DISABILITY INCLUSIVE EMERGENCY PLANNING

(DIEP)FORUM

SHOALHAVEN DIEP FORUM



Citation:

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I should say the main thing for organisations, and it just occurred to me, so as a paid body, one of the main outcomes for our project is to try to find ways... to include people with disabilities in planning at a local level (Group 3).

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 ST VINCENT DE PAUL SOCIETY AND SHOALHAVEN CITY COUNCIL IN PARTNERSHIP WITH THE UNIVERSITY OF SYDNEY

Date:	16 NOVEMBER, 2022

Location: Dunn Lewis 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 time sore 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.

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.

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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.

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., 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.

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 <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 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)⁸.

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 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.

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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

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 together¹⁰.

Australia's <u>National Strategy for Disaster Resilience</u> and <u>National 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.

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.

<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

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 <u>NDIS Quality and Safeguarding Commission signed a legislative 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 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 <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^{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

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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 &}lt;a href="https://knowledge.aidr.org.au/resources/australian-warning-system/">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-ofcommunity 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.

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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.

METHODOLOGY

Design

We adapted the **Structured Interview Matrix** (SIM) methodology¹⁹ as an innovative approach to disability-inclusive community engagement with multiple stakeholders.

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¹⁸ 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. https://doi.org/10.1016/j.ijdrr.2020.101979

¹⁹ 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 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 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

inclusive engagement. Systems Research and Behavioural Science, DOI: 10.1002/sres.2250

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? <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? Probe: 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) 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,

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

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.

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.

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., 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. https://doi/10.1002/sres.2250

- 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.

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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



The common themes were that all these disasters have a lot of clearly negative effects on people, and these were the common ones that came out, that it increases fear and anxiety for people, obviously. It triggers a lot of other traumas that service providers wouldn't necessarily see. That added fear, that added stress exacerbates underlying fears for people, and it comes out in their interaction, but they might not necessarily have seen it before. They noticed a very big increase of stress in the informal carers and the institutions for example, government programmes that really financially support, materially support, service support informal carers (Group 1).

DIEP Participants

STAKEHOLDER GROUP	NUMBER OF PARTICIPANTS
Person with Disability or Carer	0
Disability Service	9

STAKEHOLDER GROUP	NUMBER OF PARTICIPANTS
Community Service	4
Health Service	1
Organisation or Advocate representing people with disability or carers	0
Government	2
Emergency Service	0
TOTAL	16

FINDINGS

What did we learn together?

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

Key Learnings in Shoalhaven

- Impact of disasters
 Preparedness activities
 Local community assets as emergency supports
- **4.** Communication

DISCUSSION OF FINDINGS

Learning 1: Impact of disaters

The compounding impact of disasters from fire, floods and COVID-19 over the last three years was discussed at length, with the cumulative effect resulting in increased anxiety expressed by individuals and employees of support organisations. The disasters had the effect of increasing dependence on support organisations, increased time pressure because of extra work, but also had positive outcomes.

The common themes were that all these disasters have a lot of clearly negative effects on people, and these were the common ones that came out, that it increases fear and anxiety for people, obviously. It triggers a lot of other traumas that service providers wouldn't necessarily see. That added fear, that added stress exacerbates underlying fears for people, and it comes out in their interaction, but they might not necessarily have seen it before. They noticed a very big increase of stress in the informal carers and the institutions for example, government programmes that really financially support, materially support, service support informal carers (Group 1).

People were noticing that the stress of COVID, stress of bush fires, the relationship was like this. It just got very, very intense, but then that didn't die down when things started to stabilise. The intensity of the relationship maintained, so sort of entrenched their dependence on a service provider, which is linked to trauma and that kind of stuff, which makes sense... (Group 1)

...these disasters really rushed timeframes for organisations as well, general chaos, general need to get things done. But then when these other organisations come in and impose other timeframes on things to get people housed or get them enrolled into services, things like that. It like, here is a short timeframe. Make it happen now. So it just adds to general stress. There was a lot of negative stuff, but one of the things that was nice positive to come out of it was, through COVID in particular, [inaudible 00:03:55] having to speak with people remotely by the telephone, there

was a much more intimate and frequent interaction with people [inaudible 00:04:04] often speaking to people, not just the client, but sometimes their family members as well, so you get this fuller picture of that person, which helps you help them (Group 1).

Isolation, particularly in the context of COVID-19 lockdowns was discussed, however there were unexpected benefits such as adaptation, support that grew organically to mitigate the isolation, and the creation of meaningful employment.

...isolation from the support workers and organisational staff and clients was a big issue which exacerbated any existing mental health issues or developed anxiety and fear as well across all of the... like COVID, floods and the fires. From an organisational level, there was a lot of chaos and panic throughout a lot of the disasters where these plans were not in place. They were very disorganised and had to respond quickly because they had to continue to meet the needs of their clients. Many [inaudible 00:06:28] I would say it is another theme. Organisations were very resilient in responding quickly through that chaos and were very innovative in how they maintained the support. It's encouraging to see, so although they saw it as a negative, it's a big impact. Yeah, there was a lot of positive in that (Group 1).

...one of the challenges for her was they had all these kids in crisis accommodation from DCJ, and they couldn't take them to the evacuation centres because some of them were violent, and they were just unpredictable. So they really found that really hard, but the thing that [inaudible 00:18:43] told me about is they adapted really quickly and they organised to do a risk assessment of the workers' places. So the people that worked there, they actually took them to their own home, but they had to do an assessment first, so they did that really quickly. So they did that, so that adaptability stuff (Group 1).

...support workers creating their own community to support each other. They felt that they had experienced a lot of stress [inaudible 00:07:49] mental health issues, but in the same time, as a positive, yeah, they banded together and created their own support network amongst themselves, knowing that they'd understand what each other are going through in that space. So again, sort of a positive, I guess. This particular one was from a person that works in recovery, so she had a completely different tangent, saying that the disasters had affected her by giving her employment, and a job where she feels like what she's doing is really valuable and rewarding (Group 1).

It was noted that the pandemic is ongoing and that this has hampered recovery, partly due to COVID-19 having different impacts to fire and floods which has caused a re-evaluation of places that can be considered safe.

Just touching on COVID, the fact that it continues to impact, it's not over, so just talked about one organization's having current outbreaks at the moment. That's impacting participants and staff, so it's an ongoing impact. It's not that it's ended, and it's having a really negative impact on staff, continuity, I feel like...one point when I was talking to ** made is that the COVID was harder to recover from than other emergencies due to the reaches COVID has, whereas a flood or a fire is a tangible asset that's impacted. The impacts of COVID, whether it's hospital, support, supply chains, seems to, in his opinion, have a... it's harder to recover from because there's many more factors involved in the COVID pandemic, which creates... There's a lot of social isolation that came through, and also COVID hasn't helped the fragmentation within the community off the back of the bush fires. Like the bush fires, there's a lot of fragmentation, but rather than allowing for that recovery process, that couldn't happen because COVID was there, so the natural healing from bush fire, there wasn't an opportunity (Group 1).

And COVID's particularly shown how vulnerable communities can be and how many isolated people we have in the communities. Isolation continues to be a theme, and just how, as the individual... all the different disasters that we've all experienced over the last three years have changed, so have how they affect people. We're affected differently by COVID compared to how we were affected by fires. And so there's a need... people have had to adapt typically, and service providers and government needs to keep up with that as well. I quess just as a last point around COVID, some people who have special needs, so places that were in the past considered safe, the hospital, became very unsafe places, and high risk... And they had to re-evaluate what new safe places could be for them and how they... had to re-evaluate their whole interaction with people, basically, to keep themselves safe, and that's something they hadn't experienced before, so that was a challenge. So it was kind of a confronting thing to think about social connection in a... like it's a risk (*Group* 1).

Learning 2: Preparedness activities

Disaster preparedness was a prominent theme that was discussed, particularly from the perspective of disability support organisations and local council. Some organisations were prepared if evacuation was required, while others were more reactive.

Three out of four said they had no plan but said that the P-CEP would be a good plan to have (Group 2).

I was working in a group homes in the area, but we would get warning, so we would be prepared if we had to go, but I think we only went from one group home to the other. But I don't think we had a proper clue (Group 2).

- Speaker 4: I don't know. I just think the way everything happened, it was kind of like everyone was reactive.... It wasn't proactive. There wasn't something in place.
- Speaker 2: Yeah. But there's things sort of like you all have to be evacuated to evacuation points... People with certain disabilities, that might not work for them.
- Speaker 4: No, that's it. Exactly. That's right. Especially in a group home. You've got all different ranges so that make it hard (Group 2).

I should say the main thing for organisations, and it just occurred to me, so as a paid body, one of the main outcomes for our project is to try to find ways... to include people with disabilities in planning at a local level (Group 3).

From an organisational and council perspective, preparedness requires providing education about disaster preparedness, not only to staff but also to the community at large.

And I think to staff training like in our situation training our staff have them react in an emergency if they ever get caught (Group 3).

Yeah, it's the staff training... We have to go through accident counsellor, we have to go through disaster recovery training, what does that look like, how do we deal with trauma? How do we ask the questions? If someone presents and they're noticing different body language and different things like that, how to deal with yourself and take self care as well as dealing with someone who experienced trauma or in an emergency evacuation, how do you relate that? How do you think logically? How do you ... So education? Knowing the resources that are available. And using them. Knowing the structure of the disaster or emergency, so we have learned since the fires until now that there has to be a proper structure that's stating here, here, here (Group 3).

Community engagement too. Educating the communities on a community level, so whether it be by council, whether it be by a service provider, the government, whatever it is, there's community engagement in education in regards to making contact and this is a first thing to do. When would you hear about it, where would you, or how do you get that information? (Group 3).

Part of being prepared included disaster scenario drills and practicing evacuation or sheltering in place.

Someone highlighted just how important fire drills and evacuation drills are... Yeah, that's right and if you're doing them regularly then, if you think it's going to be easier when it actually happens. If you do it once every 6 months, you won't remember, let alone the clients (Group 2).

But we do fire drills all the time, evacuation of the buildings. We lead 39 kids out. I think it's four and a half minutes to get all the children out... And we put the babies in the cots. We've got cots on wheels, and we've got an evacuation bag with all the emergency contacts, a charged mobile phone, asthma puffers, Panadol. So we practise that so often, and the kids, they're all fine. It's really good (Group 4).

Preparing included having an evacuation centre but this had to carefully considered, as the recent experience of bush fires attested, and with accessibility for people with disability taken into account:

Here's a fact for you, they don't necessarily create an evacuation centre unless ... there has to be certain circumstances. There was a real push in Conjola to get the evacuation point down at the lake, but the evacuation points become magnets, in a disaster, in actually potentially creates a bigger disaster (Group 3).

And I think even with basic evacuation places, you have the clubs or wherever, a lot of them don't have accessible bathrooms or spaces. They need to look at that... They have the mops and buckets in there (Group 3).

Some individual preparedness actions were discussed, such as backing up important documents and keeping them in a fire-proof safe, and having a 'go bag' which included information about their health professionals. Some had not formalized their preparations but had thought about what they would do.

Someone bought a fireproof box to put all their personal things inside. Documents and things like that and... all their photos or insurance documents, birth certificates, things like that, that can't be replaced, have been scanned onto a USB... And that's an been given to other family members that don't live with them, so that if they lost it or they forgot to grab it out of the home and the home caught fire, at least somebody else in the family that's not being affected by the fire or an emergency, still have those copies (Group 2).

Speaker 4: They have a pack with their contacts, what their needs are.

Speaker 3: All their medication.

Speaker 5: Whom their chemist is... Whom their doctor is?

Speaker 4: In a pack or stored somewhere (Group 3).

...what do you put in place for people with disabilities when they go to places like evacuation centres and that. How the evacuation centres know how to support or get in contact with their support or their families not necessarily equipment but you know how your medication gets shipped off to the hospital just something in place that has their contacts or their support... Just describe the verbal what they might need to communicate

and who to contact to hook that communication. And who to contact to have that person come and support them in the evacuation centre if they've got no outside support (Group 3).

...that people that did have a plan hadn't necessarily communicated that to their significant others or their networks (Group 2).

Learning 3: Local community assets as emergency supports

Participants identified local assets that could be mobilized before, during or after an emergency. These are grouped into formal supports and services, and informal support people. Formal supports including services based in the area such as council and community organisations were identified as community assets who rise to the challenge during disaster events due to their knowledge and networks, or capacity to support whole of communities.

Shoalhaven Council has an emergency triage intake. Someone you can contact there, and then they, I guess, give you a category as to what sort of services you are eligible for (Group 4).

Coastal Connect, an independent organisation, and it provides all supports in the community to support staff. Sorry, to support people with a disability in evacuation or recovery centres. Support staff could potentially go to those recovery centres, and provide that service, because that's a real gap at the moment (Group 4).

Support coordinators and workers could provide support... Real estate agents could provide support, in terms of providing emergency accommodation, for providing referrals to emergency accommodation... Red Cross, Vinnie's, Anglicare, and other similar organisations. For people in group homes, evacuation centres don't work. There's too many issues there, so another possibility is to have a group home evacuation network, where people in group homes affected, are relocated to safer areas, to another group home environment where all the support resources are already there (Group 4).

...church groups... And then service clubs. So, for instance, the Lions, Rotary, Probus... And also, depending on the particular area, we have a squadron at Albatross who have chosen us as their charity, so we could reach out to those to support us as well.

The Hub at the Civic Centre, someone said was amazing, because all the services are in one place, instead of reaching out separately to all the services (Group 4).

...a pub, because pubs always know when people are missing, because you get your regular people that go in there, and they're usually the

vulnerable people who weren't listening to the radio or the news, to know that there's something going on (Group 4).

Health professionals were also recognised as a valuable community asset who could provide emergency support:

So other than all of those things, the only really different thing I've got was the pharmacists. In a smaller community, the pharmacist usually has all of the knowledge of the local people with their medication, what their needs are, so they're really a... And having a knowledge of where the local resources are, like defibrillators, people who have oxygen takes, those sorts of things (Group 4).

One strategy raised by some participants to support organisations assist people during a disaster was a register of vulnerable persons and collaboration across services to enable collaboration and reduce the need for people to repeat their story. However, privacy was recognised as an issue, and that conditions needed to be applied to the use of a register. These suggestions were also quashed by other participants in the groups, stating the practicalities of maintaining such lists.

...we should have this mythical unicorn list of vulnerable people. Where is the list? We've been sitting around kitchen chambers trying to create it and then we're running into issues around privacy... And who manages it how do you keep it up to date because it will be different next week (Group 3).

...they sign off on the confidentiality that it's only in a natural disaster or emergency that this needs to happen. But definitely something has to happen because especially in the last flood, the amount of people with disabilities that couldn't get out, and not always is it going to be a preclaimed scene that you can actually go evacuate. Because...they were dragging people out of beds, and through mud, and into boats and it was a community that was doing it (Group 3).

I'm thinking too, you have that mainframe system, but really it's up to the organisations to keep that updated then. You know what I mean? Know the participants and suddenly they have that disaster, it's all there. If they do their job properly... (Group 3).

Participants recognised the importance of effective collaboration in order to leverage the knowledge, skills, networks, and local assets during disasters.

And I spoke to *** from Red Cross. His main one thing that came across was collaboration, collaboration within the organisation, and then also collaboration in the recovery space with other agencies, other

organisations, and then also being able to rely on a compassionate and caring volunteer base that is at the evacuation centres. He said that worked really well (Group 2).

So the databases that they're working with now with the resilience from New South Wales and other non-government organisations to be able to access that information, so that when they do present, you ask them the question to get the information, you put it together, and then you find which referrals you need to do and where you need to send them. That information should be in the central place that they've given permission that they can go in as part of their plan (Group 3).

Informal support that include family, friends and neighbours were mentioned as supports that people rely on, and that it is the community connectedness and these relationships that enable an exchange of information and resources during disaster events.

But she said having local connections was a big thing for them, so they knew who to go to (Group 1).

And she also talked about local connections, having local connections as well (Group 2).

It's about community. It really is and they're all saying the same thing just how much it's reliant for all people with disabilities especially if they live alone that their neighbours then will help them (Group 3).

...family, friends. Friends could potentially provide referrals to the person with a disability to services, so they would need to be prepared with that information. And it could be in the person's care plan. And a booklet with contacts and care needs could potentially be provided. And obviously, preprepared is the key thing, so that all this information's not trying to be collected during an emergency (Group 4).

And also members of the community providing support. Although, people with a disability are often not that well connected in the community, so that's something that would need to be worked on prior to any emergencies or disasters happening (Group 4).

However, it was also noted that the nature of the area that included holiday and short stay accommodation was a challenge to relying on neighbours and informal support in an emergency.

We've relied on our neighbours looking after each other and checking in on each other, so the problem is, can we still rely on that? What about when you can't, what about, if half of your street is an AirBNB and it's Christmas time and you don't know your neighbour you live in isolation anyway because of the nature of your disability (Group 3).

One of the things someone identified as a bit of a complication or a challenge, is for areas like Ulladulla, it's a holiday area. Even your neighbours during that sort of thing, they're not the people you'd normally be with, so just checking in if there is an emergency, and knocking on those homes, people's holiday homes, to see if there's someone with a disability, or someone with additional needs. I really liked that suggestion, because they identified the complication or the challenge, and provided a solution (Group 4).

Learning 4: Communication

Communication during a disaster to be informed of the disaster event itself was discussed. This was important for people to be in contact with their formal service provider or support agency if they were not able to visit, or for contacting friends and family who were not with the individual. Social media, mobile telephone applications and other forms of media to communicate weather information and circumstances relating to the disaster was at discussed at length.

In the 2020 bush fires, I was separated from my mum, so she was living away in Tomerong, and I was stuck in Nowra. I couldn't get to her. And that's where I found all those apps, and the radio stations, really, really helpful. So I had the TV going, two different stations because you had two different stories. And we had the radio going, ABC Radio, and then we had the scanner up, so we could actually listen to what the firies were doing in that area, and who was coming, and who was going, and where the [inaudible 00:26:30] was. The struggle, once you've got all that information, is then sharing it, because there's no electricity, so all the phones were cut. Mobile phone reception's not the best, so trying to get that information to her... (Group 4).

Shoalhaven Council's got their Disaster Dashboard, their online Disaster Dashboard as well, which has got everything on it that you need to know about disasters and situations, and getting prepared (Group 4).

And that was built in there, so they actually found it was a really good tool to use and to... it's called a safe zone app that they could notify a few faculty members and a few key people about fires, so there's technology and that's great. Not everybody gets it, but because they're on campus, they're part of the university protocols around emergency preparedness (Group 1).

What works well for them is technology. They've got a thing for... it's a software thing called Deputy, which is like a... it's an app as well, but the organisation use it to communicate to each other, so it's kind of like a social media feed, similar to Workplace or something like that, where they can take a picture of something, post it, and they can send it to groups within the group. And they said that worked really well during the fires

and the flood because they could just get all that information out really quickly, which is good (Group 1).

Well, I learned from Flagstaff that actually, after the bushfires, they developed this programme called the Ember Bushfire Preparedness, and it's for people with disability and it's two apps... So, yeah, they rolled that out in June and there's one for non-verbal, and then a planning app. So, it basically just gets you ready for either emergency during an emergency. There's all these symbols and things that you can basically use with anyone, communicate with anyone (Group 2).

And then info hubs. There's screens within the community down here that show up the information during emergencies. And the radio. Radio, yeah. And this person said Power FM and 2ST were the local stations that were reliable (Group 4).

The counties have now put these solar powered info hubs in different areas when the power goes out. Mobile phone lines service and everything. Yeah, you can go to there and see what the updates are saying (Group 2).

Despite the prevalence of technology, and mobile telephone applications in particular, it was noted that there were limitations with some people reluctant or unable to access these:

Society's increased reliance on technology, it's a blessing and a curse, I think, and definitely COVID and considering the local context, and most of the context that at least we're working in, it's a curse, because people aren't particularly digitally savvy, and they're getting pushed into using it. That's just another stress (Group 1).

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

Many service providers attended this forum. There was no participation of people with lived experience of disability and no

participation from the emergency services sector. Participants did include people who worked in human and social recovery and local government, including people with experience providing disaster recovery support.

The dominance of the service provider voice at this form meant that discussions centered their experiences of providing support to people with disability and the actions organisations took to respond. Service providers discussed the impact of the disasters in terms of increased stress on individuals, informal carers, and formal service providers. Key learnings also included:

- 1. Preparedness for disaster from an individual level through to organizational preparedness is needed, and includes knowing where to seek assistance and practicing drills so that people know more of what to expect and what to do in an actual disaster.
- 2. Resources and supports exist in the community, in both formal and informal capacities. Communication and collaboration supports individuals and organisations manage during a disaster.
- 3. Leveraging existing knowledge, skills and actions is needed to support tailored emergency preparedness. Communications via telephone apps, internet and radio were discussed as important for connecting with family and friends, and keep abreast of the disaster, however these need to be accessible.



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Enquires should be addressed to:

Michelle Villeneuve, PhD

Deputy Director, Centre for Disability Research and Policy The University of Sydney, Sydney Australia <u>michelle.villeneuve@sydney.edu.au</u> <u>www.collaborating4inclusion.org</u>

