Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Emergency Planning and Response

17 July 2020

We welcome the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission), and the opportunity it provides the University Centre for Rural Health (UCRH) to inform the Royal Commission on the needs of people with disability in regard to emergency planning and response to disasters.

This submission is based on empirical evidence from two surveys exploring mental health outcomes that UCRH carried out following the devastating 2017 flooding in Northern Rivers region of New South Wales: the first, six months after the floods and the second, in a follow-up survey of a subset of the same people, two years after the floods. With more than 2000 respondents to the first survey our research provides a unique dataset about people’s experiences of the floods. In this dataset we are able to identify respondents living with a disability (n=164) and the carers of those with a long-term illness or disability (n=91).

This submission is authored by:

- Ms Jodie Bailie, Research Fellow, University Centre for Rural Health
- Dr Veronica Matthews, Research Fellow, University Centre for Rural Health
- Professor Ross Bailie, Professor of Public Health and Director of University Centre for Rural Health
- Associate Professor Michelle Villeneuve, Centre for Disability Research and Policy
- Ms Maddy Braddon, Research Assistant, University Centre for Rural Health
- Dr John McKenzie, Data Analyst, University Centre for Rural Health
- Dr Jo Longman, Research Fellow, University Centre for Rural Health.
The University Centre for Rural Health, a multidisciplinary centre situated in the Northern Rivers region of NSW (www.ucrh.edu.au), engages in education and research relevant to the health needs of rural communities. The UCRH is a collaboration between the University of Sydney, Southern Cross University, the University of Wollongong, Western Sydney University and the Northern NSW Local Health District.

We would welcome the opportunity of presenting this submission at a hearing and for it to be made publicly available.

For more information, contact Jodie Bailie:
University Centre for Rural Health
61 Uralba Street, Lismore, NSW 2480
Email: jodie.bailie@sydney.edu.au

UCRH Flood Study website: https://ucrh.edu.au/after-the-flood/
Twitter: @UCRH_NC
INTRODUCTION
River (fluvial) floods are the most common type of flooding disaster to occur globally [1], and are projected to increase due to climate change.[2] Floods are a significant public health problem, with the most socio-economically marginalised groups experiencing disproportionate exposure to flood events.[3, 4] Empirically based studies on the effects that flooding has on people with disability, while sparse, confirm that individuals with disability are disproportionately impacted as they experience higher rates of death and injury as well as increased challenges during response and recovery.[5, 6] However, this increase in the vulnerability and the needs of people with disability and their carers during floods and other emergencies is not well understood.[7] In fact, current research in Australia shows that people with disability have been excluded from local disaster risk management policy and practices designed to keep communities safe in emergencies.[6]

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Emergency Planning and Response[8] presents a timely opportunity to provide feedback on the experiences of people living with a disability (n=164) and carers (n=91) following the floods in the Northern Rivers region. The experience of the 2017 floods provides a case study that highlights increased evacuation, displacement and experience of flooding; disproportionate mental health impacts following the event; and systemic neglect experienced by people with disability and their carers during and after the floods. While we acknowledge the many individuals and organisations who worked tirelessly during and after the 2017 floods to support individuals and the community, our intention with this submission is to draw attention to the experiences of people with disability and to advocate for systemic change.

We have organised our submission as follows:

• SECTION 1: Outline of our case study including where and how data were collected and analysed
• SECTION 2: Response to a number of key questions posed by the Royal Commission
• SECTION 3: Detailed report on the findings from our study that provided the basis for our responses to the key questions
• SECTION 4: Appendices.
SECTION 1:
OUTLINE OF OUR CASE STUDY

2017 Flooding in the Northern Rivers: A Case Study

The north-east of NSW commonly experiences flooding, and had the greatest number of disaster declarations of anywhere in the State between 2004 and 2014.[3] In early 2017 extreme rainfall flooded the Northern Rivers region, inundating the major population centres of Lismore and Murwillumbah and causing extensive damage to housing and infrastructure. The region includes many areas with relatively high levels of social vulnerability including low income and educational levels, and high numbers of residents living in rented accommodation, single-parent families, Aboriginal and Torres Strait Islander people, and people with disability.[9] According to the Australian Bureau of Statistics, 6.5% of the population identify as needing assistance with core activities, compared to 5.1% for Australia overall.[9]

Socially vulnerable groups are more likely to be directly affected by disasters. This was exemplified in the 2017 floods, where 82% of people living in the flooded areas of Lismore were in the socio-economically lowest quintile.[10] People in socially vulnerable groups are also more likely to suffer negative mental health after a disaster. For example, following the 2017 floods those who were in receipt of income support (as a proxy for economic vulnerability) were almost twice as likely to be experiencing anxiety, depression or suicidal ideation compared to respondents who were not in receipt of income support.[11]

Community recovery after flood surveys

Our submission is based on empirical evidence from two surveys exploring mental health outcomes following the 2017 river flooding in the Northern Rivers.[12] We carried out the first survey six months after the floods and, in a follow-up survey of a sub-set of the same people, two years after the floods.1

Community members who were 16 years and older and resident in the Northern Rivers at the time of the floods were invited to participate. Using a community–academic partnership research approach,[12] we purposively surveyed a broad cross-section of the community, with an emphasis on including hard-to-reach populations groups. The sampling strategy was not intended to obtain representation of the broader Northern NSW population, but rather to obtain respondents from a range of groups to enable comparison of experience between key groups of interest in our research.

1 Further detail on the study methods, rationale and findings can be found in our published manuscripts.
For the purpose of this submission we identified three groups of survey respondents from the first survey who had complete data: a) respondents living with a disability or long-term illness (n=164); b) respondents caring for a person with disability or long-term illness (n=91); and c) ‘other’ respondents who did not indicate disability or carer status (n=1997). In this submission we refer to the two key stakeholder groups as ‘carers’ and ‘disability’ for the purpose of brevity, acknowledging the importance of the preferred term ‘people living with disability’.

There were 26 respondents who were in both the carers and the disability groups. To ensure we had two mutually exclusive groups we removed ‘disability’ from the ‘carers’ group. Appendix 1 contains the inclusion criteria and the socio-demographic questions in the survey that relate to establishing our two key stakeholder groups.

For this submission we undertook both quantitative and qualitative analyses. For the quantitative data, a univariate analysis of data from the first survey was undertaken to assess if there were different outcomes for ‘carers’ or ‘disability’ compared to ‘others’. Our qualitative analysis is of unstructured written responses (‘free text’) from the first and follow-up questionnaires (details of the free text opportunities used for the analyses are available in Appendix 1). To amplify the voices of people with experience of living with a disability and their carers we have used representative quotes to support key points in this submission.
SECTION 2: 
RESPONSES TO QUESTIONS POSED BY THE ROYAL COMMISSION

Our responses to questions posed by the Royal Commission are based on findings from research that is reported in detail in the following section of this submission (Section 3). Here we provide a brief synopsis of the findings.

Systemic neglect of people living with a disability and carers – People living with a disability and carers were more likely to have the living areas of their homes flooded, to be evacuated, to be displaced for more than six months, and to report disrupted access to essential services such as health, social care and food in comparison to others. Furthermore, they were twice to three times more likely than others to report that six months post flooding they were still distressed about the floods, and were more likely to have post-traumatic stress disorder and/or suicidal ideation.

Question 1: What needs to be done by governments to increase the safety and wellbeing of people with disability during an emergency?

Foster and support a culture of continual learning and reflection
Funding of research is needed to explore the experiences of people living with a disability during and after disasters, such as flooding, within a supportive culture of learning and reflection so that we can learn from past experiences and develop local adaptations. It is vital the funding allows for appropriate dissemination of findings, including working with community groups to present the findings and open access publications.

Investment in preparedness in areas known as ‘hot spots’
Given the disproportionate impacts associated with flooding events for people with disability and/or carers there is a clear need to increase their safety and wellbeing during an emergency. Greater investment in preparedness is required in areas where we know that disasters are likely to occur again and where the most socially marginalised populations reside. For example, we know that river flooding in the Northern Rivers will happen again, that its occurrence and severity will likely increase due to climate change, and that those who are most socio-economically disadvantaged often live in flood-prone areas.

Development of person-centred preparedness plans
Government, at all levels, must ensure that people living with a disability receive specific attention in the event of a disaster, and are supported to be included as active participants in all stages of disaster planning and action, including preparedness, response and recovery. Investment could be made in
supporting the development of person-centred preparedness plans\[13, 14\] for people living with a disability and carers, especially for those who are known to live in high-risk flooding areas. This could be driven by the individual, family supports, disability providers or support networks using available tools (see, for example, https://collaborating4inclusion.org/pcep/). Investing in preparedness will mitigate against the disproportionate burden of the negative consequences of flooding and improve recovery following the event both for people living with a disability and carers.

Integration of community and disability services into the emergency management system

Community and disability services are not integrated into the emergency management system so their involvement comes only after a disaster – which is too late.\[14\] The identified disruption of social supports and essential services, including food post-flooding, points to a need for governments to increase the resourcing and coordination of these important contributors to recovery so that people with disability and carers can access them.

Long-term investment in mental health and wellbeing support, and community resilience building

Attending to the mental health and wellbeing both of individuals and of the community in the longer term following a disaster should be a vitally important component of recovery and requires investment and leadership from all levels of government. Furthermore, supporting community resilience-building programs should be an important consideration in disaster preparedness, as it has been shown that community connectedness acts as a protective factor.

Work with peak (and local) disability advocacy organisations to understand and respond to housing vulnerabilities

To reduce the neglect of people living with a disability, governments could work with peak (and local) disability advocacy organisations to understand and respond to the housing vulnerabilities that our surveys found to be evident at many levels. People living with a disability and carers were more likely to be flooded, evacuated and displaced than others, with a subsequent increased need for alternative housing for both the short and long term, and assistance to access such housing. A lack of affordable accommodation resulted in people with disability and carers living in unsafe accommodation (e.g. with mould, no cooking facilities), relocating to other areas and subsequently losing their support networks, or becoming homelessness. Governments need to ensure there is access to suitable and affordable housing that is outside of flood-prone areas. Financial hardship/stress was commonly described, with affordable housing being just one aspect of this.
Improvements in communication infrastructure and support, in accessible formats

There is a clear need for government, at all levels, to invest in communication infrastructure and support for people living with a disability and carers. This infrastructure and support must consider accessible messaging, modes and format of communication to ensure access and inclusion.

Communication with members of the disability community must be viewed differently depending on the point at which it is initiated. This can be done:

- well before a potential event, as part of a preparedness outreach effort;
- prior to a potential event, as an emergency warning or notification;
- during and immediately following an event, as emergency information and instruction; or
- in the short, medium and long-term follow-up of the event, as recovery information

As people with disability are currently excluded (neglected) from disaster risk management in all stages of preparedness, response and recovery, they generally have greater difficulty learning about and accessing programs, such as clean-up and recovery efforts, and financial relief packages that are available to others in the community. Given the increased displacement of people with disability related to a flooding event, these programs and information services need to be in place for extended periods.

Question 2: What supports are required to ensure people with disability are not at risk of violence, abuse, neglect and exploitation during an emergency?

Support for carers

Both groups – a) people living with disability and b) carers – have specific needs and require specific strategies to have their needs addressed. Carers play a vital role in providing support and for people living with a disability. Given the disproportionate burden carers also experience from flooding it is important that they are identified as a key interest group.

Support for inclusion in preparedness, response and recovery plans

The disproportionate burden of the impacts of the flooding event on people with disability and on carers highlights the need for further support. As noted in our response to Question 1, people with disability also need to have greater inclusion in emergency preparedness, and purposeful supports to enable this inclusion. Assuming that carers or service providers will take responsibility for this perpetuates inequity for all concerned, because they do not yet have the tools and training to ensure inclusion, and often experience the same systemic barriers as the people they support. As noted above, this is important in areas like the Northern Rivers region where we know that not only flooding will
occur again but that it is likely to increase in frequency and severity with climate change. A further consideration is the relatively unknown effect of compound extreme weather events on rural populations.

**Support to access help, personal care, transport, housing, food and money**

People with disability and carers are particularly reliant on supports and services that are likely to be disrupted by flooding. Our survey showed that they were three times more likely than other people to report help taking a long time to arrive. Thus, there is a need to ensure ongoing access to high-quality personal care, transport, food and money – support that has been shown to be reduced, at least in the early relief and recovery phases.

**Evacuation (including transport)**

Evacuation from flooded areas presented specific challenges for people with disability and carers. Support with transport is clearly needed, as respondents noted that a lack of transport to evacuation centres or other places had been inadequate. This lack of access to transport also meant respondents were unable to move possessions in a timely way and hindered the post-flood clean up.

**Reconnection to community**

Purposeful reconnection to community and supports following a disaster will assist in mitigating the risk of violence, neglect and exploitation.

**Question 3: What is the experience of people with disability in getting assistance and information in an emergency?**

In responding to this question posed by the Royal Commission, we encourage referral to Section 3 where we refer extensively to people’s experience in obtaining information and assistance. In summary, there were a number of barriers identified to accessing timely, accurate and intelligible information related to flood warnings and evacuation, namely, access to transport, disrupted support networks, and inaccessible flood warning information.

*We couldn't leave as we didn't have any transport to leave as me and my housemate are disabled… We were unable to leave our house as we had no transport to get to the evacuation centre.* (Disability, No. 49)

People perceived flood warning messages as being inaccessible due to low literacy, confusion about the actual messages, and communication barriers for deaf people as verbal directions were not accompanied by sign language. This can affect how quickly people become aware of flooding, their access to emergency information during the flood, and their ability to seek assistance.
“Didn’t know what evacuation meant e.g. what to take, would I have to stay there, where to go... Had no idea what river levels meant, e.g. Tweed River is 4.3m” (Disability, No. 154)

The importance of sensitive communication by those tasked with evacuating people living with a disability and carers was highlighted, and additional and tailored empathetic, accessible support required in this regard.

There was a perceived neglect that many people had been left to ‘fend for themselves’. As noted above, people with disability and carers were three times more likely to report help taking a long time to arrive than others.

‘The disgusting way people were left to fend for themselves and then the lack of proper response from our Federal Government. The scammers who surfaced during the flood. The lack of help for the homeless and vulnerable. The anxiety and stress that occurred and the amount of people left homeless and still trying to find a home 5 months later. Services that were desperately needed but were very hard to find.’ (Disability, No. 1)
SECTION 3:

DETAILED FINDINGS FROM OUR CASE STUDY

Who took part in the survey? The demographics, flood affectedness and evacuation of disability and carer groups.

Of the 164 respondents in the ‘disability’ group, 64% were female and 70% were aged 45–64 years.
Of the 91 respondents in the ‘carers’ group, 80% were female and 53% aged 45–64 years (Appendix 2).

People living with a disability and carers were more likely than other survey respondents to have had the liveable areas of their home affected by floodwater, to be evacuated and to be displaced. This highlights the social vulnerability of these groups in relation to the general study population. For example, around one-third of respondents living with a disability (38%) and one-third of carers (31%) had the liveable areas of their home flooded, compared to only 20% of other respondents. (Table 1)

More likely to report adverse mental health outcomes

Respondents living with a disability and carers were twice to three times more likely than others to report that six months post-flooding they were still distressed, had probable post-traumatic stress disorder and/or had suicidal ideation (see Appendix 1). Flooding also compounded existing physical and mental health issues, which meant that the mental health impacts were profound and long lasting:

I didn’t realise how depressed I got or how upset I was until I talked with the flood recovery team and then it all hit home and has taken 6 / 12 [months] to recover and I was only minimally affected. (Carer, No. 89)

Flood-prone housing and likelihood of evacuation

Respondents living with a disability and carers were more likely to have living and non-living areas of their homes flooded than other respondents (living areas flooded: 38% vs 31% vs 20% for disability, carers, others respectively; non-living areas flooded: 62% vs 62% vs 46% for disability, carers, others respectively; see Table 1). They were also more than twice as likely to report being evacuated as others (29 vs 15%). This increased vulnerability to flooding events is related to their greater habitation rates in areas that are prone to flooding.

This issue of respondents living with a disability at times living in accommodation that placed them at risk was raised:
‘Some of my friends lived in places in the centre of Lismore CBD that perhaps should never have been rented due to the vulnerability of their buildings in floods. These type of rooms/places were really vulnerable in the flood, it would have been impossible to get possessions to safety quickly enough. And people who rent these type of places have the least resources (mental, emotional, physical (cars etc.), financial) to cope with this type of event quickly – unlike a business.’ (Carer, No. 243)

Warning systems
Challenges with information related to flood warning systems for respondents with disability and carers were commonly reported, and included receiving conflicting information, and poorly timed or incorrect warnings regarding flood water levels and the possible need for evacuation.

‘I got no warning but TV said evacuation for Lismore CBD, and when I rang SES for information I could not get through. I needed clarification for my family and I have 3 special needs kids and I needed help to evacuate. I rang the police station [and] they said I was fine where I was, I was getting more scared and finally got hold of [the] SES who told me leave now as “we expect catastrophic loss and genuine risk that your house will collapse because it’s in direct path of flood when the levy tops”. I said I need help! I was told no help for me as I was under order to evacuate hours before but no one rang, no one knocked on my door! Even the police said my house was fine! It was completely destroyed. Knocked off the pylons, condemned [to] a horrific night of hell getting the kids out by myself.’ (Carer, No. 67)

Warning messages were seen to be inaccessible due to low literacy, confusion about messages, and also communication barriers for deaf people as directions were given orally and not accompanied by sign language. This can affect how quickly people become aware of flooding, their access to emergency information during the flood, and their ability to seek assistance. Below we have included a set of quotes related to warning messages from carers and respondents living with a disability:

‘Didn’t know what evacuation meant e.g. what to take, would I have to stay there, where to go... Had no idea what river levels meant, e.g. Tweed River is 4.3m.’ (Disability, No. 154)

‘Slept through landline SES phone call x 2. Heavy, natural (no drugs) sleeper.’ (Disability, No. 100)

‘Text messages were confusing, didn’t hear the siren and wasn’t aware the water had breached the levee until Saturday am.’ (Carer, No. 128)
Experience of evacuation

As noted above, respondents living with a disability or carers were more likely to be evacuated than others. The additional challenges in evacuating people with a disability were highlighted by carers, for example:

‘... when we did evacuate it was late because we were worried about our children, one who is recovering from her last course of chemo and one who is autistic and is easily stressed when routines are disrupted.’ (Carer, No. 13)

People with autism spectrum disorders have sensory integration difficulties that include sensitivity to touch and sound. A number of carers raised the importance of the need for sensitive communication by emergency services tasked with evacuating people with autism spectrum disorders. They also noted the additional requirements needed to move someone with disability, such as extra equipment and time:

‘... some representatives of the emergency services WOULD NOT LISTEN to people who have lived through many floods. To expect infirm, aged or carers of disabled to move to other premises is silly. As an aged person with rather dicey balance, and having a disabled son equally as awkward, to DEMAND they evacuate is difficult to achieve. Large, and larger, pillows, blankets, 5 medications, an aged cat – and where and when and how and what happens then?’ (Carer, No. 177)

‘Consider that when some people who must leave the home base to a place of refuge have in their care someone who will have needs of medication; be awkward in movements and take longer to do things; and very often live in high-set houses. If these people with special needs are taken to centres e.g. the university, what of the cushions and blankets and pillows and medication and patience of the carers, who may indeed be in need of a carer themselves? Please do try not to use panic stricken or overly bossy voices – the reaction can be “I won’t do it!” rather than “thank you very much for your help”.’ (Carer, No. 206)

Respondents living with a disability noted that a barrier to evacuation was a lack of transport to evacuation centres or other places. This lack of access to cars also meant respondents were unable to move possessions in a timely way and also hindered post-flood clean up. One respondent noted the lack of transport as a reason for not evacuating, and suggested that local taxi companies could be engaged by a Government Department to evacuate people:
We couldn’t leave as we didn’t have any transport to leave as me and my housemate are disabled… We were unable to leave our house as we had no transport to get to the evacuation centre. I would like to suggest that local taxi companies take vulnerable and isolated residents to evacuation centres free of charge before flood hits… The reason why I suggest the free taxi ride is there is a lot of people with disabilities living in Lismore who don’t have family nearby to come and get them or friends or neighbours that they know nearby to take us to an evacuation centre.' (Disability, No. 49)

Housing vulnerabilities and homelessness
As respondents living with a disability or carers were more likely to be flooded, evacuated and displaced than others, there was increased need for alternative housing for both the short and the long term, and assistance to access such housing. Housing vulnerabilities were evident. There was a reported lack of affordable accommodation for displaced people living with a disability and carers, that resulted in living in unsafe accommodation (e.g. mould, no cooking facilities and structural damage), relocation to other areas and subsequent loss of support networks, or homelessness.

'I am currently homeless with 3 children, looking for help from community organisations and there are big waiting lists. Since the flood, people have increased the rental on their properties ‘cause they know there are so many people looking for a place to live. I know a lot of people who have left the area as they could not find a place to live. I personally don’t want to do this, I’m giving it till the end of the month to make that decision.’ (Carer, No. 45)

Housing in the area that flooded is generally cheaper to buy and to rent as it is in a flood-prone area. However, when so many houses are flood damaged there are a lot of people displaced from lower cost housing, which leads to a lack of affordable accommodation even for those not displaced. As this meant that there were many more people looking for accommodation, high levels of financial stress were reported:

'Where the flood did affect me was the housing crisis born of a shortage of rental properties. I was given notice to move from my rental property just before the flood. It was extremely tough to find anything affordable on the pension (&with pets) in the months after. I am currently in temporary accom till March, then who knows?' (Disability, No. 168)

Disrupted access to essential services such as health, social care and food
Respondents living with a disability or carers were more likely to report disrupted access to essential services such as health, social care and food in comparison to others (see Table 1). Challenges with accessing money were also identified as banks were closed due to being impacted by floods themselves:
‘...Some who found obtaining money to purchase their daily needs difficult due to the damage to the banks in Lismore. Older and intellectually challenged were at greatest risk; some still use “passbooks” and were not able to take advantage of the “pop-up” banks so it meant finding a way to travel great distances to obtain cash.’ (Carer, No. 11)

Reported access barriers to essential services included road blockages and damage due to flooding, closed businesses and disruption to support networks. Mental health impacts from flooding (see Table 1) further impeded access to services:

‘The shock of the flood made it difficult to get out of the house to pursue assistance or get informed.’ (Disability, No. 249)

Social connectivity acting as a protective factor
Social connectivity was identified as a protective factor for respondents with disability in terms of mental health and of being able to access assistance in many forms. For example, people living with a disability who were viewed by community and emergency workers to be well connected to the community, or ‘visible and well known’, were perceived to receive support from the wider community to access essentials such as food.

Disruption of support networks and community participation
Disruption to support networks and opportunities for community participation often resulted in social isolation. There were reports of support staff being so affected by flooding themselves that they were not able to support their clients, and that some support staff had to move away from the area because they could not secure affordable, alternative accommodation.

Emergence of ‘scammers’ and ‘looters’
Respondents living with a disability noted the emergence of ‘scammers’ and ‘looters’, who sought to take advantage of vulnerable people. There were calls for an increase in policing and security generally to prevent this occurring. One person living with a disability reported opening their home to assist with easing the accommodation crisis and found themselves targeted by ‘thieves and liars’:

‘The amount of scammers who surfaced. I offered my home to accommodate people but instead was targeted by thieves and liars and had to remove my offer of accommodation. At the time of this flood I was attached by a nasal tube to a feeding machine and I was very vulnerable. I worried for weeks afterwards that they would come back.’ (Disability, No. 1)

Perception of help taking a long time to arrive, or not arriving
Respondents living with a disability were almost three times as likely to report that help took a long time to arrive in comparison to others (17% vs. 6%, see Table 1), with this difference being highly significant. The difference was not so marked for carers, although they were still more likely to report help taking longer to arrive in comparison to others (12% vs. 16%).

There were many reports of feeling left to fend for oneself, and frustration with getting assistance in the form of financial disaster relief measures, help with cleaning up and accessing services.

‘...we haven’f finish clean up, and we are now abandoned. No one cares about South or North residents. I haven’t even done the insurance ombudsperson, creek near my place still full of flood rubbish and council no one will help, I’m in the bowl, no one cares and I’m resenting the lack of help. I’m single, older, with a disability; why do I have to do everything? And on my own??’ (Disability, No. 90)

‘The disgusting way people were left to fend for themselves and then the lack of proper response from our Federal Government. The scammers who surfaced during the flood. The lack of help for the homeless and vulnerable. The anxiety and stress that occurred and the amount of people left homeless and still trying to find a home 5mths later. Services that were desperately needed but were very hard to find.’ (Disability, No. 1)

Table 1: Comparisons of respondents with disability and carers vs others on how they were affected by the flood

<table>
<thead>
<tr>
<th></th>
<th>Disability (N=164)</th>
<th>Carers (N=91)</th>
<th>Others (N=1,997)</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>n(%)</td>
<td>n(%)</td>
<td>n(%)</td>
</tr>
<tr>
<td>Liveable areas flood water affected</td>
<td>59 (37.6)***</td>
<td>26 (30.6%)*</td>
<td>390 (20.0)</td>
</tr>
<tr>
<td>Non-liveable areas affected</td>
<td>101 (62.4)***</td>
<td>56 (62.2)**</td>
<td>911 (46.1)</td>
</tr>
<tr>
<td>Evacuated home</td>
<td>47 (29.4)***</td>
<td>17 (18.9)</td>
<td>285 (14.5)</td>
</tr>
<tr>
<td>Long time for help to arrive</td>
<td>28 (17.3)***</td>
<td>11 (12.1)*</td>
<td>119 (6)</td>
</tr>
<tr>
<td>Disrupted access to health and social care</td>
<td>62 (38.3)***</td>
<td>23 (25.3)**</td>
<td>266 (13.5)</td>
</tr>
<tr>
<td>Disrupted access to food</td>
<td>53 (32.7)***</td>
<td>25 (27.5)*</td>
<td>377 (19.1)</td>
</tr>
<tr>
<td>Probable post-traumatic stress disorder</td>
<td>67 (40.9)***</td>
<td>25 (27.5)***</td>
<td>250 (12.8)</td>
</tr>
<tr>
<td>Still distressed</td>
<td>65 (40.1)***</td>
<td>22 (24.2)</td>
<td>419 (21.3)</td>
</tr>
<tr>
<td>Suicidal ideation</td>
<td>28 (17.5)***</td>
<td>13 (14.4)**</td>
<td>120 (6.1)</td>
</tr>
</tbody>
</table>

Chi-square test for association: *p<0.05;**p<0.01;***p<0.001 indicates statistically significant association between disability/carer status and flood exposure, disruption & mental health outcome variables.
Funding and acknowledgments

The initial Flood study was funded by the University of Sydney, Western Sydney University, University of Wollongong, the NSW Department of Industry, Planning and Environment, and the Northern NSW Local Health District. The follow-up study was funded by the University of Sydney, the Northern NSW Local Health District, and Southern Cross University’s National Centre for Flood Research.

We acknowledge the Northern Rivers community of NSW who responded to the Community Recovery after Flood surveys, the active support, enthusiasm and commitment of the Community Advisory Groups in Lismore and Murwillumbah, and the Flood Study Team located in Lismore at the UCRH.

Ethics

Ethics approval for the study was granted by University of Sydney Human Research Ethics Committee and the Aboriginal Health and Medical Research Council Human Research Ethics Committee (Ethics ID 2017/589 and 1294/17 respectively).

References


Appendix 1 – Inclusion criteria and questions within the survey related to establishment of the two groups.

Inclusion criteria

1. Respondents living with a disability or long-term illness (n=164) – these were respondents who reported that they were:
   a. Unable to work due to long-term sickness or disability;
   AND/OR
   b. In receipt of the Disability Support Pension either at the time of the flood or at the time of the first survey (6 months after the flood).

2. Respondents caring for a person living with a disability or long-term illness (n=91) – these were respondents who reported that they were:
   a. Responsible for the care (in their home) of a person with disability or long-term illness;
   AND/OR
   b. Indicated that were a ‘carer’ in the Other (please specify) part of questions 40 or 41 (see below) asking about receipt of Australian Government income support at either the time of the flood or at the time of the six-month survey.

To ensure we were capturing carers we reviewed each text entry to ensure it was reflecting that participants were in receipt of the Australian Government’s Carers Payment, which is a payment for providing constant daily care for a person with disability or chronic illness, mental illness, or who is frail aged. We removed five participants from the cohort where this was not the case.

Socio demographic data and free text opportunities in the surveys

Socio-demographic data

Q36. Which of the following describes what you do (if you are in paid work, some of these won’t apply)?

Please tick all that apply.

- At school or in full-time education
- Unable to work due to long-term sickness or disability
- Looking for paid work
- Regular unpaid volunteer work
- Looking after your home or family
- Retired from paid work
• Other (please specify)
• NA

Q39. At the time of the March/April flood, were you responsible for the care (in your home) of: (Please tick all that apply)
• No one
• Children under 5
• Children 5-12
• Teenage children
• Elderly adult
• Child with disability or long-term illness
• Pets
• Other (please specify)

Q40. At the time of the March/April flood, were you receiving any income support from the government? (Please tick all that apply)
• Age-related pension
• Youth allowance
• Newstart Disability support pension
• Parenting payment (single)
• Parenting payment (partnered)
• None of these
• Other (please specify)

Q41. Are you currently receiving any income support from the government? (Please tick all that apply)
• Age-related pension
• Youth allowance
• Newstart Disability support pension
• Parenting payment (single)
• Parenting payment (partnered)
• None of these
• Other (please specify)
Free text opportunities in Survey 1 drawn upon for this analysis

- Q1 – Is there anything on your mind that you want to say right upfront about the flood?
- Q6b – [Did you have to evacuate your home?] If yes, is there anything more you want to say about this?
- Q15g – [In your view, are any of the following organisations to blame for anyone’s distress after the flood?] Is there anything more you want to say about this?
- Q16a – [Were you in the Northern Rivers when the heavy rain fell in June 2017 (about 3 months after the March/April flood?) If Yes: Did this affect you in any way? If so, how?
- Q45 – [Thinking back, have the severe rain and flood resulted in you being able to make any positive changes in your life?] If yes: could you give an example of your positive changes?
- Q58 – Is there anything else you want to add about your experience of the March/April flood or what things are like for you now?

The free text opportunities in Survey 2 (follow-up survey) drawn upon for this analysis

- Q24 – Can you comment on any actions taken by yourself and/or others since the 2017 flood to help you prepare for future floods?
- Q25 – What could be improved to help our community better prepare for future floods?
- Q34b – If the 2017 flood resulted in you being able to make positive changes, could you give an example of your positive changes?
- Feedback – If you have any queries, suggestions or feedback, please use the space below.
## Appendix 2: Respondent characteristics

<table>
<thead>
<tr>
<th>Category</th>
<th>Disability N=164</th>
<th>Carers N= 91</th>
<th>Others (Exclusive of respondents with disability or a carer) N = 1997</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 – 24</td>
<td>5 (3.1)</td>
<td>5 (5.6)</td>
<td>102 (5.2)</td>
</tr>
<tr>
<td>25 – 44</td>
<td>31 (19.1)</td>
<td>22 (24.4)</td>
<td>486 (24.7)</td>
</tr>
<tr>
<td>45 – 64</td>
<td>113 (69.8)</td>
<td>48 (53.3)</td>
<td>999 (50.7)</td>
</tr>
<tr>
<td>65+</td>
<td>13 (8.0)</td>
<td>15 (16.7)</td>
<td>385 (19.5)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>103 (64.4)</td>
<td>72 (80)</td>
<td>1357 (68.9)</td>
</tr>
<tr>
<td>Men</td>
<td>57 (35.6)</td>
<td>18 (20)</td>
<td>614 (31.2)</td>
</tr>
<tr>
<td>Indigenous status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indigenous</td>
<td>10 (6.1)</td>
<td>5 (5.7)</td>
<td>62 (3.2)</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>University degree</td>
<td>37 (23)</td>
<td>36 (40)</td>
<td>904 (45.7)</td>
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<tr>
<td>Other</td>
<td>124 (77)</td>
<td>54 (60)</td>
<td>1076 (54.3)</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid employment (part or full time)/retired</td>
<td>69 (42.6)</td>
<td>64 (71.1)</td>
<td>1741 (88.2)</td>
</tr>
<tr>
<td>Not employed</td>
<td>93 (57.4)</td>
<td>26 (28.9)</td>
<td>234 (11.9)</td>
</tr>
<tr>
<td>Flood water affected</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not flood water affected i.e. suburb not flooded, home or business not flooded, home of close friend or relative not flooded</td>
<td>7 (4.3)</td>
<td>5 (5.5)</td>
<td>193 (9.7)</td>
</tr>
<tr>
<td>Liveable areas of home affected</td>
<td>59 (37.6)</td>
<td>26 (30.6)</td>
<td>390 (20)</td>
</tr>
<tr>
<td>Evacuated home</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>47 (29.4)</td>
<td>17 (18.9)</td>
<td>285 (14.5)</td>
</tr>
<tr>
<td>No</td>
<td>113 (70.6)</td>
<td>73 (81.1)</td>
<td>1687 (85.6)</td>
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<tr>
<td>Displaced</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>115 (70.1)</td>
<td>75 (82.4)</td>
<td>1735 (86.9)</td>
</tr>
<tr>
<td>Yes, &lt; 6 months</td>
<td>31 (18.9)</td>
<td>11 (12.1)</td>
<td>199 (10)</td>
</tr>
<tr>
<td>Yes, ≥ 6 months</td>
<td>18 (11)</td>
<td>5 (5.5)</td>
<td>63 (3.2)</td>
</tr>
</tbody>
</table>