## **DISABILITY INCLUSIVE EMERGENCY PLANNING** (DIEP)FORUM

## **COFFS HARBOUR DIEP FORUM**



## **Citation:**

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The emergency, the client and the carers may not know what's in their plan, because it's an agency specific plan or it's being developed because they have to, so it's the box ticking thing. So I think there's more requirement for improvement in those plans. (Group 2)

## PURPOSE

This report documents learnings from a facilitated Disability Inclusive Emergency Planning (DIEP) forum in the Local Government Area (LGA) where it was hosted. Invitation to participate was extended to stakeholders from the community, health, disability, advocacy, emergency services, and government sectors.

#### THIS DIEP FORUM WAS HOSTED BY CITY OF COFFS HARBOUR COUNCIL IN PARTNERSHIP WITH THE UNIVERSITY OF SYDNEY.

**Date:** 28 APRIL, 2023

**Location:** Coffs Harbour Cavanbah Centre

The focus of the DIEP forum was on learning together about:

- ways we can work together to ensure people with disability are aware, safe, and prepared for emergencies triggered by natural hazards and other emergencies (e.g., house fire, pandemic).
- actions we can take to make sure people and their support needs are at the centre of emergency management planning.
- barriers and enablers to the inclusion of people with disability before, during, and after disasters.

This report is one part of a larger program of partnership research to develop Disability Inclusive Disaster Risk Reduction (DIDRR) policies and practices in Australia.

Findings, reported here, contribute multi-stakeholder understanding about knowledge, resources, and possibilities for developing Disability Inclusive Disaster Risk Reduction (DIDRR) policies and practice at the local community level.

Findings in this report are unique to the LGA where the DIEP forum was hosted. It can inform critical reflection and action-oriented planning for ongoing development of inclusive local emergency management and disaster recovery practices that leave nobody behind.

## INTRODUCTION

For too long, disability has been kept in the "too hard basket" because government and emergency services have not had the methods, tools, and guidance on how to include people with disability<sup>1</sup>.

When it comes to disaster risk reduction, people with disability have been overlooked in research, practice, and policy development. A growing literature reveals that people with disability are among the most neglected during disaster events. A key barrier to their safety and well-being in emergencies has been the absence of people with disability from local emergency management practices and policy formulation.

The research shows that people with disability:

- are two to four time sore likely to die in a disaster than the general population<sup>2</sup>.
- experience higher risk of injury and loss of property<sup>3</sup>.
- experience greater difficulty with evacuation<sup>4</sup> and sheltering<sup>5</sup>.
- require more intensive health and social services during and after disasters<sup>6</sup>.

Stigma and discrimination marginalise people with disability from mainstream social, economic, cultural, and civic participation, including participation in emergency management decision-making.

<u>http://www.daru.org.au/resource/clearing-a-path-to-full-inclusion-of-people-with-disability-in-emergency-management-policy-and-practice-in-australia</u>. Multiple formats including: pdf, word, Easy Read, infographic, video animation.

<sup>&</sup>lt;sup>1</sup> Villeneuve, M. (2021). *Issues Paper: 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.

<sup>&</sup>lt;sup>2</sup> Fujii, K. (2015) The Great East Japan Earthquake and Persons with Disabilities Affected by the Earthquake – Why is the Mortality Rate so High? Interim report on JDF Support Activities and Proposals. Paper presented at the Report on the Great East Japan Earthquake and Support for People with Disabilities, Japan Disability Forum.

<sup>&</sup>lt;sup>3</sup> Alexander, D. (2012). Models of social vulnerability to disasters. *RCCS Annual Review. A selection from the Portuguese journal Revista Crítica de Ciências Sociais*(4).

<sup>&</sup>lt;sup>4</sup> Malpass, A., West, C., Quaill, J., & Barker, R. (2019). Experiences of individuals with disabilities sheltering during natural disasters: An integrative review. *Australian Journal of Emergency Management, The, 34*(2), 60-65.

<sup>&</sup>lt;sup>5</sup> Twigg, J., Kett, M., Bottomley, H., Tan, L. T., & Nasreddin, H. (2011). Disability and public shelter in emergencies. *Environmental hazards, 10*(3-4), 248-261. doi:10.1080/17477891.2011.594492

<sup>&</sup>lt;sup>6</sup> Phibbs, S., Good, G., Severinsen, C., Woodbury, E., & Williamson, K. (2015). Emergency preparedness and perceptions of vulnerability among disabled people following the Christchurch earthquakes: Applying lessons learnt to the Hyogo Framework for Action. *Australasian Journal of Disaster and Trauma Studies, 19*, 37

Multiple categories of social vulnerability intersect with disability which amplifies risk<sup>7</sup>.

## **INTERNATIONAL POLICY**

Disability became prominent in the disaster policy agenda after the <u>United Nations Convention on the Rights of Persons with Disabilities</u> (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 preparedness and disaster risk reduction programs and services.

Built on the foundations of the UNCRPD, the <u>Sendai Framework for</u> <u>Disaster Risk Reduction (SFDRR) (2015-2030)</u> firmly established people with disability and their representative organisations as legitimate stakeholders in the design and implementation of disaster risk reduction policies, calling for "a more people-centred preventative approach to disaster risk" (p.5)<sup>8</sup>.

#### 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<sup>9</sup>.

Australia, as a signatory to the UNCRPD and SFDRR must find ways to ensure everyone is well prepared for disasters triggered by natural hazards. This includes people with disability and their support networks.

## NATIONAL POLICY

Australia's state/territory governments have principal responsibility for emergency management legislation, policies, and frameworks.

<sup>&</sup>lt;sup>7</sup> Twigg, J., Kett, M., & Lovell, E. (2018). Disability inclusion and disaster risk reduction. *Briefing Note. London: Overseas Development Institute*.

<sup>&</sup>lt;sup>8</sup> Stough, L.M. & Kang, D. (2015). The Sendai Framework for Disaster Risk Reduction and persons with disabilities, *International Journal of Disaster Risk Science*, *6*, 140 – 149. <u>https://link.springer.com/article/10.1007/s13753-015-0051-8</u>

<sup>&</sup>lt;sup>9</sup> Villeneuve, M. (2021). Building a Roadmap for Inclusive Disaster Risk Reduction in Australian Communities. *Progress in Disaster Science*. <u>https://doi.org/10.1016/j.pdisas.2021.100166</u>

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<sup>10</sup>.

Australia's <u>National Strategy for Disaster Resilience</u> and <u>National</u> <u>Disaster Risk Reduction Framework</u> invite shared responsibility with individuals and communities to help everyone plan for and respond better to disasters. But we haven't had the tools to include people with disability and the services that support them in emergency preparedness and disaster recovery planning.

<u>Research in Australia, led by the University of Sydney</u>, is helping to address that gap. This research has influenced the development of Australia's new Disability Strategy through the co-production of person-centred capability tools and approaches that support multiple stakeholders to work together to identify and remove barriers to the safety and well-being of people with disability in emergencies.

<u>Australia's Disability Strategy 2021-31</u> includes, for the first time, <u>targeted action on disability-inclusive emergency management</u> and disaster recovery planning. This is significant because it requires all governments, community organisations, and businesses to include people with disability in their emergency management and disaster response and recovery planning.

#### This means that:

- everyone must find effective ways to include the voice and perspective of people with disability in planning and decision-making to increase the health, safety, and wellbeing of people with disability before, during, and after disasters.
- emergency and recovery planning should include the services that support people with disability as a local community asset for emergency planning and recovery. Planning for emergencies must extend to working with disability service providers to help them to understand their disaster risks and make effective plans for their services, staff, and the people they support.
- government and emergency services need to find ways to work in partnership with people with disability and the services that support them – because disability-inclusive emergency planning and disaster recovery require collaborative effort!

<sup>&</sup>lt;sup>10</sup> <u>https://knowledge.aidr.org.au/resources/handbook-australian-emergency-management-arrangements/</u>

Local emergency management plans need to identify and plan for the extra support needs of people with disability in emergencies. Local Government (local level) emergency plans direct the:

- actions of emergency services 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., bushfire vs flood). 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.

To ensure inclusion, emergency management, governments and emergency planners (at all levels) 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).

# Interdependence of people with disability and the services that support them

Research has recognised the interdependence of people with disability and their support networks in achieving safety and wellbeing before, during, and after disaster. This literature acknowledges the important contribution of community, health 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

These services are optimally positioned to contribute to inclusive emergency planning and risk reduction because:

- they are on the frontline of community-based care and support.
- these relationships equip providers with an intimate knowledge of the functional needs of the people they support.
- they have a deep understanding of the accessible spaces and places within communities that promote and enable participation.
- community-based providers are often seen as the link between people with disabilities and their families and the wider community, forming a crucial component of support networks.

Research in Australia shows, however, that community and disability organisations are not adequately prepared for disaster themselves nor are they integrated into emergency planning.

The <u>NDIS Quality and Safeguarding Commission signed a legislative</u> <u>amendment</u> that took effect in January 2022. It requires all National Disability Insurance Scheme (NDIS) Registered service providers to:

- ensure continuity of supports which are critical to the safety, health, and wellbeing of NDIS participants before, during, and after a disaster, and
- work with their clients to undertake risk assessments and include preparedness strategies within their individual support plans.

The <u>NDIS Practice Standards</u> incorporate these legislated requirements. The new Practice Standards now require service providers to effectively develop, test, and review emergency plans, and to plan for the continuity of critical supports during emergencies to ensure the health, safety and well-being of the people they support.

Emergency planning is also a requirement for aged care providers. During an emergency, providers must continue to maintain quality care and services to care recipients. This is a requirement under the <u>Aged Care Act 1997</u>.

Although this requirement has been part of Aged Care legislation since 1977, **this is a new role for ALL service providers who have** not traditionally been included in emergency planning policy and practices.

## DISABILITY INCLUSIVE DISASTER RISK REDUCTION (DIDRR)

The <u>Collaborating4Inclusion</u> research team at The University of Sydney Impact Centre for Disability Research and Policy leads partnership research to co-produce methods, tools, and policy guidance for cross-sector collaborative action on Disability Inclusive Disaster Risk Reduction (DIDRR).

Our research focuses on community capacity development in the areas of **Person-Centred Emergency Preparedness (P-CEP)** and **Disability Inclusive Emergency Planning (DIEP)** to activate cross-sector collaboration to achieve DIDRR<sup>11,12</sup>. By learning and working together, our aim is to build the community capacity needed to take disability out of the "too hard basket."

**DIDRR** is an emerging cross-sector practice requiring social innovation to develop responsive disaster risk reduction practices that focus on the support needs of people with disability in emergencies and that place people with disability at the centre of development and change. DIDRR approaches seek to identify and address the root causes of vulnerability for people with disability in emergencies through participatory and community-based approaches that engage all persons.

DIDRR requires actions of multiple stakeholders working together with people with disability to identify and remove barriers to the safety and well-being of people with disability before, during, and after disasters.

**P-CEP** activates capability-focused self-assessment and preparedness actions of multiple stakeholders to enable personal emergency preparedness tailored to individual support needs; resulting in the identification of and planning for unmet needs that increase disaster risks. Certificate training in P-CEP facilitation is available through the University of Sydney Centre for Continuing Education. Learn more here:

https://collaborating4inclusion.org/leave-nobody-behind/pcepshort-course/

**DIEP** activates inclusive community-led preparedness actions of multiple stakeholders that focus on pre-planning for the extra

<sup>&</sup>lt;sup>11</sup> Villeneuve, M. (2022). Disability inclusive emergency planning: Person-centred emergency preparedness. *Oxford Research Encyclopedia of Global Public Health*. Doi: <u>https://doi.org/10.1093/acrefore/9780190632366.013.343</u>

<sup>&</sup>lt;sup>12</sup> Villeneuve, M. (2021). Building a Roadmap for Inclusive Disaster Risk Reduction in Australian Communities. *Progress in Disaster Science*. <u>https://doi.org/10.1016/j.pdisas.2021.100166</u>

support needs of people with disability in emergencies and building community willingness and capability to share responsibility for the organization and delivery of supports, so that nobody is left behind. Learn more: <u>www.collaborating4inclusion.org</u>

# Developing Shared Responsibility for DIDRR at the local community level

Our partnership research presumes that stakeholders must learn and work together toward DIDRR development and change. The DIEP forum was designed to support that objective. The following provides a brief overview of key stakeholders in terms of their potential to contribute to DIDRR.

**Emergency services** personnel include paramedics, firefighters, police officers, state emergency services workers. These personnel, who work alongside numerous emergency volunteers<sup>13</sup>, are usually the first support people think they will rely on in a disaster. Indeed, emergency services and other agencies are typically the first organized to respond. This includes issuing information and warnings for hazards (e.g., bushfire, flood, storm, cyclone, extreme heat, severe weather)<sup>14</sup>.

Community engagement is a critical component of emergency management practice which helps to build community resilience to disasters<sup>15</sup>. Before emergencies, community engagement activities typically involve providing awareness campaigns, information, tools and resources that enable people to understand their disaster risks and take preparedness steps. To be included, people with disability need the same opportunity to:

- access, understand and use this information,
- participate in emergency preparedness programs in their community, and
- be included as a valuable stakeholder in all phases of local community disaster risk management<sup>16</sup>.

**Local Council** links to community groups are a fundamental vehicle for the delivery of measures to increase inclusion for people with disability and the services that support them and build whole-ofcommunity resilience before, during and after disaster.

<sup>&</sup>lt;sup>13</sup> Varker, T., Metcalf, O., et al., (2018). Research into Australian emergency services personnel mental health and wellbeing: An evidence map. *Australian & New Zealand Journal of Psychiatry*, *52*, 129 - 148 https://doi.org/10.1177/0004867417738054

<sup>&</sup>lt;sup>14</sup> https://knowledge.aidr.org.au/resources/australian-warning-system/

<sup>&</sup>lt;sup>15</sup> https://knowledge.aidr.org.au/resources/handbook-community-engagement/

<sup>&</sup>lt;sup>16</sup> Pertiwi, P.P., Llewellyn, G.L., Villeneuve, M. (2020). Disability representation in Indonesian Disaster Risk Reduction Frameworks. *International Journal of Disaster Risk Reduction*. https://doi.org/10.1016/j.ijdrr.2019.101454

In addition to their emergency management function, local councils are linked to emergency services, Organisations of People with Disability (OPDs), and community-based service providers through their community development, disability inclusion and community engagement roles. However, there is wide variability and ineffective integration of these critical responsibilities of local government<sup>17</sup>. This impacts local emergency management and disaster recovery planning and perpetuates inequity for people with disability, their family and carers because their support needs in emergency situations are not understood.

DIDRR requires development of leadership, support, and coordination functions within local government for working together with OPDs, community service and disability support providers, and emergency services. Integrated planning and reporting across the community development and emergency management functions of local councils is needed to achieve safety and well-being for people with disability, their family and carers in emergencies.

**Organisations of People with Disability (OPDs) and Disability Advocacy Organisations** can play a significant role in disaster policy, planning and interventions. Through their lived experience, leadership, and roles as disability advocates, OPDs represent the voice and perspective of their members with disability. OPDs have in-depth understanding of the factors that increase risk for people with disability in emergencies. They also 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. Disability Advocacy organisations and OPDs play a critical role in supporting and representing the voice and perspectives of people with disability.

Carers (e.g., family and other unpaid support people) face the same barriers as the individuals they care for in emergencies. Like OPDs, **Carer Organisations** can play a significant role in safety and wellbeing outcomes for people with disability and their carers by representing their perspective in disaster policy, planning and interventions.

**Community, health and disability service providers** (e.g., paid service providers and volunteers) are an untapped local community asset with potential to increase safety and well-being for people

<sup>&</sup>lt;sup>17</sup> Drennan, L. & Morrissey, L. (2019). Resilience policy in practice – surveying the role of community-based organisations in local disaster management. *Local Government Studies*, *45*(3), 328-349. <u>https://www.tandfonline.com/doi/epdf/10.1080/03003930.2018.1541795</u>

with disability in emergencies. Harnessing this potential is a complex challenge. It requires:

- developing effective links between personal emergency preparedness of people with disability and organisational preparedness (including service continuity) of the services that support them.
- understanding how such requirements could be developed and governed within the diverse service delivery context, funding models, and roles of service providers in the community, health care and disability sectors.

In this landscape, some people receive disability supports from multiple service providers and agencies, while other people are not connected to funded disability services (e.g., NDIS) but may receive support through mainstream community groups and activities. The situation is increasingly complex for people who have limited or no support networks, fewer people they rely on and trust, and fragile connections to community programs and neighbourhood centres<sup>18</sup>. New ways of working are needed to ensure duty of care for both the staff and the people they support. This will require clarity on the responsibilities and expectations of service providers and the people they support in emergencies. This should include both specialist disability supports and mainstream community services for people of all ages.

## METHODOLOGY

## Design

We adapted the **Structured Interview Matrix** (SIM) methodology<sup>19</sup> as an innovative approach to disability-inclusive community engagement with multiple stakeholders. Inclusive community engagement is a crucial first step in redressing the exclusion of people with disability from emergency planning. It breaks down professional boundaries so that people can learn and work together to identify local community assets, tools, and resources that will impact whole-of-community resilience to disaster.

<sup>&</sup>lt;sup>18</sup> Villeneuve, M., Abson, L., <u>Pertiwi, P.</u>, Moss, M. (2021). Applying a person-centred capability framework to inform targeted action on disability inclusive disaster risk reduction. International Journal of Disaster Risk Reduction. <u>https://doi.org/10.1016/j.ijdrr.2020.101979</u>

<sup>&</sup>lt;sup>19</sup> O'Sullivan, T.L., Corneil, W., Kuziemsky, C.E., & Toal-Sullivan, D (2014). Use of the structured interview matrix to enhance community resilience through collaboration and inclusive engagement. Systems Research and Behavioural Science, DOI: 10.1002/sres.2250

#### Here's how we do it:

The academic research team partners with Local Government to host a Disability Inclusive Emergency Planning (DIEP) forum in their community.

As host, Local Government partners invite multiple stakeholder participation, striving for equal representation of:

- people with disability, (informal) carers, and representatives and advocates;
- community, health, and disability organisations that provide community-based services and supports;
- mainstream emergency services including non-government organisations involved in community resilience and disaster recovery work; and
- government staff with diverse roles involving emergency management, disability access & inclusion, community development & engagement.

The research team pre-plans the forum together with the local government host who promote the forum through their networks. To support interactive dialogue, we aim to recruit 32 participants. The makeup of participants in each DIEP forum reflects the nature of the Local Government's connections to their community as well as the availability, willingness, and capability of participants to attend. Participation can be impacted by other factors including competing demands on one or more stakeholder group and unexpected events that impact attendance of individuals (such as illness) or an entire sector (such as community-level emergencies).

## **Data Collection**

Originally developed as a method for organisational analysis and strategic planning, the Structured Interview Matrix facilitation technique has been used as a data collection method in participatory research.

The SIM methodology was adapted in this study facilitate inclusive community engagement and promote the development of knowledge and connections between different stakeholders. SIM employs a graded approach to collaboration. We applied the SIM using a three-phase process.



#### **Overview of the SIM Facilitation Process**

**The first phase** involves a series of one-on-one interviews conducted by the participants themselves. An interview guide, prepared by the researchers, consists of four questions. On arrival, participants are assigned to a group and each group is assigned one interview question. The interview matrix is structured so that each participant has the opportunity to ask their assigned question of three people and respond to a question posed by three other participants.

Participant interviewers are instructed to ask their question and listen to the response without interrupting. They are also asked to record responses in writing on a form provided.

To support dialogue between participants, pairs take turns asking their interview question over a 10-minute duration. Additional time is provided for participants who needed more time to move between interviews or who require more time to communicate or record responses. The process is repeated until each participant has interviewed one person from each of the other groups. The facilitator keeps time and guides the group so that participants know how to proceed through the matrix.

To extend opportunity for interaction and dialogue, we add a fourth "wildcard" round whereby participants are asked to conduct one more interview with someone they do not know, who they haven't yet interviewed, and who is not in their "home group."

**The second phase** involves each group coming together to discuss, review and summarise the individual responses to their assigned question. Following their summary of responses, group members are encouraged to add their perspective to the small group deliberation.

The small group discussion involves information sharing and deliberation, where participants assimilate information provided by others, express their viewpoint, develop shared understanding, and potential solutions.

To prepare a synthesis of findings to their question, each small group is invited to identify the main findings to be shared in the large group plenary. Each of these small group discussions are audio recorded.

**The third phase** involves a large group plenary discussion which begins with each group presenting their main findings followed by a facilitated discussion with all participants. The presentations and plenary discussion are audio recorded.

#### Interview Questions Guiding this DIEP forum

**Group 1:** From bushfires to COVID-19 to floods, Australia has had its share of disaster events. How have disasters impacted you, your organization, and the people you support? <u>Probe:</u> What worked well? What helped that to happen?

**Group 2:** We all need to prepare for emergencies and disasters triggered by natural hazards. What steps have <u>you</u> taken to prepare for emergencies? <u>Probe:</u> If you have, tell me more about your plan. If you haven't what could you do? Is there anyone who could help you get started?

**Group 3:** In a disaster in your community, some people with disability will have extra support needs that impacts how they manage in an emergency. How do you or your organization enable people with disability to be aware, safe, and prepared before, during, and after emergencies? <u>Probe:</u> What resources, tools, training helps you? What resources, tools, training are needed?

**Group 4:** Emergency services is usually the first support people think they will rely on in a disaster. In a disaster in your community, what OTHER SUPPORTS could people with disability count on? <u>Probe</u>: Think about where you live, work, and play and the assets near you.

#### **Facilitation Process**

The interview matrix technique has the advantage of accommodating the voices of a large number of participants in each session (12 - 40) while ensuring that the perspectives of all participants are heard. This approach overcomes common challenges to inclusive community engagement by ensuring that people can fully engage in the process and benefit from their participation while maintaining efficiency. The DIEP forum brought together diverse stakeholders who do not typically work together. Inclusion of people with disability was supported by: (a) extending invitations to people with disability and their representatives to participate; (b) welcoming the attendance and participation of support workers; and (c) providing the means to support their engagement (e.g., Auslan interpretation, barrier free meeting spaces, safe space to express ideas, accommodating diverse communication needs, participation support). Following arrival, participants were assigned to one of four mixed stakeholder groups. A morning orientation provided background information on DIDRR including what it means and the timeline of its development in Australia. It was explained that the focus of the DIEP forum is on learning together about:

- ways we can work together to ensure people with disability are aware, safe, and prepared for emergencies triggered by natural hazards and other emergencies (e.g., house fire, pandemic).
- actions we can take to make sure people and their support needs are at the centre of emergency management planning.
- barriers and enablers to the inclusion of people with disability before, during, and after disasters.

Participants were introduced to the Person-Centred Emergency Preparedness (P-CEP) framework<sup>20</sup> including a brief case study to illustrate the importance of considering extra support needs of people with disability in terms of functional capabilities and support needs rather than by their impairments, deficits or diagnosis. The P-CEP covers eight capability areas including communication, management of health, assistive technology, personal support, assistance animals, transportation, living situation, and social connectedness<sup>21</sup>. Introducing the P-CEP framework served the purpose of supporting shared learning among participants, grounded in a common language for identifying and discussing the capabilities of people with disability and any extra support needs they have in emergencies<sup>22</sup>. The remainder of the forum was facilitated according to the three SIM phases.

Each DIEP forum took place over approximately 5 hours including the morning orientation and nutrition breaks. The length of these consultations is important to ensure time invested in meeting new people and engaging in meaningful discussion with people from different backgrounds. This facilitates the development of new

<sup>&</sup>lt;sup>20</sup> <u>https://collaborating4inclusion.org/home/pcep/</u>

<sup>&</sup>lt;sup>21</sup> Villeneuve, M. (2022). Disability inclusive emergency planning: Person-centred emergency preparedness. *Oxford Research Encyclopedia of Global Public Health.* 

Doi: https://doi.org/10.1093/acrefore/9780190632366.013.343

<sup>&</sup>lt;sup>22</sup> <u>https://collaborating4inclusion.org/disability-inclusive-disaster-risk-reduction/p-cep-resource-package/</u>

community connections and the opportunity to renew or deepen existing relationships<sup>23</sup>. Opportunity for informal networking and engaging in extended discussion during nutrition breaks provides additional opportunities to develop connections between stakeholders.

At the end of the workshop, participants were invited to complete a questionnaire to provide feedback on their satisfaction with the workshop and what key things were learned.

## Data Analysis

Data consisted of: (a) scanned record forms from the individual interviews; (b) transcribed audio recordings of the small group deliberation; and (c) transcribed audio recordings of the large group plenary.

Data were analysed by Local Government Area (LGA) to produce findings that reflect the nature of the conversation in each community.

Analysis proceeded in the following way for each LGA.

- All recordings were transcribed verbatim and imported into a qualitative analysis software program.
- Data was de-identified at time of transcription.
- Record forms and transcripts were read in full several times before identifying codes.
- Open coding was used to first organise and reduce the data by identifying key ideas coming from participants. This was conducted by two researchers independently followed by discussion of emergent findings with the research team to support reflexive thematic analysis.
- Reflexive thematic analysis<sup>24</sup> was used to group codes into categories. This process involves both expansion and collapsing of codes into categories; creation of new categories; identification of patterns in the data; observation of relationships and the development of emergent themes for each LGA.

Our goal was to provide a rich, thematic description of the entire data set and report on findings for each LGA that reflects the

<sup>&</sup>lt;sup>23</sup> O'Sullivan, T.L., Corneil, W., Kuziemsky, C.E., & Toal-Sullivan, D (2014). Use of the Structured Interview Matrix to enhance community resilience through collaboration and inclusive engagement. *Systems Research and Behavioural Science*, *32*, 616-628. <u>https://doi/10.1002/sres.2250</u>

<sup>&</sup>lt;sup>24</sup> Braun, V. & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4),

https://doi.org/10.1080/2159676X.2019.1628806

contributions of everyone who participated in the forum (i.e., this report).

Since this is an under-researched area and the consultations involved multiple stakeholder perspectives, our aim, here, is to identify predominant themes and give voice to the multiplicity of perspectives in each LGA report.

DIEP reports are shared back with our government hosts and all participants to support ongoing feedback and dialogue on disability inclusive emergency planning.

Stakeholders are encouraged to use the report to progress inclusive community engagement and DIDRR actions in their community.



And I'll be honest with you, from an organisational point of view, I think that we do as much as we can with as little as we have. And I think that what we find is that our messaging then becomes very standard, and our approaches become very standard. And I think that that's something that has been pointed out today, from a lot of the people that I spoke to, is that it's not tailored to individual needs and in that respect, we're missing the mark. So you can have all the messaging that you like, but at the end of the day, if people aren't taking action and making plans and knowing what they need to do, then we are failing. And we are failing the community as well. And ultimately that's who we're here for. (Group 1)

## **DIEP Participants**

STAKEHOLDER GROUP	NUMBER OF PARTICIPANTS
Person with Disability or Carer	5
Disability Service	8
Community Service	4
Health Service	4
Organisation or Advocate representing people with disability or carers	1
Government	4
Emergency Service	5
TOTAL	31

## FINDINGS

#### What did we learn together?

Findings are grouped into five themes, summarized in the following table and discussed below.

### Key Learnings in Coffs Harbour

- **1.** Underprepared for emergencies and ticking boxes
- **2.** Communication access and warning systems gaps
- **3.** Evacuation centres are not accessible to all; hospitals are not an evacuation centre
- **4.** Diverse forms of support
- 5. Registers vs. Community asset mapping

## **DISCUSSION OF FINDINGS**

# Learning 1: Underprepared for emergencies and ticking boxes

While some people reported having an emergency plan and grab bags, most people said they do not have a sufficient emergency preparedness plan. Plans are mostly in people's heads and not communicated effectively with people in their support network. Some people had put together "grab bags" but had not regularly reviewed and replenished supplies. More commonly, people think about preparing only after a disaster has happened. For some participants with additional support needs, they experienced challenges finding someone to support them with emergency planning. I found that most people that work in, so like paramedics, whatever, didn't have their own plans for their own selves, for their own families. They all went, "Oh, I should have that." (Group 2)

I spoke to three different people and none of them have plans. And it doesn't matter whether they were carers or whether they were firefighters or whatever, they don't have a plan. (Group 2)

It's interesting, I was talking to other people here and no one else had planned. What do you do? "But I don't have a grab bag." So there you go. And this is what I do for living. I teach people about this and we don't do it. (Group 2)

I also learned was that people now think about emergency plans after they've experienced a disaster... When it's a little bit too late. "How do we prepare for the next one?" (Group 1)

...they either didn't have a written plan, they had a thought plan, but it still had a few gaps at the end. It only went so far. It only went to getting out of the house, not, "Where do I go next?" Or, "What do I do?" (Group 2)

Plan was in their head, not written down, and the challenge is finding someone that can help them do that planning process. (Group 2)

But the inventory of what's in your grab bag and to go over your grab bag every now and again, someone just looked in their grab bag the other day and their passports are no longer in there because they obviously got them out to go and do something, and didn't happen to put it back in. And now they have no idea where their passports are in the house. So you need to relook at your grab bags. (Group 2)

So basically, very few people have a detailed emergency plan, and even within the emergency services, so people were a little bit embarrassed about that. And the plan actually needs to last for three days, as well. But yeah, very few people had a detailed plan, which is a problem obviously. (Large Group)

People have an "appetite to be more prepared" because of the disasters they have experienced in the recent three-year period. Participants discussed the importance of leveraging the interest and momentum. They recognised that if there is a period without disaster events, people my lose interest.

At the moment, I believe the community has appetite to grow our responses because of all we've been through in three years. Human nature says that if we don't have a major event in the next three or four years, that is gone. Speaker 3: That's not even possible. Speaker 5: And we're starting scratch again. Speaker 2: So we need to be going on this now. Speaker 5: We need to rely on more than position. It's actually got to be embedded within organisations within the community... It's the jump on that now though, when everybody's got that appetite and then everybody's like, "Oh my gosh. (Group 2)

Emergency personnel also shared the importance of building on the momentum from the DIEP forum to make changes, including increasing disability inclusion in emergency management training. For many emergency personnel, disability inclusion was a new concept. One participant acknowledged that standard approaches are insufficient for people with disability and worried that we are failing individuals and the community if people cannot use the information to make a plan and take actions to keep themselves safe.

I teach people about evacuation management and as I said, in a three-day course, there's two sentences on disabilities... Absolutely. It's just something that's not on the radar and it should be. And I'm going to take some learnings out of this and try and build on that and hopefully with a bit of luck, we'll be able change that training. (Group 2)

Sorry, this is all quite new to me. And I'll be honest with you, from an organisational point of view, I think that we do as much as we can with as little as we have. And I think that what we find is that our messaging then becomes very standard, and our approaches become very standard. And I think that that's something that has been pointed out today, from a lot of the people that I spoke to, is that it's not tailored to individual needs and in that respect, we're missing the mark. So, you can have all the messaging that you like, but at the end of the day, if people aren't taking action and making plans and knowing what they need to do, then we are failing. And we are failing the community as well. And ultimately that's who we're here for.

The DIEP forum got emergency personnel thinking about what "best practice" should look like for tailored preparedness support and inclusive planning.

So to have a central point where we can go to start thinking around what does best practise look like for emergency management, just like we've been talking about this morning, I think, is a big step forward. (Group 3)

One of the messages from this is that it isn't there to... The emergency services will never have the capacity to provide a person-centred approach for everybody, and that's where it is up to service providers to fill that gap so that everyone is safe and prepared. (Group 3)

I think we need the media here at the table. What's the media's role in all this? ... Turn your pot handle on your stove in so your kids don't knock it off. We could have some really significant media campaigns based off the new training ideas that we'll talk

about here so people will inform their neighbours as to what their special needs are. (Group 3)

Others also recognised the role of community and disability services as instrumental in preparedness that is community-led. However, they also recognised the capacity building is needed for effective planning by service providers.

Plans need to be community led, and then fed through to emergency services. Often, plans also may not be shared with other carers and family members, so that was another thing about the co-designing and the education of everyone, within the person's sphere of care.

We absolutely have the same. Those people may not have that specialist knowledge to even design the plan. They're just the people who've put their hand out. "Yep, all right. We'll be part of that."

Disability support services provider that is known to the client, and their support workers could be rostered on to assist the client." Say, for instance, if they had to go to a new location, like a motel or a hotel, if it was a flood disaster or something like that. (Group 4)

The next interview person we spoke with, again, brought up the disability service provider could have a huge role in assisting, family and friends, possibly neighbours. (Group 4)

A repeat theme coming from the community and disability services sector participants was that emergency plans are not "*co-designed with clients*". They expressed concern about perpetuating risks for people with disability because planning has become "*a tick-box exercise.*" Some participants felt that the "*tick and flick*" approach happens when people perceive that there are individuals (e.g., with cognitive impairments or complex disabilities) that cannot be included in emergency planning).

So a different issue that came out of one of my conversations was... This was from someone who works from a provider, and she made the comment that training always seems to be about maintaining registration. It's more about how do we tick the box so we can move on, and less about what does that person need.(Group 3)

Training of staff regarding emergencies, so training of support workers... Training support workers is more of a technicalistic thing rather than holistic and focused. (Group 3)

Yep. But then what you're saying is really sad because that's a disability service, and I experienced it at exactly the same time as you. It's a generic emergency and evacuation planning... Yeah, that's it... Yeah, there's no person centred approach or anything. But you also have to have an evacuation plan for each individual participant, but again, I think it's like a tick the box. That's probably done at the computer there, just someone ticking the box saying, "Oh, yeah. We could do this." They're making it up as they go along rather than stepping through what would actually happen in an emergency. (Group 3)

Yeah, so instead of training folks on an individual, it's about what does a provider need to maintain their registration... Right, looking at the process and not at the person or people... Yeah. And so the thought is well, that needs to be embedded into internal training is the person needs to be the centre of that training regardless of what their legislation passes to do. (Group 3)

The emergency, the client and the carers may not know what's in their plan, because it's an agency specific plan or it's being developed because they have to, so it's the box ticking thing. So I think there's more requirement for improvement in those plans. (Group 2)

I'll go one step further on a couple of my guys in that it was an organisational based plan, not the support worker who knows the client. Inclusive... Okay, so the client maybe cognitively can't be included in terms of making conscious decisions, but this person wasn't included where they are the main support, not that organisation, and sitting in an office person... So, if that becomes the tick and flick up here, not the reality of how it's actually is... I would add to that there are very few people who can't be included in their plan in some level- if you adapt the way that you're including them... There is very few people that can't be included in their plan. (Group 2)

One thing I'm taking away is that training support work is needed...currently a bit of a tokenistic box ticking exercise, and we're talking about trying to drill down to that individual person's approach and the use of scenarios. Realistic scenarios is the important thing. Just hearing different things here that make me think as an emergency manager about how the greatest good for the greatest number, so a very, very strong cultural thing in there. (Group 2)

# Learning 2: Communication access and warning systems gaps

A dominant theme surrounded information access. Participants discussed challenges around sharing of correct information, how information and warnings get disseminated, and whether people are able to "*get information in a format relevant to them"*. This led to discussion about people who are isolated from information and the impact of ineffective communication further isolating people (e.g., people who are Deaf). There were at least three Deaf people at this

forum, so the conversation, particularly at Group 1, centred on their communication support needs.

We had a massive discussion around isolation and communication around the warning systems, and in particular the deaf community. They can't access the usual media messaging that comes out around disasters, so that in itself is a whole piece of work that we need to take one look at locally, as service providers, as local plans, regional plans, et cetera. I think it's a massive gap that we've just got to try and cover as best we can moving forward. They rely on just their own community support networks, so I've they've also been impacted, then they're actually at danger of having those disasters with poor outcome. (Large Group)

And there was a feeling in addition to not being able to get information in the format that was relevant to them, there was also a feeling of isolation. And I think that's really important to recognise because people aren't going to feel like they can make the right decisions if they're not given the tools and if they're feeling isolated. (Group 1).

So, I think it's really hard for deaf people to be able to connect. So how do we actually make contact? So, say for the SES, how do we contact them? So, if there's Transport New South Wales, cancel disability workers, guides, is there guides to be able to assist us neighbours? Do our neighbours know how to access and help us? (Group 1)

Hearing people don't know, we're waiting to watch TV to hope that there's Auslan interpreting on there, generally on the news. So often it's not local, though. So usually local it would be somebody around me that would reach out and let me know what was going on. So there's not really a lot of people that they help me. (Group 1)

So where I am, if they were knocking on the door or whatever, nobody would know, but there's four of us, one hearing, three deaf. So I don't really have that access. (Group 1)

I've been living on my own for many, many years. So you do get used to it, and I know what to do when it comes to that sort of thing. So maybe my sister might reach out to me and let me know what's going on. She might text me or text my neighbour to let them know. (Group 1)

" lot of deaf people that might live further out, whatever, they might not even have that access to stuff." So yeah, that's impossible. I think now with NDIS, that's kind of changed. Most people have a smart watch and a mobile phone and data. Most. Yes, I have deaf-blind clients. I have one hearing contact, actually I have two. So they don't even know...So when the internet is down and no power, how do you get the message and no mobile phone? (Group 1)

For example, literacy, poor hearing, that kind of thing which we just heard about as well, and where to get reliable info. That can be another thing that really increases anxiety in those times, is where you actually get the right information, and there's a lot of misinformation, which impacts safety and mental health, et cetera. (Large Group)

#### Learning 3: Evacuation centres are not accessible to all; hospitals are not an evacuation centre.

Participants discussed the fact that evacuation centres may not be "*fit for purpose"* to ensure access to a wide range of people with different support needs. They recommended that audits of evacuation centres should include whether those facilities are accessible and incorporate plans for improvement.

The EVAC centres was something that came up for me that was something I didn't even realise when designing EVAC centres, clearly not good enough to cater for the diversity people that they need to. So there needs to be alternatives to that. So that's a really important team message, I think, from an emergency management planning point of view. (Group 1)

And places say they've got, "Yes, we've got it." But the example he gave was there was a ramp into the room but that was it. The shower was over a bath and all this kind of stuff. So people think they're doing the right thing but they're not...And if we've got a major emergency where we are trying to fit people, as emergency management agencies, we need to consider it's not just about putting someone in a room just because there's room there. (Group 2)

And a hospital is not an evacuation centre, that was a thing that came up. (Large Group)

And the evacuation centre is also not necessarily appropriate for everyone, and particularly for people with disabilities for example. It could be really overwhelming of sensory needs, et cetera, and not set up well for a lot of disabilities. And there needs to be a safe, accessible accommodation identified within the community that people can go. It's an alternative to hospital or the evacuation centre. (Large Group)

Excessive and increasing evac points to the necessary facilities, so there were some awesome examples that were brought, but this was also a takeaway. So, the examples had accessible places for evacuation centres but also quiet rooms. If you've ever been to an evacuation centre, it is quite chaotic, so that was another takeaway we had. (Large Group)

#### Learning 4: Diverse forms of support

One group addressed the question of other assets that people with disability can rely on in emergencies. Responses to this question revealed numerous forms of support including: **people** (e.g., informal support from friends, family, neighbours, formal support including mental health services, peer support and recovery programs); **mainstream community programs and services** 

(e.g., community leaders, religious communities, transportation, community and neighbourhood organisations). Types of support included **psychoemotional support**, including recovery support services for people impacted by disasters), and extended to **accessible accommodation** suitable for people with disability who may be displaced in a disaster. Emphasis in these discussions was support to people <u>AFTER</u> disaster.

Support from family, friends and neighbours – the people you are socially connected to – dominated these conversations. There was also recognition that community, health, and disability support providers had a broader understanding of available supports for people with disability in the community compared with emergency services personnel or those working in the disaster resilience space. With this recognition, the conversation turned to how community services can bring their knowledge of accessible services and supports together with what those from emergency management and disaster recovery planning sector know and access.

I think what stood out for me, and I'm not sure whether anybody else experienced, the difference between when I was talking to somebody who was from another community organisation, they had a lot broader ideas on the types of supports that may or may not be able to, compared to, sorry, but people who were employed more in the actual emergency services, and the actual sector itself, not so much on the ground. (Group 4)

Us in the actual community services, we're the ones who actually work with the clients. We have the knowledge; we have the information. It's about how do we actually bring those two things together and make it work.

I've spoken to the manager of the service that I use about that, and he said that's another conundrum altogether, to try and get disability services to work with, because of all the privacy concerns. (Group 4)

In these discussions, service providers shared examples that illustrated why they are important asset in emergencies; explaining that it is because they have deep knowledge of the people they support and trusting relationships.

...if the emergency service would turn up, and we would be able to direct who needed to do what. Like who's got autism, who needs to be [inaudible], and we would [inaudible] know how to work with each client. (Group 4)

One of my clients, in an incident would be trying to get him out of his home, because he wouldn't want to leave all his computers and technology. "You can't bring it with you." (Group 4)

Importantly, these conversations circled back to the need for training support to community, health, and disability support providers and the requirement for them to have plans tailored to the support needs of the people they provide services with (see Learning #1). The call to action for service providers was to move beyond "*tick box"* planning to person-centred and meaningful preparedness in partnership with the people they support.

#### Learning 5: Registers vs. Community asset mapping

What started with a conversation about registers for people who are "*vulnerable"* and need support in emergencies quickly turned to a discussion about community asset mapping as a more effective tool for ensuring the safety and well-being of people with disability in emergencies. This discussion proved fruitful as participants identified a number of challenges and potential ways to overcome them.

So I think what I've learned today is we have a lot of people with a lot of experience in the room and with the answers that I've been provided through this, I really think that the biggest thing that came out of it was something that I didn't necessarily agree upon when I was in the situation, but it's probably that it takes a whole community to help in these situations to understand what's required. (Group 1).

The stuff I've learned today is that I think there needs to be a bit more coordination around local disability service providers about what assets each service has. And the example I have was from one fellow. They had a whole fleet of modified vehicles and other services didn't access that. So it's stuff like that that maybe can be mapped out better moving forward. (Group 1)

I'm thinking more. If you are a key contact social, [name of participant], you're a key contact to these people. How do we map that level of contact? So, five people, ten people, how do you do that? [name of participant] is a contact into doing that. Plus communities. (Group 1).

We haven't heard from Nanny in a while, someone go over and check in on them." But who were their services? Who did they engage? Where their parents were going to be? So if something was to happen and say a company like mine was to step in and go, "Our person needs help, let's start our process." (Group 2) And so therefore it's forgotten about. We go down this street, we know that that's an aged care facility, we know that that's an over 50-year-old retirement village, but we don't know where our disability services are. (Group 2)

So as an on-call firefighter, when it's flagged to us that there is a group home or people with disabilities living somewhere, they can call us and we can go do a site assessment and talk to these people and find out what their needs are in case of a fire. But in saying that, I don't know if that's actually shared inter-agency. So I don't know if the SES is getting that, the RFS is getting that [information] (Group 2)

Community Resilience Teams (CRT) (Red Cross street level teams), Community Resilience Networks (CRN) (Council-level interagency networks focused on resilience) and Community Resilience Officers (CRO) were all considered as part of the discussion about how to effectively map the network of community organisations and agencies providing disability services and supports in the local government area. During these discussions, participants recognised that these teams and networks were familiar only to those with roles in government and emergency services. The principle that was raised about mapping was that it should extend to services and their networks and include assets. Other participants included the need to map training for these groups in emergency and disaster risk reduction.

You take that knowledge and the resources and those networks to the next thing, so maybe part of the mapping is also mapping these trainings and [inaudible] and where they go to, and how do we keep engaged with these people. (Group 2).

And it starts within the community and is now the community resilience teams because they know who's up the hills in a wheelchair that needs to be able to get out first if a disaster strikes. It's starts in the community, and that's what we're advocating. (Group 2)

Again, it's just reinforcing that message that it has to be neighbourhood and it has to be local groups that know what's going on in a community and can provide that person the same level of support in whatever form- Speaker 4: Neighbourhood care. Speaker 6: So be trained up, yeah. Speaker 3: Trained up. But then there's a community, like information has to filter up and it has to filter down. (Group 3)

It also came up about aged care home network, apparently there's a network where all the aged care facilities, if there's a disaster, they all communicate with each other about how many beds they may have available to be able to assist people who need a bed, especially the elderly and the disabled people in the community. And it has even gone as far as, I think they've registered with each other how many spare beds, that they're not using them, they're in storage. And they could potentially set them up in an activities room or something like that if there was a real emergency. I think from my chats individually, most of the services are pretty resourceful, operating in their own space, but when you break it down here, I think there needs to be a collective collaboration between service providers around what resources are available so they can share that. And the example was, access to modified vehicles, to help transport around communities. So, I think there's opportunity there for that to be mapped out better moving forward. (Large Group)

To support this mapping idea, one participant shared what they know about Service Connect.

The national emergency management agency, the Australian government has put a website together, and your local NEMA rep might be a good asset for you to think about this. It's called service connect, I believe, Australian government, and if you Google service connect, you can put your post code in and the type of service you're looking for, and see who's in your community. So, there's already some ways to map and access that data. And my understanding is your local NEMA person here, who's working in a resilience and recovery role, can take more information and put it into that database, and input it into the system so that it's there. So, that might be one way on our journey to help coordinate information across Australia. (Large Group)

## **KEY MESSAGES**

This facilitated DIEP forum brought multiple stakeholders together to learn about:

- ways we can work together to ensure people with disability are aware, safe, and prepared for emergencies triggered by natural hazards and other emergencies (e.g., house fire, pandemic).
- actions we can take to make sure people and their support needs are at the centre of emergency management planning.
- barriers and enablers to the inclusion of people with disability before, during, and after disasters.

#### Summary

- 1. On the whole, people reported being under-prepared for emergencies. Participants expressed a strong appetite to use recent disaster experiences and leverage the interest (e.g., from the forum) that people have to learn about and use this momentum to support people to make an emergency plan. At present, planning happens after disasters strike.
- 2. Access to communication in formats that everyone can understand and use was identified as a priority topic. This was

*influenced by the relatively large number of people from the D/deaf community at this forum. They shared specific examples of barriers and ways to overcome them.* 

- 3. If people with disability are to evacuate to safety, they need accessible places to evacuate to. While recognising that hospitals are not an evacuation centre, participants identified that people with disability have limited choices during evacuation.
- 4. Participants identified the need to incorporate diverse forms of support into disaster risk reduction initiatives that are inclusive of a wide range of people and their support needs.
- 5. Participants identified community assets and asset mapping as a viable alternative to individual risk registers.



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