

# Actions people with a disability and their representatives can take on DIDRR

📅 17 April, 2023

🕒 2pm - 3.30pm AEST

📍 [aidr.org.au/events](https://aidr.org.au/events)



Leave Nobody Behind webinar series



THE UNIVERSITY OF  
SYDNEY

Centre for Disability  
Research and Policy

# Welcome

## Dr Margaret Moreton

Executive Director, AIDR

# Acknowledgement of Country

AIDR acknowledges the Traditional Custodians of the various lands on which you all join us from today and the Aboriginal and Torres Strait Islander people participating in this event.

We pay our respects to Elders past and present and celebrate the diversity of Aboriginal peoples and their ongoing cultures and connections to the lands and waters across Australia.

# Housekeeping

- Today's event is supported by Auslan Interpreters and Live Captions
- Today's event will be recorded and made available after the event.
- Please enter questions for our speakers in the Q&A function, not the chat box.
- Please use the chat box to share any thoughts or reflections during the presentation – remember to select 'all panellists and attendees' to ensure everyone can read your message.
- Please be respectful to each other when posting your comments or questions.
- You will remain muted and your camera will not be activated for the duration of today's event.

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# Leave Nobody Behind Project

**Dr Margaret Moreton**

Executive Director, AIDR

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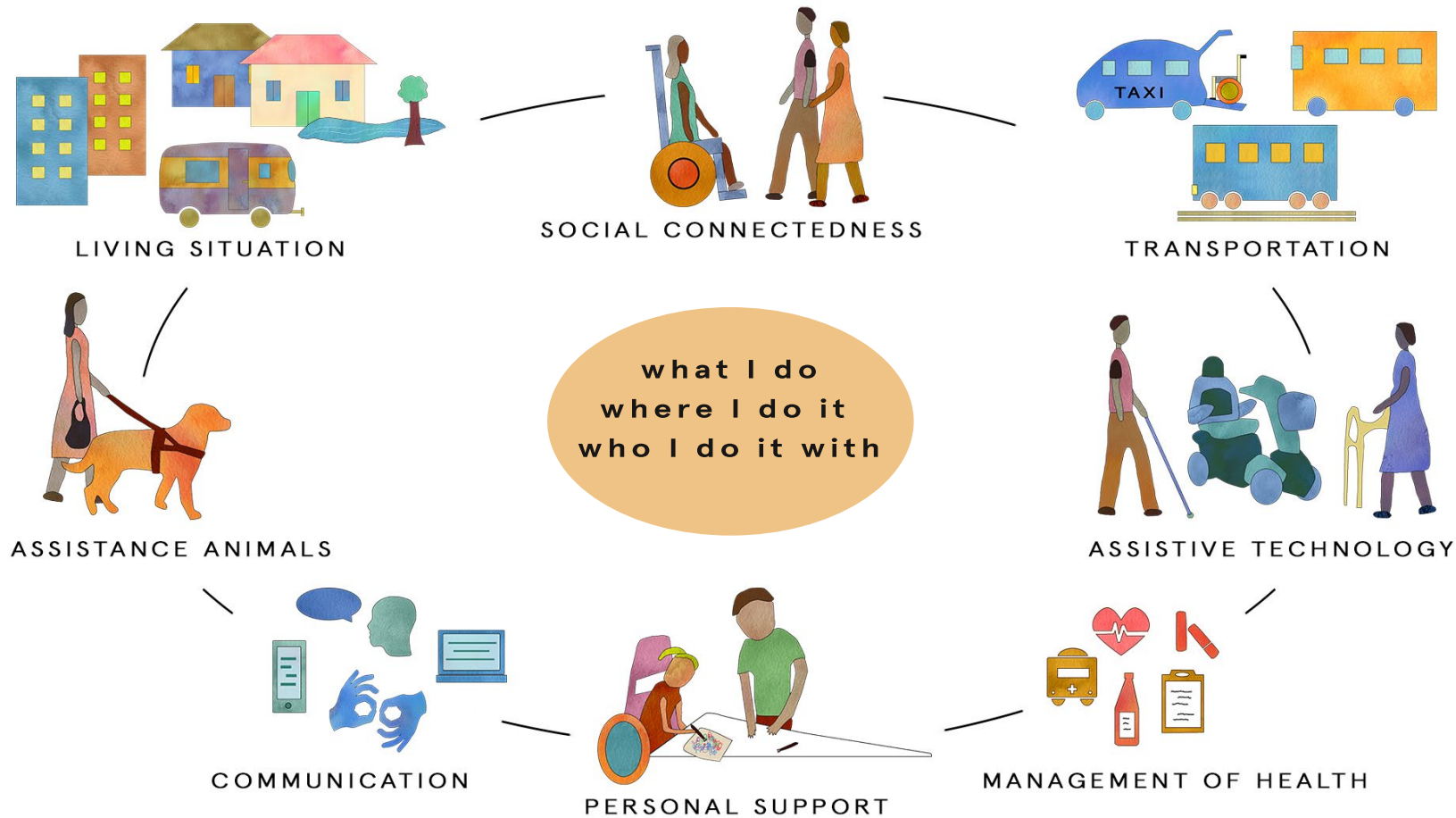
# Speaker introduction

## Associate Professor Michelle Villeneuve

*Deputy Director, Centre for Disability Research and Policy,  
The University of Sydney*



# Person-Centred Emergency Preparedness (P-CEP)







Bushfire



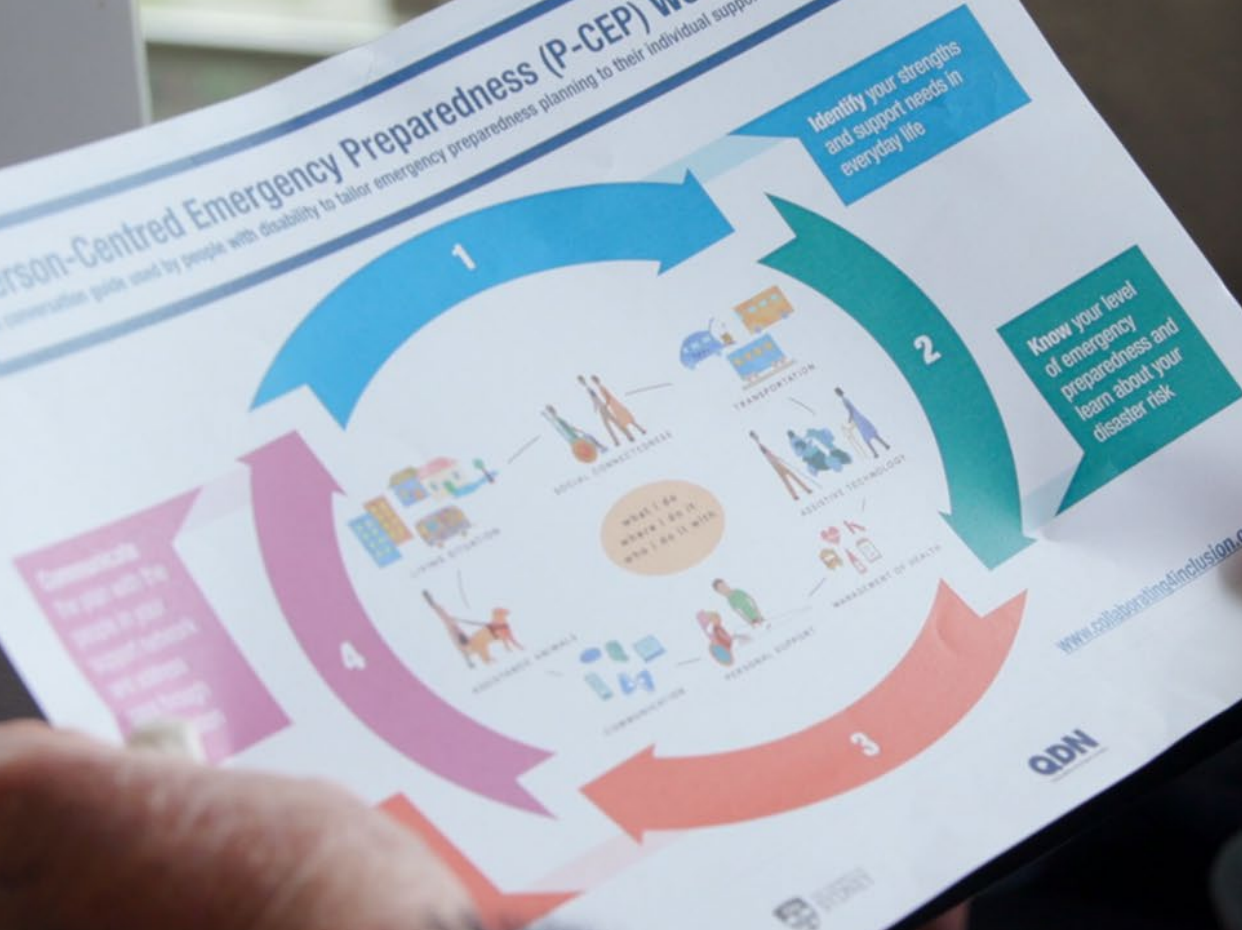
Flood



Cyclone

# Person-Centred Emergency Preparedness (P-CEP) Workbook

A conversation guide used by people with disability to tailor emergency preparedness planning to their individual support needs.





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# Speaker introduction

## Michelle Moss

*Chief Executive Officer,*  
Queenslanders with Disability Network

## Peter Tully

*Board Member,*  
Queenslanders with Disability Network

# Co-designing, leading and partnering

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April 2023





## About Queenslanders with Disability Network

- State-wide network of, by and for people with disability
- 2000+ members diverse disability
- 32 Peer Support Groups
- Emerging leaders program
- QDeNgage
- Projects – NDIS, DIDRR, Digital Inclusion
- Peak body Queensland

**Nothing about us without us**





# GET READY, PLAN AHEAD

A PROJECT TO SUPPORT QUEENSLANDERS WITH DISABILITY TO BEGIN PLANNING FOR EMERGENCIES AND DISASTERS.

ASSISTIVE ANIMALS

MANAGEMENT OF HEALTH

PERSONAL SUPPORT

ASSISTIVE TECHNOLOGY

THIS PROJECT IS JOINTLY FUNDED UNDER THE COMMONWEALTH/ STATE DISASTER RECOVERY FUNDING ARRANGEMENTS.

CITY OF GOLDCOAST. THE UNIVERSITY OF SYDNEY QDN

DO YOU WANT TO KNOW MORE ABOUT MAKING A PLAN FOR YOUR SAFETY AND WELLBEING IN AN EMERGENCY OR DISASTER?

COME ALONG TO TWO P-CEP WORKSHOPS HAPPENING IN CENTRAL GOLD COAST







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# Speaker introduction

**Ainslie Whitburn**

*Project Coordinator,*

Australian Federation of Disability Organisations (AFDO)



**Australian Government**



**Australian Federation of  
Disability Organisations**

# **Fire Proofing Vulnerable Communities**

**Jointly funded by the  
Australian and NSW Governments**



Australian Federation of Disability Organisations

# AFDO and our members

**AFDO** is a Disabled Peoples Organisations (DPO) working for long-term social change for people with disability. We work to make sure the rights and interests of people with disability are served through legislation, policy and practice.





Australian Federation of  
Disability Organisations

# How we began Fire Proofing

A series of videos to increase disability awareness in Fire and Rescue NSW staff.



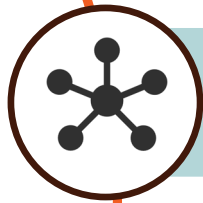
A collaborative state wide risk reduction information and training initiative



# Our Objectives



**Build the capacity of people with disability** to engage with disaster risk reduction strategies



**Connect people with disability** with their local firefighters and other emergency responders



**Develop and deliver** disaster risk reduction information resources to local communities and disability training programs for emergency services staff



**Reduce**, in the long term, the disproportionately high number of people with disability sustaining harm in fire events such as house and bush fires.



# What we are doing

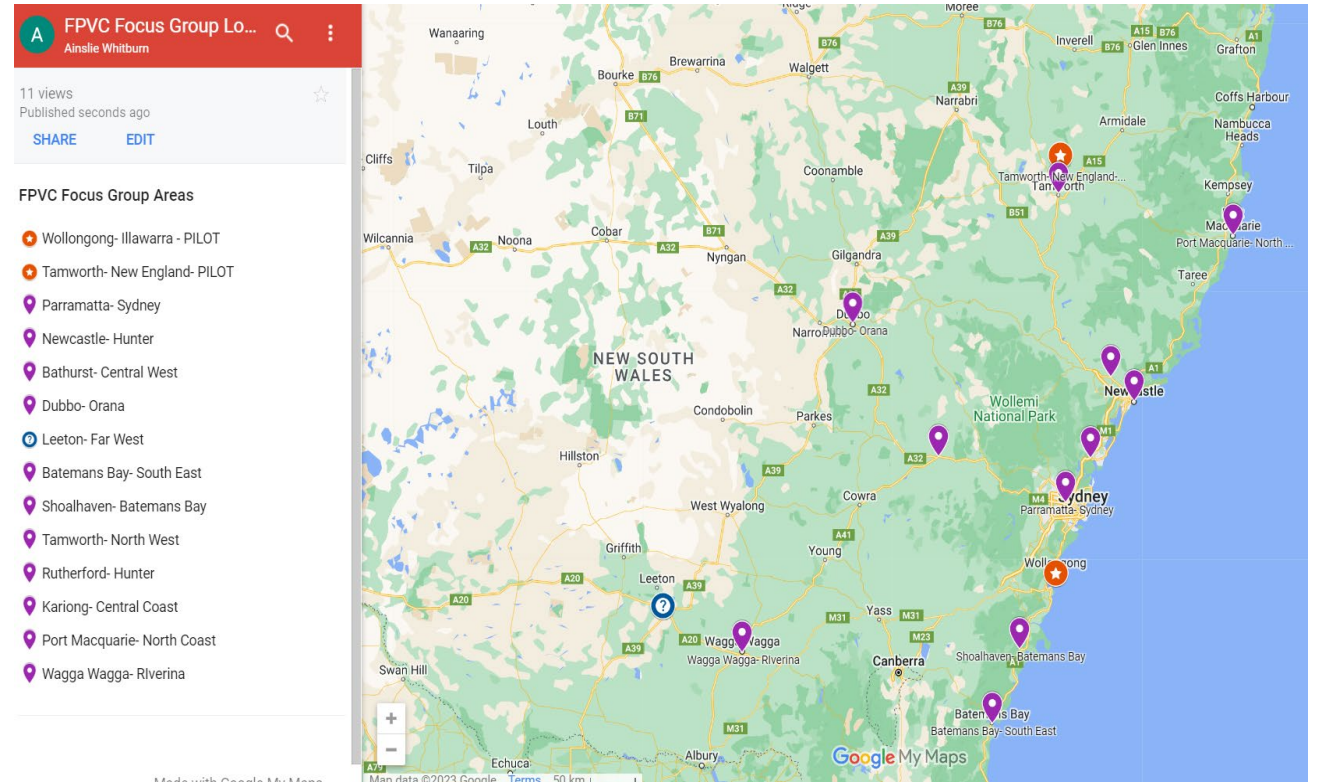
**Review** - current resources for accessibility, readability and understandability

**Engage** - at least a total of 100 people with disability in 14 focus groups

**Create** - disaster risk reduction information in various formats that increase actionability

**Promote** - resources across partners, stakeholders and on all platforms

**Implement** - provide input into training and resources for Fire & Rescue NSW





# Project Partners and Stakeholders

## Fire and Rescue NSW

- **Delivery partner** working with us to organise focus groups, collect data and create resources
- Internal disability awareness training and information resource development

## University of Sydney

- The Centre for Disability Research and Policy is our **research and evaluation partner**
- Reviewing of resources, data collection methods and processes and project evaluation

## NSW Rural Fire Service

- **Resource delivery partner** to promote focus groups and resources in their local communities
- Utilize disability awareness resources in staff and volunteer training

## Fire and Rescue ACT

- **Resource delivery partner** to promote newly created resources in their local communities
- Utilize disability awareness resources in staff and volunteer training

## Local Governments and Government Agencies

- Distribute and promote disaster risk reduction resources
- Does our project link in with similar projects in their area?

## Local organisations, and networks

- Connect with local people and provide support to participate in focus groups
- Distribute and promote disaster risk reduction resources



Australian Federation of  
Disability Organisations

# At the centre of it all

## People with disability are:

- Project Staff
- Project Steering Group members
- Focus Group participants
- Local Community members
- Part of Community Organisations, Services and other agencies







Australian Federation of  
Disability Organisations

# Thank You

If you would like more information please contact:



Ainslie Whitburn

AFDO Project Coordinator



[ainslie.whitburn@afdo.org.au](mailto:ainslie.whitburn@afdo.org.au)



0431 927 276



[www.afdo.org.au](http://www.afdo.org.au)

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# Speaker introduction

## Dr Tonia Crawford

*Director, Pre-registration programmes & Senior Lecturer,  
Susan Wakil School of Nursing and Midwifery*

# Survey of informal carers of people with disability:

## Overview of findings

### Presented by

Dr Tonia Crawford, Co-Investigator on the Leave Nobody Behind Project

Susan Wakil School of Nursing and Midwifery  
Faculty of Medicine and Health



# National study of carers of people with disability

## What we explored:

Preparedness

Capabilities

Support needs

of informal carers before,  
during and after a disaster.



Photo: Ivan Semkov

# The respondents

- 84% female,
- 48% mothers of care recipient
- 87% primary carer
- 52% lived in a city
  
- 41% physical disability
- 34% chronic health condition
- 30% intellectual disability



*iStock photos*

# Preparedness

- Preparing home/property to reduce damage
- Stockpiling with emergency supplies
- Reviewing/purchasing insurance policies



<https://www.cityofpasadena.net/fire/disaster-preparedness/>

# Capability: maintaining independence

## Shelter in place

- Stockpiling of food, medications, consumables
- Having a generator & batteries
- Family/friend support

## Evacuation

- Accessing physical &/or psychological assistance from family/friends/neighbours to evacuate
- Assistance with transport to evacuation centres/alternative accommodation
- Communication re what was going on

# Support needs



- Physical and practical assistance
- Transport (and/or moving)
  - *‘Help to evacuate - rural area. Animals to care for. Quiet area once in the (evacuation) centre’.*
- Psychosocial and emotional support
  - *‘Just reassurance that things will return to normal’.*



## Lived experience of evacuation

*The evacuation point we were encouraged to transfer to was the local club, but this was inappropriate for a child in a wheelchair and who also needed time to lie down on a pressure mattress and have specific personal and medical requirements carried out. If my parent's home was not available, the only other option would be to go to the hospital which was familiar with her needs, or stay at home, which I felt was not safe? However, I did need to go home on the way to my parent's home, to collect medication, chair chargers, bathing aids, etc. If this was not safe to do so, the only option was going to hospital.*

(Carer respondent 14, physical and neurological chronic condition)

## Lived experience of evacuation

*... to be honest, as much as we had escape routes planned, our property wasn't as prepared as what it could have been...that's because... have eyes on him 24/7. So, all that time is taken up around him... We couldn't go early to the evacuation centre because he'd never been in that kind of environment and the people there under stress wouldn't cope with him either... I would have had to strap him into his mobility chair and he would have been screaming the place down... If [name] wasn't affected with what he has, we probably would have left a lot earlier...some environments don't work.*

(Carer 2, mother of person with developmental disability)

# Recommendations

- Advice from informal carers to other carers

***You know** your child or person you care for best and how they react to stress, **think about** how to prepare them for emergencies... know what their favourite comforting item is to bring, know what are clothes or foods that will be comforting under duress. **Practice** breathing exercises and use Smiling Mind so everyone is familiar.*

- Advice to emergency services

- Consider accessibility of emergency shelters
- Listen, respect and understand

- Include informal carers & perspectives of women who are disproportionately impacted by disasters in DIDRR training, preparedness and planning.

# Conclusion

- This project **gave voice to informal carers** of people with disability for their experiences to be heard.
- Informal carers and **their experiences are as diverse as the people that they care for**.
- Informal **carers reported**
  - **actions** they would take to maintain independence,
  - the **type of support they would need** to evacuate or shelter in place, and
  - **advice they consider useful** for informing education and training of other informal carers and the emergency services.

## Acknowledgement

We thank:

- our partners including Carers NSW, Rural Fire Service, State Emergency Service, Red Cross for help with survey design and recruitment.
- our participants for their time in contributing their experiences and perspectives.

Funding:

- This work was supported by an ARC Linkage Grant (LP180100964) and the NSW Government.

<https://www.arc.gov.au/news-publications/media/research-highlights/new-research-support-people-disabilities-disasters>

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# Speaker introduction

## Sarah Judd-Lam

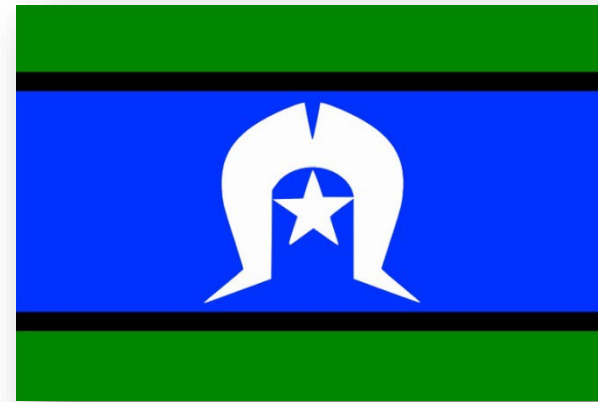
*Executive Manager, Policy, Development and Research,*  
Carers NSW

## Courtney Jones

*Program Lead - Care2Prepare,*  
Carers NSW



# Acknowledgment of Country



I would like to acknowledge the Traditional Custodians of this Land. I would also like to pay respect to the Elders both past and present and extend that respect to other Aboriginal people here today.



# About Carers NSW



**Carers NSW is the peak non-government organisation for family and friend carers in New South Wales (NSW).**

Carers NSW is part of the National Carer Network and a member of Carers Australia.

Our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

# About Carers NSW



## Who are carers?

- Provide care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.
- This definition does not include:
  - paid care workers
  - formal volunteers
  - parents / foster carers / kinship carers
- 854,300 carers in NSW, including approximately 273,900 primary carers \*

\* 2018 Survey of Disability, Ageing and Carers



## About Care2Prepare

- Focuses on increasing the **inclusion of people with disability, older people and carers** in local disaster responses
- Aims to improve **household and community readiness** to reduce the impact of flood and bushfire
- Funded from 2022-2025 through an Australian Government *Preparing Australian Communities - Local Stream* grant
- Led by Carers NSW and delivered in partnership with the Physical Disability Council of NSW (PDCN) and GoCo
- Delivered in **Central Coast, Shoalhaven and Gunnedah**
- Steering Group includes Michelle Villeneuve and Jade Chang (University of Sydney)







## Older people, people with disability and carers

- May require access to essential medication, equipment, treatment and support that can be cut off during natural disasters
- May experience mobility, cognitive or behavioural challenges that affect timely evacuation or safe access to evacuation and recovery centres
- May experience greater challenges with recovery and re-integration due to socio-economic disadvantage and reliance on formal services
- May require tailored support to plan for, and navigate, evacuation and recovery
- Are often overlooked in natural disaster planning and emergency responses



## Key outcomes

-  Increased inclusion of the needs of people with disability, older people, people living with a health condition or mental illness, and their family and friend carers in local disaster planning and response frameworks.
-  Increased community awareness of the needs and experiences of, and the supports and services available to, people with disability, older people, people living with a health condition or mental illness, and their family and friend carers.
-  An increase in the number of people receiving and providing care with individualised disaster plans in place.
-  New, ongoing local connections and collaborations between key community stakeholders, including people giving and receiving care, and local government, business and community groups.

## Planning skills are transferable

The complexities of caring roles demonstrate high levels of resilience and broad capacity to understand and appropriately prepare for the risks of disasters.

Largely, carers have the capacity to develop appropriate disaster plans but lack access to relevant information and support pathways.



## Prioritising priorities

When considering disaster preparedness, carers focus on exigencies first and property risk reduction second. These exigencies may include:

- Maintaining routines, familiarity or calm environments to regulate emotions and behaviour and avoid triggers
- Continuity of access to life sustaining medical equipment or scheduling of medications or physical care activities
- Managing the carers own health needs alongside those of the carer recipient

## Carer recognition matters

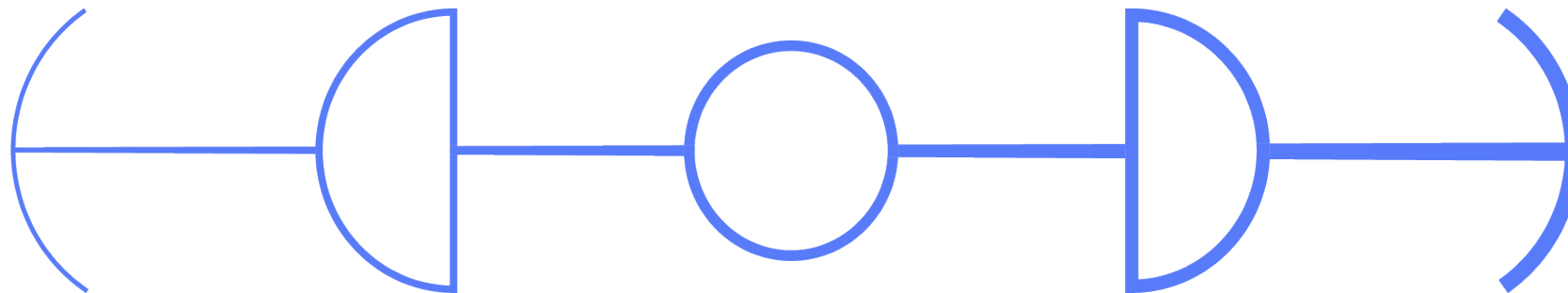
Carer recognition, identification and awareness of the many ways in which family and friends provide support and care is a key factor in developing systems that improve inclusion in planning and response activities for carers and care recipients.

Care2Prepare will bridge this gap by:

- working with local government and the community sector to understand the varied and often complex roles of carers
- identifying opportunities to improve response protocols such as evacuation to mass centres and advocating for better ways to support priority populations
- supporting organisations to embed carer-centric approaches into planning and response protocols



## Implementing the project



Consultation



Co-design household  
readiness tools



Co-design sector  
training modules



Pilot phase



Roll-out



Courtney Jones | Program Lead  
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Q & A



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Don't forget to enter you questions into the Q&A box.

# Actions that service providers can take on DIDRR

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🕒 2pm - 3.30pm AEST

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# Event concludes

Thank you for attending today's webinar.

# Actions people with a disability and their representatives can take on DIDRR

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