

DISABILITY INCLUSIVE EMERGENCY PLANNING (DIEP)FORUM

HAWKESBURY DIEP FORUM



Citation:

Villeneuve, M., & Crawford, T. (2023). *Disability Inclusive Emergency Planning Forum: HAWKESBURY*. Centre for Disability Research and Policy, The University of Sydney, NSW, 2006



THE UNIVERSITY OF
SYDNEY

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Since the flood in March, there's been very much an active WhatsApp presence and that capability mapping of knowing for example, where people in the community are that are deaf, for example. (Group 1)

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 HAWKESBURY CITY COUNCIL AND PEPPERCORN SERVICES IN PARTNERSHIP WITH THE UNIVERSITY OF SYDNEY

Date: 16 MARCH, 2023

Location: Hawkesbury Leisure and Learning 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 disability¹.

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 times more likely to die in a disaster than the general population².
- experience higher risk of injury and loss of property³.
- experience greater difficulty with evacuation⁴ and sheltering⁵.
- require more intensive health and social services during and after disasters⁶.

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

¹ 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.

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

² 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.

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

⁴ Malpass, A., West, C., Quail, 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.

⁵ 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

⁶ 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 risk⁷.

INTERNATIONAL POLICY

Disability became prominent in the disaster policy agenda after 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 preparedness and disaster risk reduction programs and services.

Built on the foundations of the UNCRPD, the Sendai Framework for Disaster Risk Reduction (SFDRR) (2015-2030) 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)⁸.

People-centred approaches place people and their needs at the centre of responsive disaster management and position them as the main agents of development and change⁹.

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. Australia’s national strategy, frameworks, and principles guide how

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

⁸ 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. <https://link.springer.com/article/10.1007/s13753-015-0051-8>

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

emergency response is scaled. It is underpinned by partnerships that require government, emergency services, NGOs, community groups, emergency management and volunteer organisations to work together¹⁰.

Australia's National Strategy for Disaster Resilience and National Disaster Risk Reduction Framework 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.

Research in Australia, led by the University of Sydney, 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.

Australia's Disability Strategy 2021-31 includes, for the first time, targeted action on disability-inclusive emergency management 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 well-being 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

¹⁰ <https://knowledge.aidr.org.au/resources/handbook-australian-emergency-management-arrangements/>

emergency planning and disaster recovery require collaborative effort!

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 well-being 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 NDIS Quality and Safeguarding Commission signed a legislative amendment 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 NDIS Practice Standards 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 Aged Care Act 1997.

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 [Collaborating4Inclusion](#) 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^{11,12}. 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/pcep-short-course/>

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

¹¹ 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>

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

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: www.collaborating4inclusion.org

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 volunteers¹³, 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)¹⁴.

Community engagement is a critical component of emergency management practice which helps to build community resilience to disasters¹⁵. 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 management¹⁶.*

Local Council links to community groups are a fundamental vehicle for the delivery of measures to increase inclusion for people with

¹³ 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>

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

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

¹⁶ 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>

disability and the services that support them and build whole-of-community resilience before, during and after disaster.

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 government¹⁷. 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 well-being outcomes for people with disability and their carers by representing their perspective in disaster policy, planning and interventions.

¹⁷ 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. <https://www.tandfonline.com/doi/epdf/10.1080/03003930.2018.1541795>

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 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 centres¹⁸.

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.

¹⁸ Villeneuve, M., Abson, L., Pertiwi, P., 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*.
<https://doi.org/10.1016/j.ijdrr.2020.101979>

METHODOLOGY

Design

We adapted the **Structured Interview Matrix** (SIM) methodology¹⁹ 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.

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

¹⁹ O'Sullivan, T.L., Corneil, W., Kuziemy, 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

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.



1:1 Interviews
conducted by
participating
stakeholders

Small group
deliberation

A facilitated
plenary
discussion with
all stakeholders

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? Probe: 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 you taken to prepare for emergencies? Probe: 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? Probe: 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? Probe: 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 many 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) framework²⁰ 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 connectedness²¹. 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 emergencies²². 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 community connections and the opportunity to renew or deepen existing relationships²³. 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.

²⁰ <https://collaborating4inclusion.org/home/pcep/>

²¹ 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>

²² <https://collaborating4inclusion.org/disability-inclusive-disaster-risk-reduction/p-cep-resource-package/>

²³ O'Sullivan, T.L., Corneil, W., Kuziemy, 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. <https://doi/10.1002/sres.2250>

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 analysis²⁴ 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 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.

²⁴ 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>



But if people like me knew that, that we're dealing with people with disabilities every single day, I would be able to help them prepare their plans. So, we need a lot more training on it because if anything happens to them, they will come to us first. We do welfare checks but we need to know other things. So if anything, it's maybe more frustrating around there now. There's not much access to people living with a disability, and that people like us should be able to help a lot more. (Group 2)

***DIEP Participants**

STAKEHOLDER GROUP	NUMBER OF PARTICIPANTS
Person with Disability or Carer	9
Disability Service	7

STAKEHOLDER GROUP	NUMBER OF PARTICIPANTS
Community Service	10
Health Service	4
Organisation or Advocate representing people with disability or carers	1
Government	9
Emergency Service	4
TOTAL	44

*Several people in attendance held more than one role.

FINDINGS

What did we learn together?

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

Key Learnings in Hawkesbury

- 1.** Gaps & Assets
- 2.** Personal Emergency Preparedness
- 3.** Organisational Emergency Preparedness
- 4.** Need for Training

DISCUSSION OF FINDINGS

Learning 1: Gaps & Assets

The participants at this DIEP forum had recent experience of disasters including multiple flood events/evacuations, and COVID-19, noting that, "everyone has been impacted" in some way, "directly or indirectly". As a result, participants were well positioned to identify persistent gaps as well as local assets that support resilience building for the whole community.

Communication was identified as both a gap and an asset that could be better mobilized in the Hawkesbury. Gaps for people with disability included information access. Participants spoke about the importance of "easy to understand resources", "access to Auslan for disaster information", and the need for "tailored communication" to support people with diverse access and support needs, including recognition that not all people will have access to computers and phones or be "digitally literate".

There was increased communication, increased online presence. However, with that online presence, it wasn't always accessible to everyone. So, some people don't have access to phones, computers, to internet. So that was a barrier there... Also, the fact that a lot of our clients are really low socioeconomic status so they don't necessarily have a mobile phone or a computer or access to either or any knowledge of how to use them.

(Group 1)

One of the things that was also evident was people with disability is...access and the biggest key point was communication. So not being cut off from communication. Communication's really, really important and vital. So in the event of a disaster happening, having communication open but available as well. So that was a key thing that stood out for me because that's what they really rely on is the communication. (Group 1)

The other thing that came up was all of the website information, some of these websites are really good. They were saying they don't think that they're website is setup where somebody can actually view what's being said. They can read it, but they can't hear it. Or they may not be able to read it, but they can hear it, what's being said. (Group 3)

Participants also spoke about the ways that communication was or could be mobilised. Discussions emphasized community-led actions, leveraging

community connectedness, and involving neighbours in pre-planning together.

...the need for community hubs with resources, having centralised locations, and the communication of where those locations are. (Group 4)

Since the flood in March, there's been very much an active WhatsApp presence and that capability mapping of knowing for example, where people in the community are that are deaf, for example. (Group 1)

It just became very evident to have these kind of practice exercises in community, community led. Beforehand and get all the neighbours involved to agree on those rules of communication or engagement. So what's exactly going to happen in that situation with our vulnerable members of the community. (Group 1)

I spoke to a range of people so... I think the most important thing is having easy to understand resources, in single easy to understand language and accessible to different people, I think that's the biggest one just simplicity. (Group 3)

The person is also a team leader of other people with vision impairments or who are blind. And so being connected with SES and police means that she's a communication hub for those people in her team. So it's vitally important to have, as she said, and as I believe, consistent communication and information, not inconsistent information and inconsistent communication, and accessibility of information also, which means I think technology has a big role to play there when we can... and also considering non-verbal communication as well. So making sure if someone needs a communication board, for example, that there's, that's built into things. (Group 4)

Also, really valuable to be in contact with your neighbours so that you are sharing information with each other and aware of what's happening. (Group 2)

Participants also spoke about the challenge of **knowing who has a disability and what supports they need.**

How do we find these people that are high-needs? How do I find them before I've taken them out of their house, before it's too late? (Group 2)

Like SES have a gap, RFS have a gap, the emergency officer has a gap because they don't know where these people live, and it's quite hard to map these people out unless there's a lot of people onboard. (Group 2)

They don't necessarily know where people with disability are, because that's data held at the federal level and they're local. (Group 3)

There was discussion around gaps in plans, the fact that emergency services and other agencies didn't necessarily know where people with a, I don't like to use the word disability, so I use the word that have challenges in their life, are located. (Large Group)

At the same time, **community-based services recognized their own role as key to overcoming the challenge.** Service providers from the community, health and disability sector were viewed as a key local asset to support the identification of people and their support needs as well as engaging in pre-planning with them to enable tailored preparedness support.

From my point of view and this is talking about the interest of it is questioning some, one of the things we really rely heavily on was touched on before was we can't possibly keep track of all the people with different needs. Because that way we can do it so if they try and build those relationships with all the different community organisations, and know who to talk to, to get the right information about the people that we're dealing with. We've got pretty good relationships with and know where to go to, to get information. (Group 3)

Service providers were also well positioned to "reach out" to people who may need support to pre-plan, respond, or to access recovery supports after a disaster.

But if people like me knew that, that we're dealing with people with disabilities every single day, I would be able to help them prepare their plans. So, we need a lot more training on it because if anything happens to them, they will come to us first. We do welfare checks but we need to know other things. So if anything, it's maybe more frustrating around there now. There's not much access to people living with a disability, and that people like us should be able to help a lot more. (Group 2)

And the only other one thing I would say is I think mental health, I work with complex mental health, they don't always have a voice and they will be avoidant and they will withdraw. And when there's no voice and people

aren't present, we need to be their voice and we need to reach out. So we can't assume people are going to seek help. So we need to be their support. (Group 4)

Some service providers acknowledged the current situation that, "we don't really even talk about any of this stuff with our clients."

And I work for the NDIS, I work under the NDIS for [name of organization] as a partner. And we don't have, we don't have a screening where it says, "What's your prepared plan? What resources do you need? Who's your emergency services? Where's your medication from?" Because if that was the case, people like us could work with emergency services. SES, RFS would be like, "Okay, this one's like literally on life support. This one needs this many resources, needs this many resources." So people that know, know. People that don't know, they need something. So I think people like us, at our review meetings with people with disability, we could probably prompt this conversation and be like, what is your preparation? (Group 2)

Learning 2: Personal Emergency Preparedness

Participants described personal emergency preparedness as tailoring emergency plans to individual risk and support situations, having contingencies in place, with the outcome being that people can "look after themselves". Preparedness was identified as a critical community capacity development need. Emergency personnel spoke about the need for their sector to shift the conversation from telling people how to prepare to listening and learning with people to provide just in time information that will help them to take actions that increase their preparedness level.

So, it's not up to me to tell them what they need to do. It's up for us to listen to them, to how we can better help them. (Group 2)

Participants recognised that increased "self-sufficiency" is good for everyone in the community because it frees up resources for emergency services to support people who really need their help.

Yes. So therefore, the ones that we actually have to attend to, really do need help. And those that have been empowered to look after themselves, and there's a lot of people out there that have challenges in life, whether they're able-bodied or they're not, that have taken control of what they do and make those right decisions to look at a catastrophic fire day. Whilst

there's no fires in the area, they will leave their home and go to a safer place. We need to encourage that with everyone. (Group 2)

And then we discussed the other reason is that how about we throw that on its head and let's have a look about empowering everyone. So not only people with challenges in life, because I think able-bodied people have challenges in their lives as well. But how about we look at empowering people to develop their own plan to help themselves make a better and safer decision for themselves to enact stuff during an emergency, to ensure that they're safe so that the emergency services, whether they be ambulance, fire, SES, whoever is there, then has the arms and legs to deal with the people that actually really need help. (Large Group)

There were participants in the room who provide lived experience support to others with disability to help them develop emergency plans and contingencies. They have expertise that can be leveraged to support people to pre-plan.

So, a lot of the clients I work with, particularly with executive function difficulties, they're so reliant upon digital times, calendars, their entire organisation and medication regime structure is almost digital dependent and always... Digital is great, but you need a physical backup. (Group 4)

Participants also shared information about the Rural Fire Service program that can "assist infirm for elderly and disabled to manage their properties during the disasters".

The need for contingencies was a common theme as participants explained how common it was for people to be separated from their support services during recent disaster events.

People, there was a massive decline in mental health, huge decline in mental health with the floods, COVID-19, especially. Especially for those that have got a disability. They were very socially isolated. They had no access to their usual supports or family because, A, they were scared to have people come into the home, which is perfectly understandable. But then they also didn't have access to the supports they required. (Group 1)

Because you can't get a GP, they may be affected by the floods, only telephone service provider at that time, and they don't know how to access Tele house service, it's all too stressful. For people who are carers, so that respect feedback.(Group 3)

A lot of their supports were actually cut off when we had the floods. So I know with us a lot of our participants were stuck on the other side of the bridge and their support workers were on this side of the bridge. So what do we do? They were literally stuck with no support calling us in a panic going, "find someone for us," which we had to in a panic. What else did I have here?

How might we build any points of redundancy, especially for those of us who may have a disability that affects our need to communicate or requires that we use methods of, especially digitally dependent assisted technology. Whenever we run out of power for our phones or our generators fail, how do we go about advocating for our needs? (Large Group)

Key challenges that participants identified was that people generally didn't have sufficient plans in place. They "*didn't know where they would evacuate to*". People lacked specific details, including what would "*trigger them to enact the plan*". Participants spoke about the need for people to "*practice drills*" so that they could work out the problems with their plan and make improvements. They also talked about involving their friends, families, neighbours, and support workers in practicing their plans. Participants reported that the consequence of "*unpreparedness*" was high levels of stress and overreliance on "*already stretched emergency services*". The benefit of preparing with others and practicing plans was reportedly that the plan would have "*a better level of detail*". Additional worry was expressed at this forum as participants learned that those in formal roles where their job is to prepare others were often unprepared personally.

Then they work in an area that puts together emergency plans for others, so we had a discussion around what they should do for themselves to better prepare themselves. (Group 2)

If you're vision impaired and you don't have access to that stuff then that becomes a bit of a problem. I guess somewhere in there, there needs to be training and awareness of the hazard that you're living in and what you need to do. (Group 3)

a well organised plan is a must to have with all your meds and your contacts on it and your information. (Group 4)

He's had discussions around the plan, but nothing is solid yet and there's nothing in detail. We had discussions around that person getting better assistance, and where they could get better assistance. (Group 2)

Learning 3: Organisational Emergency Preparedness

Participants reported getting better at preparedness because of the practice they have had reacting to recent emergencies, not because they have pre-planned and practiced their organisational and service continuity methods.

I spoke to a few different people today, all impacted by multiple different types of disasters. There's been a few different things that they discussed. There's been, from one of them, there's been a lot of improvement for their organisations and that came from multiple people. So it could be in a way of getting, they've got more resources, more planning, more structure in place. So even with these events that have happened, if each one that does happen, they have gotten better with how they react to it and how they get involved, how it's initiated for them to take action. In saying that, it also helps with say like extra fire trucks, extra staffing, things like that as well. (Group 1)

As an organisation, we do not really have a plan, I'll be quite honest. We're slowly learning. Every time there is a flood, we are getting somewhat better, and having half of a plan, we will say. Whether it's we implement new resources, extra resources, extra temporary annual sessions in those areas. Unfortunately, we also rely on the community. We rely on RFS, SES, all of those volunteer services. But we've also got to understand that they have their own business as usual, as well. (Group 2)

There were a few organisations who have made greater strides with organisational emergency preparedness.

So some people worked for disability organisations. Some people, they do regular drills. They have a section too. Some people have behavioural problems that are under that organisation, so they do regular drills, and they say, it really helps with the planning and the preparation, so I'm right. (Group 2)

Organisations that provide services and supports to people with disability, chronic health conditions, mental health needs, etc. were stretched during the recent disaster events. This impact was compounded as a result of COVID-19 restrictions. Staff of these organisations spoke about having a “skeleton staff” to deliver the same number of services and supports. They were delivering supports with a “shortage of supplies”. “Fatigue and burnout” was a common phrase shared by participants at this forum. At the same time that “everything went online”, staff recognised that this was not always the best mode of delivery for some of their clients/participants.

Areas where organisations have stepped up is in understanding and responding to the needs of the people they support.

One of the main points they made was ensuring they have up-to-date information on clients. So contacts and emergency contacts, requirements or special requirements they may have, due to their disabilities. What they are able to do for themselves in an emergency situation and anything extra they need help with. And also having effective communication with management. (Group 2)

For the organisation, he had a plan for how to handle, the organisation works with neuro-diversity. So how to handle outbursts, meltdowns, be able to deescalate situations, using emotion regulation skills. Dealing with angry, aggressive people or anxious people. And having a conflict, ability to be able to deal with conflict resolution. Yeah, introducing regulation and conflict resolution. (Group 2)

And they'd have morning meetings with participants and staff to discuss the day. They'd discuss weather, they'd discuss if there were any emergencies pending possibly and what to do and how to evacuate. (Group 2)

Learning 4: Need for Training

Outside of talking about preparedness and self-reliance, training was the most common thing discussed at this forum. Forum participants talked

about the "need for training" on multiple levels.

- Training for individuals to "tailor preparedness" to their support needs and situation.
- Training for service providers on "disaster risks" and "organizational preparedness".
- Training for service providers on enabling personal emergency preparedness with the people they support.
- Training for emergency personnel on disability awareness.
- "Collaboration training" for everyone that helps "to clarify individual and shared roles and responsibilities".

Everyone's learning but we are improving and a lot of people have said that they like workshops like this because it shows them where there are potential gaps where they can improve and they can keep improving, improving, improving. That's the main thing that I come across. (Group 1)

Then more from the more community organisation perspective it was also training, training for themselves. Clarity on roles and responsibilities between community organisations and emergency sector responders. Trying to build those relationships so that they're in place, they're strong, and everything is clear before an emergency hits. I think those are the biggest take away. (Group 3)

Deaf people in the Hawkesbury region have very limited resources or information. We don't have any workshops tailored for us. (Group 2)

...there needs to be training and awareness of the hazard that you're living in and what you need to do. (Group 3)

There was feedback though and that was if training was provided for people with autism ADHD complex needs to be able to advocate, and to be able to find the information for themselves. If assistance were provided that would be good, so that they could manage their own complex needs during disasters independently. (Group 3)

An overwhelming message coming from this forum was a readiness and willingness for multiple stakeholders to work together more effectively and to learn the skills required to take on roles that contribute to tailoring preparedness support in partnership with people with disability and the services that support them - for more effective disaster response. Key council partner, Peppercorn Community Services, was involved in hosting the DIEP forum. So, at the close of the large group plenary, they took the

opportunity to share information about how individuals can get support to make a Person-Centred Emergency Preparedness (P-CEP) plan. Several participants with disability started making appointments with Peppercorn's P-CEP facilitators who were ready and able to help them make a personal emergency preparedness plan. This is a novel service led by Peppercorn with support from Hawkesbury Council. It provides an opportunity to extend personal preparedness to everyone in the community, starting with those at greatest risk. More can be found here:

<https://peppercorn.org.au/person-centred-emergency-preparedness/>

Participants were also made aware of the opportunity to join the P-CEP Certificate Course offered through The University of Sydney Centre for Continuing Education. This is the same program that Peppercorn's P-CEP Facilitators have taken. Individuals, service providers, government and emergency personnel were invited to join in this interdisciplinary learning opportunity. More information can be found here:

<https://collaborating4inclusion.org/leave-nobody-behind/pcep-short-course/>

Hawkesbury Council also sent a follow up email to share these opportunities and other resources with all DIEP participants who were encouraged to share them through their networks.

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

Hawkesbury participants at this DIEP forum know what needs to happen and are ready to take the challenging steps of putting that awareness into collaborative action. However, disaster fatigue is a very real risk to this community's sustained engagement. Local

Council and their interagency partners can support and sustain this activated community by continuing the conversation with their interagency groups including their disability/access & inclusion committees, community services interagency networks, and local emergency services. Council is further supported in their efforts by a strong program of flood risk awareness that has been initiated via the Hawkesbury-Nepean Flood Valley Directorate and projects that have focused on “communities of concern”. These foundations will go a long way to supporting and sustaining community-led preparedness actions and cross sector collaboration.

Participants at this forum recognized local assets as enablers of community-led and cross-sector collaborative action so that nobody is left behind in disasters. The local government and their partners are in an optimal position to leverage the interest and willingness of their community to share responsibility for disability inclusive disaster risk reduction in the Hawkesbury.



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