

ISSUES PAPER

# Clearing a path to full inclusion of people with disability in emergency management policy and practice in Australia



Disability Advocacy Resource Unit



THE UNIVERSITY OF  
SYDNEY

## Acknowledgement

This report relied on the insights and reflections of many people who are contributing toward the development of disability inclusive emergency management.

Thank you to the individuals with lived experience of disability and disaster, disability advocates and organisational representatives from the emergency, disability, community and government sectors who generously shared their ideas, experiences, expertise, and time.

Thank you to Ivy Yen who provided research assistance and support in the analysis of data and consultations with stakeholders that contributed to the generation of this issues paper.

### **Issues Paper prepared by:**

Michelle Villeneuve

### **To cite the Issues Paper:**

Villeneuve, M. (2020). Clearing a path to full inclusion of people with disability in emergency management policy and practice in Australia. Centre for Disability Research and Policy. The University of Sydney, NSW, 2006.

### **Contact:**

Associate Professor Michelle Villeneuve  
[michelle.villeneuve@sydney.edu.au](mailto:michelle.villeneuve@sydney.edu.au)



# Executive Summary

Australia experienced multiple disaster events in 2020 including the longest drought and most intense bushfires. The experience of disaster was compounded by the current global pandemic. The emergency situation in Australia brought into sharp relief shortcomings in Australia's capability to plan with people with disability for how to manage the disproportionate impact of disasters on people with disability.

Australia's emergency management arrangements<sup>1</sup> direct emergency management practices and activities of different actors (government, emergency services, non-government), including how these practices are organised and delivered across all levels of government. State and territory governments have primary responsibility for emergency management within their jurisdiction. These arrangements recognise that individuals, families, communities, and businesses must share responsibility with government and emergency services by preparing for and safeguarding against emergencies, including their ability to recover from disaster.

What's missing are methods, tools and programmatic guidance on how to include people with disability and their support needs in emergency management practice and policy formulation. This presents significant risk to the safety and wellbeing of people with disability before, during and after emergencies.

This issues paper:

- Brings together lived experience and literature to build a picture of the roadblocks to safety and wellbeing for Australians with disability.
- Outlines six key issues (identified below) that present barriers to the full inclusion of people with disability in emergency management.
- Puts forward a suite of practical actions that institutions with responsibility for emergency management and other stakeholders can undertake.

The evidence and recommendations can be used by disability advocates and peak organisations to advocate for change toward disability inclusion in disaster risk reduction.

The six issues identified and discussed are:

1. Disproportionate Risk
2. Overlooked, Excluded
3. Higher Demands, Fewer Choices
4. Underprepared Support Services
5. Extra Supports and Equal Access to the Same Supports
6. Unclear Responsibilities

The issues paper concludes with recommendations on how to include people with disability and their support needs in emergency management arrangements. Five recommendations focus on how to clear the path to full inclusion:

1. Build nationally consistent standards for including disability representation into all emergency management arrangements (policies, practices and activities) at all levels of government.
2. Prioritise collaborative and inclusive disability research that will assist government and emergency personnel to understand and respond to the extra support needs of people with disability in emergencies.
3. Provide person-centred resources, support, and advocacy where needed for people with disability to self-assess their risks and tailor personal emergency preparedness to their support needs and situation.
4. Develop a nationally consistent approach to capacity development for community and disability service providers and disability advocates in person-centred emergency preparedness and service continuity planning.
5. Provide explicit policy guidance on who takes responsibility for the extra support needs of people with disability in emergency situations including, how that support should be organised and delivered before, during and after disaster, and how the responsibilities of different stakeholders will be guided and outcomes measured.

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# Introduction

**On 27 August 2020, the Disability Advocacy Resource Unit (DARU), under the auspices of the Victorian Council of Social Service (VCOSS) and Disability Advocacy Victoria (DAV), held a forum on Disability and Disaster Resilience. The aim of the forum was to explore priority issues in emergency management for people with disability and look at why responses are failing to be consistently inclusive, despite the rights-based frameworks and policies that are in place.**

DARU committed to developing a paper that:

- outlines the issues;
- puts forward a suite of practical actions that institutions with responsibility for emergency management can undertake; and
- can be used by disability advocates and peak organisations to advocate for change toward disability inclusion in emergency management.

That path forward must involve multiple stakeholders working together to remove the barriers to the full inclusion and meaningful participation of people with disability in disaster risk reduction. Therefore, the target audience for this issues paper includes:

- People with a disability and their representatives, including advocates
- Family and carers
- Individuals, businesses and organisations that provide services and support to people with a disability
- Emergency management personnel, agencies, and organisations
- Governments and policy makers

## Purpose

This paper centres on what has been learned from the lived experiences of people with disability in disasters in order to:

1. reflect on, learn from, and advocate for improved pre-planning for how to include people with disability at every stage of emergency management (preparedness, response, and recovery); and
2. advise on a way forward that will ensure Australia meets its obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the Sendai Framework for Disaster Risk Reduction (SFDRR) to ensure the rights, protection, and active participation of people with disability in emergency management policies and practice.

## Guiding Question

*What has to change to ensure the rights of people with disability are embedded in a meaningful way into all government programs, plans, strategies and policies designed to increase the resilience of all Australians to disaster?*

*How do we clear a path to full inclusion for people with disability in emergency planning to increase safety and wellbeing when disaster strikes?*

## Principles

The following principles guided the development of this issues paper and recommendations:

- **People with disability are experts in their own needs** – what they need are the right tools, time, supports and opportunities that enable them to optimise their self-reliance and planned reliance on others in emergencies.
- **Meaningful participation of people with disability enables more effective emergency management practice** that is responsive to the support needs of people with disability in emergencies. There is no question that people with disability must be included in disaster management planning, response and recovery decision making. What is needed is direction to entities with responsibility for emergency management on how ensure the rights of people with disability to adequate protection, full inclusion and meaningful participation in emergency management programs, plans, strategies and policies.
- **Disability inclusion in emergency management requires cross-sector collaboration.** Ensuring that nobody is left behind in disasters requires cross-sector engagement and meaningful collaboration to address the barriers that increase risk for people with disability before, during and after a disaster.

## Approach

The following steps were taken:

1. Synthesis of the research literature on disability and disaster in relation to the guiding question with a focus on the perspective of people with disability and contextualising findings to the Australian emergency management context.
2. Review, analysis and synthesis of the lived experience of people with disability in emergencies. Two data sources were appraised:
  - a. Experiences of people with disability shared at the DARU Disability and Disaster Resource Forum held on 27 August 2020 accessed at: <http://www.daru.org.au/resource/disability-and-disaster-resilience-forum-session-up-on-youtube>; and
  - b. Witness statements made by people with disability to the Disability Royal Commission (DRC) Public Hearing 5 on the Experience of people with disability during the ongoing COVID-19 Pandemic accessed at: <https://disability.royalcommission.gov.au/public-hearings/public-hearing-5>
3. Group discussions and feedback from stakeholders from the disability, community, government and emergency services sectors on the identified issues and action-oriented solutions, including an examination of the feasibility of those recommendations in the Australian emergency management context.
4. Synthesis and representation of issues and recommendations in the following formats:
  - Issues Paper (word version, PDF version, and an Easy Read translation developed by the Council for Intellectual Disability and tested with people with intellectual disability)
  - Presentation of the findings at the DARU Advocacy Sector Conversations forum series (held on 3 June 2021)
  - Infographic overviewing the issues and recommendations

# Issues

**Six issues were identified.**

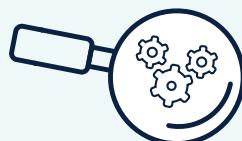
These issues informed five recommendations to increase disability inclusion in emergency management. Each issue is discussed in turn.

**1**



**Disproportionate risk**

**2**



**Overlooked, excluded**

**3**



**Higher demands, fewer choices**

**4**



**Underprepared support services**

**5**

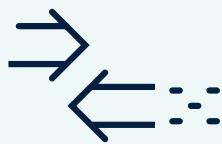


**Extra supports and equal access to the same supports**

**6**



**Unclear responsibilities**



## Disproportionate risk

The 2019-2020 Black Summer Bushfires that devastated Australian communities and the ongoing COVID-19 pandemic have pointed to Australia's deficiencies in realising protections under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>2</sup>. These events have shown the disproportionate impact of disasters for Australians with disability and carers<sup>3</sup>.

A growing literature confirms that people with disability are among the most neglected during disaster events, with particularly restricted access to social networks and other sources of support<sup>4</sup>.

People with disability:

- are two to four times more likely to die in a disaster than the general population<sup>5</sup>;
- experience higher risk of injury and loss of property<sup>6</sup>;
- have greater difficulty with evacuation<sup>7</sup> and sheltering<sup>8</sup>; and
- require more intensive health and social services during and after disaster events<sup>9</sup>.

These impacts stem from a range of factors including stigma and discrimination that marginalises people with disability from mainstream social, economic and cultural participation<sup>10</sup>. Multiple categories of social vulnerability intersect with disability. This amplifies risk in emergencies.

Research on the experience of Australians with disability in disasters<sup>10</sup> showed that perceptions of being a burden to others are exacerbated in emergencies. These self-perceptions influence individual choices that heighten risk during and after a disaster (e.g., not reaching out to neighbours; not asking for needed supports). For example,

*“...some people were saying, ‘there’s something that I could take that makes my life a whole lot easier, but I don’t feel that I’m allowed to ask whether I can take that because it might take up space in the boat or the helicopter and we need that for other people, I don’t want to be pulling the disability card. I don’t want to be putting up my hands being special and different. Or I’m afraid that they might say no and that would be really embarrassing if I’ve asked to have that equipment and they say no to me.’ So, just issues that people might not always think about.”*

(Participant perspective<sup>10</sup>)

A poignant example from a witness with hearing impairment at the Disability Royal Commission (DRC) Hearing 5 on COVID-19<sup>3</sup> similarly illustrates how stigma influences help-seeking behaviours. In this case, S.Y. relies on lip reading to understand verbal communication, but did not feel comfortable disclosing her hearing impairment to people wearing masks even when she couldn't understand what they were saying,

*I don’t tend to come forward that I am hearing impaired...Whereas I do note that it is better for me to come outright with it, I just don’t quite feel comfortable being very open to strangers about these things, especially since I don’t know how they would perceive it and how they would understand and communicate.*

(S.Y. DRC Hearing 5 on COVID-19)

Social isolation and everyday discrimination experienced by people with disability, underly these decisions and reinforce social inequalities in emergency situations<sup>10</sup>. This observation was made by a witness at the Disability Royal Commission (DRC) Hearing 5 on COVID-19,

*At the start of the pandemic, they became isolated from the community. Their access to caregivers was also reduced and they were afraid to present to a hospital to a mounting complication that they had. When they did present to the hospital, it was very late in the course of their problem and they ended up requiring intensive care for a period of time and they were in a very precarious situation as a result. It's arguable that if they presented to a hospital earlier and if they had more comprehensive care in the community, that this could have been avoided and their life may not have been put at risk. (D.P.)*

Disability inclusion in disaster risk reduction cannot be achieved without challenging the social discrimination, marginalisation and institutional neglect experienced by people with disability<sup>4</sup>.

The social vulnerability approach<sup>11</sup>, which has dominated the small body of disability and disaster research, has served to advance our understanding about the disproportionate risk experienced by people with disability. Like the social model of disability<sup>12</sup>, the vulnerability framework has helped to call out the pre-existing structural barriers for people with disability that increase risk in emergencies and advocate for their removal.



## Overlooked, Excluded

The vulnerability of people with disability in emergencies is increased because people with disability have not been included in community-level disaster preparedness<sup>13</sup>.

Where the needs and perspectives of people with disability are mentioned, they:

- are assumed by non-disabled professionals without adequate consultation<sup>14</sup>;
- focus narrowly on one aspect of disability (e.g., physical impairment)<sup>15</sup>;
- are limited to the response phase of emergency management with limited attention on preparedness and recovery phases<sup>10</sup>;
- emphasise doing for, not with people with disability<sup>16</sup>.

This perpetuates inequality for people with disability and increases their vulnerability to disaster because the full diversity of their support needs is not understood<sup>17</sup> or responded to before, during and after a disaster event. Further, the capabilities and potential contributions of people building community resilience to disaster are overlooked<sup>18</sup>.

In addition to taking individual responsibility, contributing to community resilience implies becoming involved, volunteering your time, knowing your neighbours, lending a hand, and looking out for others, particularly those who are at greater risk when disasters strike. These are valued roles that help communities to prepare, respond and recover. Building resilience for everyone in the community means making sure that people with disability have the same opportunity to participate in these valued roles too.

This is a global challenge. People with disability are being left behind in disaster preparedness activities worldwide<sup>13</sup>. The first UN survey on disability and disasters found the majority of respondents with disability (85.57%) from 137 countries had not participated in community-level disaster risk reduction. Only 20% were able to evacuate effectively. However, when appropriate information was made available, this increased to 38%<sup>13</sup>.

Australian research similarly showed that people with disability have not had access to disaster risk information and education that other community members enjoy<sup>10</sup>.

## An Afterthought

**Too often, people with disability are an afterthought and only included as an appendix in disaster management plans.**

(Council Emergency Manager)

Although people with disability are best placed to identify their support needs in emergencies, they are absent from emergency management practices and disaster risk reduction policy formulation. The same is true for health emergencies.

At the start of the global pandemic in 2020, Australia's public health response and management of COVID-19 failed to recognise the needs of people with disabilities. The DRC Report on Hearing 5 confirmed that, “*no agency of the Australian Government, including the Department of Health, made any significant effort to consult with people with disability or their representative organisations*” (p. 5)<sup>19</sup>.

An underlying issue is that if people with disability are even mentioned in emergency planning documents, they are typically only included as one of many “vulnerable” groups in emergencies alongside others such as, children, pregnant women, and people from culturally and linguistically diverse communities. This may obscure the specific needs and experiences of people with disability in emergencies<sup>20</sup>.

In his DRC<sup>19</sup> witness statement, Simon Cotterell, First Assistant Secretary, Primary Care Division, Department of Health explained that the people with disability were included in one of a number of “vulnerable groups” but were not specifically identified as an at-risk group for COVID-19<sup>20</sup>.

*I think it is an omission that “disability” is not mentioned, but as you point out, the word “vulnerable groups” is used, I think the intention of using that language in that context is vulnerability to the virus, whether it’s exposure or severe impacts of the virus and via that mechanism, people with disability would be covered. (Simon Cotterell, Australian Government Department of Health)*

Labelling people with disability as vulnerable can increase risk because it does not help us to understand what person is vulnerable to, what factors heighten risk, or what can be done to remove those barriers. Instead, it classifies people as “special” and, as such, puts them into the position of being passive recipients of support. When people are put into this role, they are not expected to take a meaningful place as participants, decision-makers, and drivers of change. Two DRC witnesses explained how this perpetuates stigma and discrimination toward people with disability:

*We repeatedly are classed as being “vulnerable” and myself and other disabled people, advocates, friends around me also find that this language is very problematic and creates a lot of stigma surrounding our position in the world, especially in the middle of what we are experiencing right now. (N.L.)*

*It comes back to the inherent view of disability as deficit, and so people are seen as less and as not able and in need of care or treatment or protection in some way. And so, it denies the dignity of the human being, it denies the personal resilience that that person may have, it denies the capabilities that that individual holds. And so, by that reference of being inherently vulnerable you are in some ways denying the humanness of that person and defining them only in terms of their disability, so the physical manifestations of their disability. And so, that deficit defines the individual. And so, you don’t look beyond the deficit to see what capabilities, and the whole of the person. (R.K.)*

The reality of the situation is that people with disability are not one group. People with disability have diverse capabilities, experiences, and support needs. People manage their everyday support needs in situations that are often inaccessible. Consequently, they are best positioned to identify what their support needs are and strategies for how they might be best managed in situations of uncertainty.

Since 2015, partnership research on Disability Inclusive Disaster Risk Reduction (DIDRR) in Australia ([www.collaborating4inclusion.org](http://www.collaborating4inclusion.org)) has focused on:

- co-design of person-centred emergency preparedness tools and training needed for people with disability to tailor emergency preparedness to their support needs and situation.
- active participation of people with disability in identifying their capabilities and support needs in emergencies.
- developing cross-sector mechanisms needed to address gaps through collaboration to improve individual preparedness and community-level planning.

This program of research is contributing to new ways of working to achieve disability inclusion in emergency management policy and practice<sup>21</sup>. The website is an excellent repository of free resources (for example, planning guides, videos, and case studies) that researchers have co-produced with people with disability and other emergency management stakeholders. These resources show DIDRR in action and provide tools for learning and working together to increase the inclusion of people with disability in emergency management.



## Higher demands, fewer choices

The job of government and emergency services is to provide the tools so that people can help themselves during times of emergency. This is a fundamental principle of Australia's National Strategy<sup>22</sup> and Framework for Disaster Risk reduction<sup>23</sup>. **The problem is that tools designed for the general population are insufficient for people with disability<sup>24</sup>.** Additional resources, supports, or advocacy may be needed for people with disability to take effective action before, during and after an emergency<sup>24; 25</sup>.

The current situation is that people with disability have fewer choices and opportunities to access and use risk information and preparedness resources<sup>10</sup>. This influences what information people have access to and how they are able to use information to make an emergency plan, or to respond effectively during a disaster, or to access recovery services and supports after a disaster. This perpetuates inequality for people with disability in emergency situations. Villeneuve et al. (2021) point to the following as examples of the impact of limited choices in emergencies for Australians with disability,

- transportation challenges may force decisions to evacuate without needed equipment influencing health and well-being during and after a disaster;
- inaccessible environments (e.g., homes of friends or family; evacuation facilities) restrict the choices available to people with disability and impact their safety and well-being in emergencies;

- inaccessible emergency management arrangements determine the timeliness, availability and accessibility of resources needed to take actions that decrease risk, such as: preparedness information; disaster warnings; location of evacuation shelters; rules for evacuating with animals;
- service providers make decisions about continuity of supports and services during times of uncertainty (e.g., COVID-19 pandemic) which impacts choices of people with disability.

Personal preparedness is one of the most important things that people can do to reduce their risk and increase resilience to disaster. We must recognise that emergency planning places high demands on people with disability, particularly for those who rely on others to assure their safety and well-being in the face of disasters and other emergencies.

Villeneuve<sup>21;27</sup> points out that for people with disability in Australia, personal emergency preparedness planning:

- requires individuals to renew their plans every time their support needs or situation changes;
- takes place against a backdrop of changing policies and systems for how mainstream and disability-specific services are organised and delivered;
- demands (re)negotiation with others about how support needs will be managed in an emergency;
- is further complicated when the supports that people receive come from multiple community, health and disability service providers operating across distributed networks; each with varying capacity to support preparedness planning with the people they serve or to sustain continuity of needed services during times of disaster;

- creates confusion when the information, resources and warnings, designed to increase the safety of all citizens, are not available in accessible formats that people with disability can understand and use;
- brings to the surface all of the barriers that restrict choices for people with disability and that impact their sense of safety and well-being. This includes ingrained perceptions of being a burden to others and pre-existing stigma, discrimination and marginalisation that influence one's sense of belonging and that negatively impact people's decisions in times of uncertainty.

This is what people with disability mean when they say that emergency preparedness is, “*overwhelming, messy and confronting.*” They concede that, in the face of these challenges, “it must be done”<sup>10; 27</sup>. Given this context, it is not surprising that people with disability do not feel confident in their ability to prepare and respond to disasters.<sup>28</sup> Research in Australia has demonstrated with the right tools and supports, people with disability can self-assess their risk and tailor emergency preparedness to their individual support needs and situation.<sup>29</sup> The Person-Centred Emergency Preparedness (P-CEP) process tool and framework was co-designed with people with disability and the services that support them to address this need.

The P-CEP<sup>30</sup> has three components:

1. a *capability framework* consisting of eight elements to support self-assessment of strengths and support needs;
2. three *principles* guiding the joint effort of multiple stakeholders to enable tailored emergency preparedness planning; and
3. four *process steps* enabling the developmental progression of preparedness actions and facilitating linkages between people with disability, their support services and emergency managers.

The P-CEP:

- brings emergency personnel together with people with disability and the services that support them to address the factors that increase risk for people with disability.
- provides the tools that people with disability need to optimise their self-reliance and planned reliance on others.
- enables people with disability, family and carers to assess their level of preparedness and learn about their disaster risk.
- enables emergency managers to personalise risk and preparedness information so that it can be better understood and acted upon.

Interactive dialogue between emergency managers, people with disability and the services that support them means that people with disability have input into the process and emergency managers learn about the capabilities and support needs of people with disability. This increases stakeholder understanding about their role and contributions to enabling inclusive emergency planning. It supports Australia's principle of shared responsibility.



## Underprepared support services

**Service provider refers to an individual, business, or organisation providing funded services and supports to people with disability.**

Recent research has recognised the interdependence of people with disability and their support providers in achieving safety and well-being before, during and after disaster<sup>14;10</sup>. This literature acknowledges the important contribution of community and disability service providers to enabling preparedness with the people they support and leveraging their routine roles and responsibilities to build local community resilience to disaster<sup>26</sup>. Research shows, however, that community and disability organisations are not integrated into emergency planning<sup>31;17</sup>. These services are not intentionally resourced to fulfil this potential, nor is there explicit policy guidance for the development, implementation, and evaluation of these capabilities across the community and disability service sector.

In Australia, peak community service organisations have raised issues around the role and capacity of community service providers to contribute to building resilience of people with disability (and other high-risk groups) and the services that support them. Too often, experience for community services comes only after a devastating disaster. This is too late<sup>17</sup>. Indeed, the COVID-19 pandemic identified deficiencies and amplified recommendations made to improve the capability of the service system to respond more effectively to the support needs of people with disability in emergencies<sup>3</sup>.

Community services and disability support organisations are an untapped local community asset with potential to increase safety and well-being for people with disability in emergencies<sup>32;17</sup>.

**Harnessing this potential is a complex challenge.** In the Australian service landscape, some people receive disability supports from multiple service providers and agencies. Other people are not connected to specialist disability services but may receive support through mainstream community groups and activities. Still others may receive services through the health, aged care, or social welfare support sectors.

There is an ongoing need for capacity development for service provider responsibilities in two areas<sup>17</sup>:

1. Enabling personal emergency preparedness with the people they support to optimise individual self-reliance and planned reliance on others in emergencies.
2. Developing business continuity plans and practices so that the provider can sustain service continuity with the people they support in times of disaster (e.g., natural hazard disaster, pandemic and other emergencies).

Policy attention – and investment – is needed in regard to:

- the development of these responsibilities in the community and disability services sectors; and
- methods to ensure the capability of service providers to fulfil those responsibilities.

## Personal Emergency Preparedness

In their review of the international research on the role, capacity, tools and training needs of service providers, Subramaniam & Villeneuve (2019) revealed seven roles of service providers in enabling emergency preparedness with the people they support including:

1. Identifying people at greatest risk to disaster events (e.g., geographic proximity to hazards; individual or contextual factors that increase risk)
2. Conducting assessment (support needs; risks and resources; level of preparedness and willingness to engage in preparedness planning)
3. Making a preparedness plan
4. Preparing an emergency kit
5. Strengthening support networks
6. Providing education and recommendations about disaster risk
7. Practicing drills (e.g., evacuation).

These authors found that:

- A range of different types of service providers held these roles such as: disability support workers, general practitioners, occupational therapists, physical therapists, psychologists and social workers.
- Not all providers engaged in all seven roles.
- Although providers held a common focus on enabling individual responsibility and self-sufficiency, service providers made various interpretations of their responsibilities which led to either active or passive participation of the people they support in emergency preparedness. See Box 4.1 for an example of the two approaches.

Australian community services providers are arguably well-positioned to enable the people they support to be active engaged participants in emergency preparedness:

- They are on the frontline of community-based care and support. This relationship equips providers with an intimate knowledge of the functional needs of the people they support.
- Service providers are often seen as the link between people with disability, their families and the wider community.
- They form a crucial component of an individual's support network.

These factors place providers optimally to enable the inclusion of people with disability in emergency preparedness, just as they might any other area of life and civic participation (Subramaniam & Villeneuve, 2019, p. 2). **It is important to recognise, however, that this is an emerging role in Australia with limited policy guidance on how it should be implemented.**

Developing this role requires:

- Education to service providers about their own disaster risk and preparedness actions before they can be an effective resource to others. This should include learning about the roles of government and emergency services personnel and how to access and use emergency information.
- Use of person-centred capability tools that promote choice, opportunity and active participation of people with disability in emergency preparedness planning<sup>17; 26</sup>.
- Effective links between personal preparedness of people with disability and organisational preparedness of the services that support them.

### Box 4.1. Passive versus active participation of people with disability in emergency preparedness planning

Example of passive participation	Example of active participation
<ul style="list-style-type: none"><li>• Service providers provided emergency information to people with disability in the form of an information binder left at their initial home visit.</li><li>• No follow up activities were reported to monitor or support the engagement of the individual with the material.</li></ul>	<ul style="list-style-type: none"><li>• Service providers provided information to people with disability in various formats including via health fairs, seasonal letters, manuals and candid conversations.</li><li>• Use of the information to make emergency plans was monitored and strengthened through discussions facilitated by the service provider during their routine interactions.</li></ul>

Consideration needs to be given to how these responsibilities will be developed and governed within the diverse service delivery context, funding models, and roles of service providers. This is important because many services provide essential supports that impact the safety and wellbeing of people with disability (Villeneuve et al., 2021).

## Service Continuity

The examples provided in the Boxes below illustrate how disruption to support services in emergencies impacts safety and wellbeing for people with disability in a natural hazard (Box 4.2) and pandemic context (Box 4.3).

In its review of submissions to Public hearing 5 on the experiences of people with disability during the ongoing COVID-19 pandemic, the DRC pointed to the NDIS Quality and Safeguarding Commission's **reliance on service providers to assess and manage risk** in the event of an outbreak. Evidence provided by service providers to the DRC also revealed that they did not have pandemic plans in place prior to COVID-19 arriving in Australia. In her witness statement, Anne Kavanagh, Professor of Disability and Health at Melbourne University, pointed out that service providers do not have the knowledge, skills or training to make an effective assessment of risks nor do they have the tools and training in how to manage them (DRC, 2020, p. 103; 181). The DRC called for the Commission to take a more active role in identifying and supporting service providers to manage risk (DRC, 2020, p. 107). This will require clarity concerning the roles and responsibilities of service providers in disaster risk reduction with the people they support and a coordinated approach to developing the capacity of service providers and tools needed to undertake those responsibilities.

## Capacity Development for Service Providers

Importantly, developing effective processes, training, and tools that address duty of care to service recipients and providers cannot be ad hoc and must not rest with individual service providers. A coordinated approach is needed to develop capacity at pre-service, induction, and in-service levels across a wide range of service providers from diverse service organisations and community contexts with different hazard risks.

To ensure a nationally consistent approach, training on person-centred emergency preparedness and service continuity planning for community and disability service providers needs to:

- be developed in accordance with any reviews of the NDIS Practice Standards and Quality Indicators (see DRC recommendations 15 and 16);
- involve experts in public health, emergency management, and disability inclusive disaster risk reduction in the design of training programs/packages;
- be co-produced with people with disability and their representatives; and
- be delivered through accredited/recognised pre-service and professional development channels.

## **Box 4.2. Disruption to support services in natural hazard context**

In a study on the capabilities of people with disability in the context of natural hazard emergencies in Queensland<sup>10</sup>, people with disability repeatedly identified their support workers as the key person they would rely on in an emergency while at the same time being uncertain about how their support workers could practically help.

*The consistent theme I saw was for the people I spoke to with disabilities, was their support network. Their support person or their carer was always one of the first ones [they would rely on] which sort of resonates. It highlighted to me the importance of those networks and the importance of understanding those networks.*

*Another big one, support workers... That person also has a family. You have someone with a disability who's totally reliant on their support workers. They could have a team of support workers but in a disaster, they're down to one, two, none, because they can't get in. So, what then, if they're not available?*

In that same study, community and disability providers discussed their own lack of preparedness and uncertainty about how to provide support during and after an emergency, especially if they were also affected by the same event.

For example,

*But my support coordinator had no idea, she had never been through anything like this before, so she wasn't really sure of what she was doing either.*

## **Box 4.3. Disruption to support services during COVID-19**

During COVID-19, some services changed how they provide supports to people in the community. This caused disruption to the supports that people normally rely upon.

At the DRC Hearing 5 on the experience of people with disability during COVID-19, five witnesses with disability pointed out that the service system changed on them, not the other way around.

*There was no change to the way I accessed support. A lot of my services were cancelled and I wasn't able to access them. (S.D.)*

*..there has been disruption to my support network. Support workers have to cancel shifts due to having to quarantine because of family members returning from overseas or has a comprised immune system because of food intolerance and so has to cut back hours. (T.C.)*

*If any of these people were infected there is a high risk of it spreading to others, including me. Three of my carers have taken (unpaid) time off and been tested at the first sign of mild symptoms. (K.H.)*

*During this second wave, I have had 4 of my support workers shifts cancelled due to the worker who was scheduled to work being in contact with other workers or people they live with who were being tested for COVID-19. Fortunately, these were not consecutive shifts so there was not a big impact for me but it meant that I would go without a meal. (R.B.)*

*This also raised the issue of the lack of communication from the provider. There was no backfill of a worker so no one was able to provide support to me for four days. That put myself and my husband in a potentially dangerous situation. (T.M.)*

## 5



## Extra supports and equal access to the same supports

**We've got to do more work ourselves to raise awareness because people with disability are not considered or are last to be considered. Local knowledge is key. Local knowledge can be used to stimulate the systems into caring. (Disability Advocate)**

People with disability rely on different levels and types of function-based support every day. Access to these supports can be compromised during and after a disaster<sup>33;25</sup>. This challenges the capacity of people with disability to take effective action in emergencies, increasing their risk and impacting recovery<sup>28</sup>.

Disability became prominent in the disaster policy agenda after the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>2</sup> entered into force in 2008. The UNCRPD is a treaty to promote, protect and ensure the human rights of the one billion people with disability globally. The UNCRPD reinforces the right of people with disability to have equal access to programs and services that all citizens enjoy. This includes local community Disaster Risk Reduction (DRR) activities. Article 11 of the UNCRPD specifically requires nations to take all necessary measures to *protect* the safety of persons with disability in situations of risk, including disasters triggered by natural hazard events and other emergencies (e.g., house fire; pandemic). This may require the provision of **extra supports** when needed to achieve equitable access on par with everyone else in society.

**A significant challenge to fulfilling rights and protections for a heterogeneous group of people with disability is understanding what those extra supports are and how they should be resourced, organised and delivered in an emergency context.** In Australia, governments and emergency services lack information about the support needs of people with disability in emergencies. This influences the capability of governments (at all levels) to make effective emergency plans.

Australian Bureau of Statistics (ABS) data provides information that can be used to profile the needs of people in their communities. ABS data are commonly used as part of developing community risk assessments. Valuable as they are, statistics give emergency planners only a superficial impression of the factors that increase risk for people with disability in emergencies<sup>34</sup>.

A helpful way forward is to consider the experience of people with disability, which raises such questions as:

- What is it like to be a person with a disability during and after an emergency?
- Can one hear or understand the warnings?
- Can one quickly exit a home or workplace?
- Can one move about the community after evacuating?
- Are there necessary or vital daily items that are not likely to be available in emergency shelters or alternative places of accommodation?
- Does the person require assistance from people? What is the nature of that personal support?

Answering these questions requires meaningful partnerships with the disability community (e.g., through their representative organisations). Despite advancement of the Disability Inclusive Disaster Risk Reduction (DIDRR) agenda globally, there are very few examples of people with disability leading policy and practice development (with a few exceptions<sup>35</sup>). More often, people with disability are excluded from decision-making, particularly at the local community level<sup>14</sup>. This body of research has identified the need to move beyond advocacy to realise the rights of people with disability through data-informed research, practice, and policy on DIDRR. This will require effective communication, meaningful engagement, and active participation of people with disability and their representatives.

Communication and engagement with members of the disability community must be viewed differently, depending on the point at which it is initiated,

Such as:

- **Well before** an event, as part of community engagement and preparedness outreach efforts of government and emergency services or when engaging in community-level risk assessment.
- **Prior** to an event, as emergency warnings, notifications, and advice.
- **During** an event, as emergency information, and instructions for all citizens to follow.
- **Following** the event, as recovery information and access to services and supports.

Understanding the support needs of people with disability at each of these stages may support more effective data and information gathering needed for disability inclusive emergency planning.

## Data and Information is Needed for Informed Planning

People with disability have not traditionally been included in emergency planning. Emergency managers and disability groups will bring different ways of thinking about disability and emergencies. They have a different need and focus for gathering and using information.

If the tools that support planning are not inclusive of people with disability, then people with disability will be overlooked in planning processes. This requires consideration at both the individual and community level.

Information and tools are needed to support:

- People with disability to be actively engaged in identifying what their extra support needs are in emergencies and planning for how they will be managed.
- Government and emergency services to conduct community-level risk assessments and make emergency plans that are inclusive of everyone in their community, including the extra supports that some people with disability will need to be safe in emergencies.
- Governments to assess the impact of disaster risk reduction programs and services before, during and after a disaster, including the access to and impact on people with disability.

When these tools are co-designed with people with disability, they lead to more effective data to support the development of programs and services that are accessible and responsive to the needs of people with disability before, during and after emergencies (See Box 5.1). Article 31 of the UNCRP requires Nations to collect appropriate information, including statistical and research data, to enable the formulation and implementation of policies to meet their obligations under the UNCRPD.

Despite this obligation, deficiencies in the collection and dissemination of data meant that it was not possible to obtain a complete or accurate picture of the infection or mortality rates from COVID-19 for people with disability throughout Australia (DRC Hearing 5 Report, 2020; 160.3). Based on this gap, the DRC called for the introduction of measures to ensure that the Australian Government

complies with its obligations under article 31 of the UNCRPD (p. 92 – 93). Importantly, the DRC's recommendation (Recommendation 14) should be expanded to ensure disability disaggregated data for all disasters including those triggered by natural hazards such as bushfire, flood, severe storm, and heatwave.

### **Box 5.1. Tools needed by stakeholders to reduce risk**

**Individual citizens** need to develop capability to assess risk and make effective plans for themselves, their family and household. To do so, people with disability need effective self-assessment tools to help them tailor emergency preparedness planning to their individual support needs and situation. Such tools need to involve people with disability in identifying and planning for any extra supports they may need to manage in an emergency.

It is important to point out that it is not just about the provision of tools, but the co-design of these tools with people with disability and the provision of support if/where needed for people to know about the tool and how to use it. Co-design and testing with people with disability and dissemination through disability networks has been fundamental to the development of the Person-Centred Emergency Preparedness toolkit in Australia.

**Government and emergency services need** risk assessment tools and practices that enable information gathering about the preparedness, capabilities and functional support needs of people with disability in their community. Only then can effective emergency planning and disaster risk reduction activities be developed in response to the factors that increase risk for people with disability in emergencies.

**Government and non-government organisations involved in disaster risk reduction need** to assess the impact of programs and services for people with disability.

Since disability and disaster is under-researched, very little is known about the experience of people with disability following a disaster event. Collection and disaggregation of data by disability is needed in order to understand how disaster impacts people with disability in Australian communities.

Data is also needed to determine whether people with disability have equitable access to:

- community-level preparedness programs and community engagement opportunities designed to increase resilience to disaster; and
- disaster recovery programs and services.

Evaluations are then needed to determine the impact of these programs and services on the safety and well-being of people with disability before, during and after emergencies.

**Governance Mechanisms** are needed to support collaboration between people with disability, government, community, disability and emergency services. Collaboration is central to the development of disability inclusion at every stage of disaster management: preparedness; response; and recovery.

## Giving Structure to Collaborative Planning Practices

***The support needs of people with disability need to be central to emergency planning processes and people with disability need to be at the centre of emergency planning conversations to address those support needs<sup>21</sup>.***

Structure is needed to facilitate meaningful participation of the disability community in dialogue about emergency management planning and practices. One way to structure that dialogue is use the Person-Centred Emergency Preparedness (P-CEP) framework for thinking about the functional support needs of people with disability in emergencies (See Box 5.2)

### **Box 5.2. Person-Centred Emergency Preparedness (P-CEP) Process Tool and Framework**

The P-CEP helps to match emergency planning to the supports people need for their health and safety in emergencies.

Developed in Australia, the P-CEP is an open access resource that is freely available ([www.collaborating4inclusion.org/pcep/](http://www.collaborating4inclusion.org/pcep/)). It was co-designed and tested with people with disability, and service providers in the community, disability, and emergency services sectors in diverse regions of Australia with different hazard risks.

The P-CEP helps to structure emergency planning conversations around the function-based capabilities and support needs of people with disability. The P-CEP Framework or “Capability Wheel” guides self-assessment and tailored emergency preparedness planning in eight areas: Communication; Management of Health, Assistive Technology, Personal Support, Assistance Animals and Pets; Transportation; Living Situation; and Social Connectedness<sup>25</sup>.

Three principles guide person-centred emergency preparedness conversations. They are:

1. Emergency preparedness is a process, not a one-time event.
2. People are experts in their own lives, planning starts with them.
3. Person-centred planning conversations build capability of multiple stakeholders to improve disability inclusive emergency planning.

As a process tool, four steps bring emergency personnel together with people with disability and the services that support them to enable effective risk communication and preparedness actions.

As a framework that classifies support needs based on function, P-CEP elements may support the design of universal approaches that focus on what can be done to reduce risk. For example, assistive technologies and accessible information can enhance universal access to disaster warnings and hazard information<sup>37</sup>.

Implementation of the P-CEP over the past five years in Australia has shown this model to be effective in making sure that people with disability and their support needs are included in emergency management. Research is showing how the P-CEP process contributes to inclusive emergency management practices that are responsive to the support needs of people with disability in emergencies<sup>21</sup>. The P-CEP was used to inform the new National Disability Strategy targeted outcome on disability inclusive emergency planning<sup>38</sup>.

Classifying support based on function (versus impairment or diagnosis for example) leads to more effective planning well-before an event<sup>39</sup>. For example, identifying risks for a person with spinal injury does not provide any information related to their support needs or how they will manage in an emergency situation. More effective problem solving about what extra supports are needed for that individual to shelter-in-place or evacuate to a place of safety comes from consideration of their functional support needs such as reliance on, for example:

- **assistive technology** (e.g., the need for electricity to recharge batteries on a powered wheelchair, an alternating air mattress for sleeping, and lifting device to transfer from wheelchair to bed and toilet),
- **personal support** with transfers and personal care, or
- **accessible transportation** to evacuate in a timely manner.

Understanding the nature of the functional support needs in emergencies, from the perspective of people with disability, can be used to develop more effective emergency plans and response strategies to reduce barriers to safety and wellbeing. Analysis of lived experience witness statements from DRC Hearing 5 on the experience of people with disability during COVID-19 revealed that functional support needs grouped into the following four P-CEP elements: *Communication, Management of Health, Personal Support, and Social Connectedness*. In the natural hazard emergency context, consultation with a diverse group of people with disability revealed functional support needs in all eight areas of the P-CEP (refer to Villeneuve et al., 2021<sup>10</sup> for detailed findings).

See Box 5.3 for an example of how planning, based on function, can support more effective public emergency responses to impact safety and wellbeing of people with disability in emergencies.

### Box 5.3. Planning based on functional support needs of people with disability

Planning for people with different disabilities can be daunting. However, if the P-CEP framework is used, it can break that problem down based on function. When we plan based on function, we:

- increase clarity about actions that different stakeholders can take (see issue #6); and
- discover stakeholders who should be included to support safety and wellbeing for people with disability in emergencies.

Take communication as an example. Communication refers to getting, giving and understanding information. Communication is a commonly identified barrier for people with disability in emergencies. Many people with disability need extra support to access, understand and use emergency information and disaster warnings in order to follow the advice provided by government and emergency services.

Consider the following lived experiences of communication as a barrier for people with disability in emergencies:

*One of the people I spoke to was very clear on one thing: The disability did not allow them to be able to recognise the danger was there, nor for the people responding to be able to provide assistance in the conventional way, because they couldn't hear. He couldn't hear the knocks at the door, couldn't hear the fire alarms.* (Brisbane participant)

*Something that did come through was when the emergency notifications came out with the floods, they felt the communication was poor and confusing at times. For instance, getting messages to say evacuate but nowhere to go and evacuate to.* (Townsville participant)

*When I did get evacuated, where I got put in, I didn't then also get the accessibility options of being told where I was and where, say the bathroom was in relation to my room, which is something, being severely vision impaired, I really needed.* (Brisbane participant)

*Have you ever watched TV or the news with closed captions on? The subtitles are something to be laughed at, but not so much when you are Deaf. Not every Deaf person can sign and there needs to be more clarity.* (Ipswich participant)

*We have a number of deaf students who attend a deaf learners program at the Deaf Society and Deaf Services Ltd, many of whom have an intellectual disability. Some students have come to class when they are sick because they did not understand that they needed to have a test for COVID-19 and self-isolate.* (L. J. DRC Hearing 5)

*So, what was done for COVID was focus on NDIS recipients. Now I know this because I personally am not an NDIS recipient. So, I know what it's like to be a person with a disability and not included in that COVID framework. So, all information went through NDIS structures and so if you are not in that, you weren't getting the information. I mean, that came down to something as bog simple as getting groceries. So, to have them delivered you needed the seven-digit NDIS number and if you didn't, you couldn't get your groceries delivered. So, that is one of the things that we need to recognise, is that impairment in Australia doesn't stop with being an NDIS recipient* (R. K. DRC Hearing 5)

Working with people with disability to identify and address communication barriers could lead to improvements in:

- emergency warnings that everyone can access and understand and Communication channels that reach everyone;
- better evacuation planning (e.g., way-finding at evacuation centres);
- accessible information (such as Easy English or Easy Read information) about disaster risks, preparedness steps, how to respond in different situations, and where to access recovery services and supports; and
- more effective communication channels to reach everybody.

## Inclusive Emergency Planning Conversations

Meaningful and active participation of people with disability in emergency planning involves intentional, structured, and supportive engagement. Planning conversations cannot be improvised. They need structure to support constructive engagement.

Box 5.3, provides guiding questions that are organised according to the phases of the disaster management cycle, typically referred to as preparedness (before), response (prior to and during), recovery (after). These questions offer a way to enable productive dialogue between emergency managers and the disability community (e.g., representative organisations of people with disability) to improve disability inclusion in emergency management.

The guiding questions in Box 5.4:

- cover key concerns raised by multiple stakeholders about the safety and wellbeing of people with disability in emergencies contained in the research and lived experiences of people with disability; and
- are intended to broaden focus from the current emphasis on evacuation to include a wider range of important considerations needed to reduce risk and increase the resilience of people with disability to disasters.

The guiding questions should be used to:

- support dialogue between the disability community and those responsible for emergency planning; and
- guide the future development of data-informed risk assessment, emergency planning, and disaster recovery practices.

These questions are intended as a starting point when initiating planning conversations to co-design approaches to disability inclusive emergency management. New questions can and should be added to strengthen planning conversations.

#### **Box 5.4. A guide to facilitate dialogue between emergency planners and the disability community**

##### **Well before an event**

- Do people with disability have access to risk information, preparedness tools and resources that they can use to learn about their risk and make a plan? Can people with different access and support needs use that information to learn about their risk and make a plan?
- What support do people with disability need to make an effective personal emergency preparedness plan?
- In an emergency, what can people do for themselves? What do they need support for?
- What is the nature of the support required prior to, during and after an event?
- Are there gaps in emergency plans of people with disability? Are extra supports needed to fill those gaps in a disaster? What is the best way to organise and deliver that support?
- Why are people with disability vulnerable? What are they vulnerable to? What factors heighten risk? How can they be addressed?

##### **Prior to an event**

- Can people with different access and support needs understand and use emergency warnings and information to respond in ways that increase safety and well-being?
- Are emergency warnings reaching everyone in our community? Who doesn't have access? Why?
- What is the impact of these warnings on the decisions and actions of people with disability in emergencies?
- How can we make sure nobody gets left behind?

##### **During an event**

- Are (temporary) evacuation shelters accessible and welcoming for people with disability? Do they enable maintenance of independence for people with disability?
- How have the accessibility of the physical, sensory, social and attitudinal environment been taken into consideration when engaging in evacuation planning?
- How are the function-based access and support needs of people with disability addressed in the operations of evacuation shelters?
- What other evacuation options are there for people with higher support needs in our community?
- Are emergency services and disaster recovery staff/volunteers trained to identify people with diverse functional support needs; respond in a way that ensures safety & wellbeing; and connect them to services and supports that keep them safe and well?

##### **After an event**

- What was the impact of the disaster on people with disability?
- What could have been done differently to improve the situation?
- Do people with disability have equitable access to disaster recovery information, services, supports?
- What is the impact of recovery services on the safety and well-being of people with disability recovering from disaster?
- How can we make sure that people with disability have the services they need?



## Shared but Defined Responsibilities

The vision of shared responsibility<sup>40</sup> is embedded in Australia's national policy frameworks for disaster risk reduction. Australia's National Strategy for Disaster Resilience<sup>22</sup> calls on individuals and community organisations to share responsibility with emergency managers to increase whole-of-community resilience to disaster. The National Disaster Risk Reduction Framework (NDRRF)<sup>23</sup> further advocates for the development of shared but defined responsibilities so that individuals and community organisations can contribute to disaster risk reduction within their capabilities.

### Individual level capability for personal emergency preparedness

Individuals need to:

- learn about their risks;
- take responsibility for their own safety through personal emergency and household preparedness planning; and
- act on advice from government and emergency services.

To do this effectively, people with disability need guidance that will help them to match their individual support needs with available resources. The Person-Centred Emergency Preparedness (P-CEP) process tool (see issue #5) was developed in response to the need for tools that enable people with disability to tailor emergency preparedness to their unique support needs and situation (visit [www.collaborating4inclusion.org/pcep/](http://www.collaborating4inclusion.org/pcep/) for more information).

As a process tool that enables self-assessment of preparedness, capabilities and support needs, the P-CEP addresses:

- step-wise actions that individuals themselves can take together with their support network to increase their self-sufficiency in emergencies; and
- the coordinative, cooperative and collaborative actions that other community stakeholders (e.g., community and disability services, emergency services, government) can take<sup>17</sup>.

Personal emergency planning is important because it is most often individuals, their neighbours and community who are first on the scene in a disaster. They provide the first response in an emergency.

### Shared responsibility and inclusive community-level planning

*The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) entered into force in 2008. Article 11 of the UNCRPD requires nations to take all necessary measures to protect the safety of persons with disability in situations of risk, including disasters triggered by natural hazard events. The UNCRPD also reinforces the right of people with disability to have equal access to programs and services that all citizens enjoy, this includes emergency management<sup>21</sup>.*

Notwithstanding individual responsibility in preparing for how they will act together with their support network in emergencies, emergency services and other agencies are typically the first organised to respond. Community-level emergency plans direct the:

- actions of these agencies, emergent groups (e.g., spontaneous volunteers); and
- use of local resources (e.g., emergency management NGOs) to help with emergency response, incident management support, relief and recovery.

Coordination at the regional level may be needed to ensure the response is effective and tailored to the situation and nature of the emergency (e.g., flood vs bushfire). When the scale or intensity of the emergency increases:

- State/territory arrangements may be activated to provide support and resources locally.
- Inter-state/territory may be activated for additional assistance.
- National emergency management arrangements are also in place when assistance exceeds the capability of the state/territory to respond.
- National coordination may also occur in times of catastrophic disaster, national or global disaster (e.g., pandemic) and when international assistance has been offered.

Australia's state/territory governments have principal responsibility for emergency management legislation, policies, and frameworks within their jurisdictions that govern these responsibilities. Australia's national strategy, frameworks, and principles guide how emergency response is scaled. It is underpinned by partnerships that require government, emergency services, NGOs, community groups, emergency management and volunteer organisations to work together.

Australia's National Disaster Risk Reduction Framework<sup>23</sup> advocates for local governments to work together with communities in building resilience to emergencies. However, there are currently no nationally consistent emergency management standards in Australia to ensure the access and inclusion of people with disability in emergency management planning<sup>10</sup>. **Lack of methods, tools and programmatic guidance for how to include people with disability and their support networks presents significant risk to the**

**safety and well-being for people with disability before, during and after emergencies.** If people with disability are not included in the planning, then their capabilities to contribute and their extra support needs are not considered.

Community emergency plans need to be responsive to and incorporate the access and function-based support needs of people with disability. To ensure inclusion in emergency management, governments and emergency planners need to understand the support needs of people with disability, review current plans, and develop community assets and contingencies that are better matched to the support needs of people with disability at all stages of disaster management (preparedness, response, recovery).

Built on the foundations of the UNCRPD, the Sendai Framework for DRR (SFDRR) (2015-2030)<sup>41</sup> established people with disability and their representative organisations as legitimate stakeholders in the design and implementation of disaster risk reduction practices and policies<sup>42</sup>, calling for “*a more people-centred preventative approach to disaster risk*” (41, p.5). People-centred approaches place people and their needs at the centre of responsive disaster management and also position them as the main agents of development and change. Australia's National Disability Strategy<sup>43</sup> is the mechanism to ensure that the rights, protections and meaningful participation of people with disability are incorporated into emergency management. The new National Disability Strategy will incorporate, for the first time, disability inclusive emergency planning<sup>38</sup>. This is an important development for the progressive realisation of the rights of people with disability in emergency management.

Disabled People's Organisations (DPOs) can play a significant role in disaster policy, planning and interventions<sup>4</sup>. Through their lived experience and leadership roles as disability advocates, DPOs:

- represent the voice and perspective of their members with disability;
- have in-depth understanding of the factors that increase risk for people with disability in emergencies; and
- have access to informal networks of support and communication.

This information is not readily available within mainstream emergency management. Listening to people with disability and learning about their experiences is essential to understanding and removing the barriers that increase vulnerability in disasters<sup>44</sup>

Gippsland Disability Advocacy Inc (GDA), stepped into a new advocacy role during the Black Summer bushfires, supporting people with disability who had been, as Denise Lamble, GDA Disability Advocate said, “*forgotten in the mayhem and the chaos of the fire and evacuations.*” GDA went to the inaccessible relief centres and took action by supporting people with disability who did not have family or an advocate to rely on. They found accessible transportation, places for people to sleep, and negotiated with organisations (nursing homes and taxis) to waive expenses<sup>45</sup>. GDA has continued this support throughout the bushfire recovery and during COVID with funding secured through VCOSS, the Lord Mayor’s Charitable Fund, and Bass Coast Shire Council via the Business

and Community Resilience Grants Program<sup>46</sup>. GDA are evidence of the critical capabilities that advocacy organisations bring to ensuring the safety and wellbeing of people with disability during the response and recovery stages of disaster. They are actively working with CFA Victoria to increase person-centred preparedness for those at elevated risk of bushfire impacts<sup>47</sup>.

Since 2018, the P-CEP (see Box 5.2) has been used to engage multiple stakeholders from the disability, community and emergency services sectors to work together to enable people with disability to optimise their self-reliance and plan for how they will act together with their support network before the next emergency. Uptake and implementation of the P-CEP is rapidly expanding across Australia, including through the leadership of DPOs and disability advocates who play a crucial role in identifying extra supports needed by people with disability and advocating for the inclusion of those supports in emergency management planning processes (See Box 6.1).

### Box 6.1. Disabled People's Organisations (DPOs) and Disability Advocates Leading P-CEP

DPOs and advocacy organisations in Queensland and Victoria is supporting capacity development for people with disability to develop personal emergency preparedness plans and enable P-CEP in others through peer support and mentoring. These peer leadership programs focus on people with disability identifying the extra supports that people with disability need in emergencies and sharing that information as they work with government and emergency planners to improve understanding in the emergency management sector about:

- factors that increase risk for people with disability; and
- what is needed to ensure the safety and wellbeing of people with disability before, during and after disaster.

An important part of this work is the collaboration between people with disability and emergency managers working together to increase disability inclusion in emergency management practices. A four-part capacity development series<sup>48</sup> shares lessons for person-centred emergency preparedness, business continuity planning for the disability and community service sector, and collaboration for community-level planning towards disability inclusive disaster risk reduction.

# Key Messages

▶ **People with disability have fewer choices and opportunities to access and use risk information and preparedness resources because of systemic barriers. This impedes their ability make emergency plans and to turn those into plans into effective actions that keep them safe. This perpetuates inequality in emergency situations.**

▶ **Disability inclusive disaster risk reduction requires coordinated cross-sector collaboration involving multiple stakeholders working together with people with disability to identify and remove the barriers to safety and wellbeing for people with disability before, during and after disaster.**

▶ **To fulfil the rights and protections of people with disability, emergency planners need better understanding, backed by evidence, about what extra supports are required and how they should be resourced, organised and delivered in an emergency context. Disability representation must be integrated at all levels of emergency management arrangements to fulfil these rights.**

▶ **Person-centred capability approaches must inform the development of disability inclusion in disaster risk reduction because the path to full and meaningful participation cannot be achieved without challenging the social discrimination, marginalisation and institutional neglect experienced by people with disability.**

▶ **Effective institutions with supportive attitudes and mechanisms are needed to ensure meaningful representation and participation of people with disability. This requires development of legitimate roles for people with disability in gathering data about the diversity of their support needs and using that information to ensure that those support needs are at the centre of emergency management and disaster recovery planning.**

# Recommendations for Action

## **Five recommendations and associated actions to achieve disability inclusion in emergency management:**

**These interrelated recommendations will require multiple stakeholders to work together to ensure that the rights of people with disability are embedded in a meaningful way into all government programs, plans, strategies and policies designed to increase the resilience of all Australians to disaster. While some progress has been made, the journey has only just begun. Action-oriented strategies are provided to help people get started today.**

# 1



## Inclusion and representation

**The Australian government should develop nationally consistent guidance on disability inclusion and representation in Australia's emergency management arrangements at all levels of government. Disability representation is key to getting the right information, products, responses, and positive outcomes for people with disability in emergencies. It is the first step in clarifying how people with disability and the services that support them will share responsibility (see Recommendation 5) with government and emergency personnel to increase their safety and wellbeing before during, and after disaster.**

### Actions:

- 1.1** The Australia-New Zealand Emergency Management Committee (ANZEMC)<sup>49</sup> is the peak government committee responsible for emergency management. The ANZEMC should work in partnership with National Disability Representative Organisations<sup>50</sup> and the Australian Government Department of Social Services to provide explicit policy guidance on disability representation in emergency management arrangements at all levels of government.
- 1.2** The Australian Institute for Disaster Resilience (AIDR)<sup>51</sup> develops, maintains and shares knowledge and learning to support disaster resilience in Australia. AIDR should work in partnership with National and State Disability Representative Organisations<sup>49</sup> and researchers to develop capability, resources, and programmatic guidance for government and emergency services on how to include people with disability and their support networks in emergency management arrangements (e.g., through the development of a Handbook on Disability Inclusion and Representation in Emergency Management).
- 1.3** State and territory governments, through their State, District/Regional Emergency Management Committees should work in partnership with peak national and state-wide Disability Representative and Advocacy Organisations to review their emergency management arrangements (policies, practices, and activities) to identify gaps in disability inclusion and representation in emergency planning, develop strategies for improvement, establish targeted outcomes and indicators, and methods to measure progress.
- 1.4** Local Government, through their Local/Municipal Emergency Management Committees should work in partnership with local Disability Representative and Advocacy Organisations to review their emergency management arrangements (policies, practices and activities) to ensure disability inclusion and representation in local emergency management planning practices.
- 1.5** People with disability have the right to know what plans are in place for managing emergencies in their community. This information is available to everyone by accessing their Local Council's emergency management plan. If the plan is hard to access or not accessible, this provides an opportunity for dialogue with Council emergency managers about ways to improve the accessibility of those plans for people with disability. It enables mutual learning to support responsive emergency management planning practices and individual preparedness capabilities.

## 2



## Collaborative and inclusive research

The National Disability Research Partnership<sup>53</sup> should prioritise collaborative and inclusive disability research that will assist government and emergency personnel to understand and respond to the extra support needs of people with disability in emergencies and enable their full inclusion in emergency management.

### Actions:

**2.1** Expand the Disability Royal Commission recommendation (Recommendation 14) to ensure collection and disaggregation of data by disability for all disasters including those triggered by natural hazards such as bushfire, flood, severe storm, and heatwave. This measure is needed to support the Australian Government to comply with its obligations under Article 31 of the UNCRPD. Such data should be included in the National Disability Data Asset<sup>52</sup> to provide a better understanding of how people with disability are supported in emergencies and set targets for improvement.

**2.2** Researchers should work collaboratively with people with disability, self-advocacy organisations/self-advocates to co-design new approaches for:

- gathering data and evidence on what people with disability can do for themselves and what they need support for in emergencies;
- mapping local community assets (including Disability Representative Organisations and Disability Advocates) that can be mobilised in an emergency to provide needed supports;
- building local capabilities and resourcing those assets for effective mobilisation in emergencies; and
- evaluating the impact of those extra supports and their deployment on the safety and wellbeing of people with

disability in emergencies in different Local Government Areas having different resources, supports, and different hazard risks.

Recognising Australia's principle of shared responsibility, Recommendation 2.2 should happen in concert with the development of:

- individual capability and opportunities to develop person-centred emergency preparedness plans (see Recommendation 3); and
- workforce capability of service providers in person-centred emergency preparedness and service continuity planning (see Recommendation 4).

Both of these are important roles that individuals and community organisations can take to mitigate the risks for people with disability in emergencies.

**2.3** Local Government Associations should work collaboratively with Local Councils, Disability Representative and Advocacy organisations, service providers, and emergency services agencies to develop, implement, and evaluate local community-level disability inclusive emergency planning practices that are responsive to the identified (unmet) support needs of people with disability in emergencies.

### **How can research be co-designed with people with disability?**

Australia's National Disability Research Partnership (NDRP)<sup>53</sup> was developed to enable collaborative and inclusive disability research that builds evidence for successful innovation in policy and practice. The NDRP principles can support and guide research in partnership with people with disability. They are:

1. Deliver high-quality collaborative research
2. Recognise the knowledge of people with disability in research
3. Value all forms of knowledge
4. Build research capability

Guidelines for Co-Producing Research with People with Disability have been developed by the Disability Innovation Institute (DIIU) at the University of New South Wales (UNSW). The Guidelines set out key benefits, principles and strategies that underpin the DIIU and UNSW's approach to co-producing research with people with disability. <https://www.disabilityinnovation.unsw.edu.au/digital-content/doing-research-inclusively-guidelines-co-producing-research-people-disability>

# 3



## Person-centred information, services, and supports

**State and territory governments with primary responsibility for emergency management should prioritise the rights of people with disability to have access to information, services, and supports to keep them safe before, during, and after a disaster and invest in disability advocates and information services who are best placed to make sure that people with disability have information, resources, and supports they need for their safety and wellbeing in emergencies.**

### Actions:

- 3.1** National, state and territory governments should provide funding and support for disability advocacy and information services to engage collaboratively with government and emergency services in the following tasks to protect the safety and wellbeing of people with disability before, during and after a disaster, including:
  - supporting people to know about and learn to use self-assessment tools (e.g., Person-Centred Emergency Preparedness) to identify their risks and tailor personal emergency preparedness to their support needs and situation well before disaster strikes.
  - supporting people to access emergency information, warnings, and risk communication in accessible formats that they can understand and use to plan for and take action in emergencies.
  - connecting people with disability to the supports and services they need during and following a disaster to maintain their health and wellbeing during disaster recovery.
  - advocating for the access and support needs of people with disability before, during and after emergencies.
  - ensuring that people with disability and their support needs are included in all emergency management arrangements.
- 3.2** Governments and emergency services should work with disability information services to make their disaster risk information, programs and services available in accessible formats that everyone can understand and use. This should include pre-planning for accessible community engagement programs and activities and the co-production of resources into different formats (e.g., Braille, Easy Read and Auslan, Captioned, Media Description).
- 3.3** The National Disability Insurance Agency (NDIA) should prioritise the rights of people with disability to engage in personal emergency preparedness by enabling people to access National Disability Insurance Scheme (NDIS) funding to obtain support to make an emergency preparedness plan that is tailored to their support needs and communicated with their support network – so they know how they will act together with their support network in an emergency. The need for support with emergency preparedness could be identified by support coordinators early in the person-centred planning process and be revisited when plans are renewed to ensure that the plans are up-to-date. Support coordinators and Local Area Coordinators can link people to service providers with capability to enable personal emergency preparedness that is tailored to an individual's support needs and situation (see Recommendation 4).

- 3.4** The NDIA should prioritise the rights of people with disability to access NDIS funding for essential supports they need for their safety and protection in emergencies.
- 3.5** The NDIA should prioritise and support people with disability to access mainstream emergency services as to ensure that they have knowledge of their local emergency risks and can use that information to make a personal emergency preparedness plan that is communicated with their support network. The Local Area Coordination functions should include enabling people to access person-centred emergency preparedness resources, mainstream emergency management activities, and information about local hazard risks.
- 3.6** Local Council and emergency managers should prioritise and support “place-based” community programs and services that enable people with disability and the services that support them to learn about their local emergency risks and use that information to develop emergency preparedness actions (e.g., through Council access, inclusion, and community interagency networks). Councils and emergency personnel can expand their engagement efforts to include mainstream programs (e.g., local libraries, clubs, neighbourhood centres, etc) to help connect people with disability to risk information, access and use person-centred emergency preparedness resources.

Embedding supports into the community engagement and other functions of councils (e.g., library programs; community events) may support people with disability (who are not connected to formal services) to access and use self-assessment tools to learn about their risk and make emergency plans. A number of people with disability do not access the NDIS. Consideration needs to be given to these people.

# 4



## Service provider capability

The contribution of service providers to disaster risk reduction is an emerging practice in need of a workforce capacity development strategy<sup>54</sup>. Community services, disability support organisations, and disability advocates are an untapped local community asset with potential to increase safety and well-being for people with disability in emergencies. Research, policy and practice guidance is needed for the development, implementation, and evaluation of these capabilities across the community, disability, and health services sectors.

### Actions:

- 4.1** People with disability, family and carers make choices about the services they use. When making decisions about services, they should ask their service provider about their capabilities in emergency planning. Individuals should expect prepared services and can make choices to work with services that have effective plans and that are prepared to engage in person-centred emergency preparedness and service continuity planning to ensure the safety and wellbeing of both service users and staff during times of uncertainty.
- 4.2** Service providers have a duty of care to their staff and the people they support. Services routinely engage in risk assessment and risk management actions together with the people they support. They also engage their work health and safety policies and practices to support safety for staff and service users. Providers should review their existing practices and expand them to include planning for disasters triggered by natural hazards and other emergencies (e.g., house fires; health emergencies).

The COVID-19 pandemic provided an opportunity for services to review how they support personal safety and service continuity. These practices can be expanded by:

- working in partnership with local Councils and emergency services to learn about the disaster risks where their service operates.
- expanding preparedness actions to address the impact of disasters on the people they support and their capability to provide services during times of natural hazard disaster and other emergencies (e.g., pandemic).
- enabling Person-Centred Emergency Preparedness planning with the people they support.

- 4.3** The NDIS Quality and Safeguarding Commission should take an active role in identifying, supporting, and monitoring service providers to manage risk. Practically, providers will require guidance on what they should have in place to prepare, prevent, manage and respond to emergency and disaster situations. The Quality Indicators should take an all-hazards approach that includes managing risks triggered by natural hazard disasters and other emergencies (e.g., house fires; pandemic).

**4.4** Local Councils and emergency personnel should expand their community engagement efforts to target capacity development with community services and disability support organisations. There are now tools do this and organisations that are building their capabilities and experiences in disaster risk reduction (See Box R4). Local Councils have networked connections to community and disability organisations, disability advocates, and representative organisations of people with disability. Local councils, with support from their local emergency services agencies, should convene training for service providers to support ongoing capacity development in Person-Centred Emergency Preparedness and Business Continuity Planning. This will benefit Councils when they review and renew their local emergency management plans because they will also build their knowledge of the local assets, capabilities, and opportunities that service providers can bring to managing the impact of a disaster.

**4.5** There is a need for national consistency and oversight so that service providers (who may be individuals, businesses or organisations) have access to and are included in capacity development programs regardless of where they live and work. National and State peak organisations (e.g., Disability Advocacy Network Australia; National Disability Service; Councils of Social Service; Community Services peak bodies) should work with their members to build capability and should be called upon support the development and implementation a workforce capacity development strategy for service providers in disaster risk reduction.

To ensure a nationally consistent approach, training on person-centred emergency preparedness and service continuity planning for community and disability service providers needs to:

- be developed in accordance with any reviews of the NDIS Practice Standards and Quality Indicators;
- involve experts in public health, emergency management, and disability inclusive disaster risk reduction in the design of training programs/packages;
- be co-produced with people with disability and their representatives; and
- be delivered through accredited/recognised pre-service and professional development channels.

**4.6** Educational institutions should work with peak organisations, professional associations, regulatory bodies, and government to develop teaching and scholarship practices that support the development of evidence-based education and workforce development (i.e., competencies; pre-service learning; induction programs; continuing professional development) for service providers and disability advocates so that they can effectively contribute to building individual and organisational resilience to disaster within their role and scope of practice. This should be expanded to health care and allied health services. All efforts must include the lived experience contributions of people with disability and their representative organisations (see also Recommendation 4.5).

## Box R4. Resources and support for developing disaster risk reduction capabilities in service providers

There are resources that can support service providers to get started building their capabilities. There are also organisations with growing knowledge, skills, and leadership that can be called upon for support.

### Resources:

- Victorian Council of Social Services (VCOSS) Resource Page: <http://vcoss.org.au/social-justice/emergency-management/>
- Disability Advocacy Resource Unit (DARU) Disability meets Disaster Case Study resources: <http://www.daru.org.au/resource/disability-meets-disaster-case-studies>
- The University of Sydney leads research on DIDRR in Australia and overseas. The Collaborating4Inclusion Website has a wealth of resources on Person-Centred Emergency Preparedness and Disability Inclusive Emergency Planning, including webinars targeting service provider capability in DIDRR [www.collaborating4inclusion.org](http://www.collaborating4inclusion.org)
- ACOSS has developed a Resilient Community Organisations toolkit to support community organisations develop business continuity plans <https://resilience.acoss.org.au/about>
- The Community Services Industry Alliance developed the Disaster Management and Recovery Toolkit and strategies to enable community organisations to learn together to strengthen their planning practices <https://csialtd.com.au/2020/05/14/disastermanagementandrecoverytoolkit/>
- Tools have been developed to support service continuity planning for COVID-19. For example, [https://static1.squarespace.com/static/57c65af5cd0f68b1295663dc/t/5e72fd5833d5965c41b880b4/1584594266318/DSC\\_Business+Continuity+Plan+Guide.pdf](https://static1.squarespace.com/static/57c65af5cd0f68b1295663dc/t/5e72fd5833d5965c41b880b4/1584594266318/DSC_Business+Continuity+Plan+Guide.pdf)
- CFA Victoria has developed two online learning and resources targeting service providers: (a) Bushfire safety for service providers and (b) Bushfire planning – how to support your clients <https://www.cfa.vic.gov.au/plan-prepare/your-local-area-info-and-advice/e-learning-for-workers>

### Organisational Capability:

- Queenslanders with Disability Network (QDN) has a network of Peer Support Leaders with knowledge, skills, and approaches for enabling personal emergency preparedness through peer support and mentoring <https://qdn.org.au/our-work/our-projects-2/disability-inclusive-and-disaster-resilient-queensland/>
- Gippsland Disability Advocacy Inc <https://www.gdai.com.au> and VALID <https://www.valid.org.au> have been building on the work of QDN to establish a P-CEP Peer Leadership network in Victoria. They have partnered with local councils and emergency services to enable mutual learning for Disability Inclusive Emergency Planning at the local community level and are a local community asset with knowledge of P-CEP and inclusive emergency management.
- There are examples of services who are developing their capabilities in Person-Centred Emergency Preparedness and Business Continuity Planning. Some case studies can be found here: <https://collaborating4inclusion.org/disability-inclusive-disaster-risk-reduction/disability-inclusive-emergency-planning/>
- The Community Services Industry Alliance has developed expertise and networks that are supporting community services and disability organisations to develop Business Continuity Plans and support each other through peer-to-peer mentoring: <https://csialtd.com.au>

*This list is not exhaustive*

# 5



## Shared and Defined responsibilities

The Australian Government should prioritise the development of explicit policy guidance on who takes responsibility for the extra support needs of people with disability in emergency situations including, how that support should be organised and delivered before, during and after disaster, and how the responsibilities of different stakeholders will be guided and outcomes measured.

To ensure effective planning, governments and emergency planners need to understand the support needs of people with disability, review current plans, and develop community assets and contingencies that are better matched to the support needs of people with disability at all stages of disaster management (preparedness, response, recovery).

### Actions:

- 5.1** Australia's National Disability Strategy is the mechanism to ensure that the rights, protections and meaningful participation of people with disability are incorporated into emergency management. The Department of Social Services is working across the Commonwealth, and with states, territories and the Australian Local Government Associate to develop a new National Disability Strategy that will incorporate, for the first time, disability inclusive emergency planning<sup>55</sup>. This is an important development for the progressive realisation of the rights of people with disability in emergency management that will require oversight and regular review throughout its early development, implementation, and evaluation. Of particular focus should be on how the inclusion of people with disability in emergency planning enables identification and planning for how the extra supports that people with disability need will be responded to before, during, and after disaster.
- 5.2** State and territory governments and Local Government Associations should support Local Governments and emergency services agencies to work in partnership with disability representative and advocacy organisations to develop their capabilities in disability inclusive emergency planning for more effective disaster response and recovery.
- 5.3** Disability representative and advocacy organisations should enable their members to know about and learn to use the Person-Centred Emergency Preparedness toolkit to develop their personal emergency preparedness. Disability representative and advocacy organisations should work with researchers to gather information about the preparedness, capabilities, and support needs of their members and use this information to contribute to disability inclusive emergency planning to remove barriers that increase risks for people with disability and utilise capabilities for more effective response and recovery.

Until recently there were no tools for people with disability to tailor emergency preparedness to their capabilities and support needs in emergencies. We now have the Person-Centred Emergency Preparedness (P-CEP) toolkit that is freely available.

- 5.4** Disability representative and advocacy organisations should be called upon and supported to provide feedback on the extra supports needed by people with disability and advocate for how to include essential supports into emergency management planning processes to ensure the safety and wellbeing of people with disability before, during, and after disaster.

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- <sup>55</sup> [https://www.dss.gov.au/sites/default/files/documents/04\\_2021/australian-government-response-disability-royal-commission-public-hearing\\_5-covid-19-report.pdf](https://www.dss.gov.au/sites/default/files/documents/04_2021/australian-government-response-disability-royal-commission-public-hearing_5-covid-19-report.pdf)

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