emergencies (e.g., obtaining and managing supplies) and rely on help from others to respond effectively during an emergency (e.g., to collect specialised equipment and evacuate).
- Barriers to evacuation (e.g., inaccessible environments, lack of transport) impact the safety and well-being of people with disability in emergencies. For these reasons, several participants favoured remaining in place during an emergency, which may bring its own risks and support requirements.

- Peer group convenors played an important in role supporting their peers with the emergency preparedness journey by providing guidance and support for tailoring preparedness to support needs.
- Peer mentoring is a skilled role. Peer leaders need to develop these skills, which will often require support from their representative or advocacy organisation and emergency personnel.
- Disabled People's Organisations (DPOs) and disability advocates have an important role to play in connecting their members to emergency managers and emergency service organisations to foster dialogue and build understanding about what people with disability can do for themselves and what they need support for in emergencies.

Next steps

Follow our program of research to learn about how findings from this study have been used to develop a P-CEP Education Program and evaluation methods. Learn how we are working together with disability representative and advocacy organisations to develop their capacity to play a key leadership role in person-centred emergency preparedness.

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