



## PAPER 18

# Experiences of people with disabilities during and after Tropical Cyclone Pam and recommendations for humanitarian leaders

## 1 Introduction

The United Nations Convention on the Rights of Persons with Disabilities promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and promotes the importance of equitable approaches to inclusion in situations of risk and humanitarian emergencies (United Nations [UN] 2008).

In recognition of this, the Sendai Framework calls for a disability perspective in all policies and practices, including the collection and disaggregation of disability data to enable analysis and monitoring of disability inclusion within disaster risk reduction (DRR) efforts (United Nations International Strategy for Disaster Reduction [UNISDR] 2015).

Disasters disproportionately affect people with disabilities in different ways. Inaccessible early warnings and evacuation shelters, and response efforts that are not inclusive can affect the health, safety and recovery of people with disabilities and their families. The loss of assistive devices during a disaster can compromise mobility and independence. People both with and without disabilities are at risk of hazard-related injuries which can create disability, or compound existing functional difficulties (Raja & Narasimhan 2013; Twigg 2014).

A 2013 survey of over 5000 informants with disabilities from 137 countries found that over 85% had never participated in community disaster management and risk reduction processes (UNISDR 2014). Given approximately a billion people, fifteen percent of the world's population, are people with disabilities (World Health Organisation [WHO] & World Bank 2011), this represents a large proportion of people who have most likely not been included in disaster risk reduction efforts.

Tropical Cyclone Pam (TC Pam) hit Vanuatu on the 13th of March, 2015. Over half the population of Vanuatu, an estimated 188,000 people, were affected and eleven people died (United Nations Office for the Coordination of Humanitarian Affairs [UN OCHA] 2015). In the hardest hit provinces of Shefa and Tafea, severe winds destroyed up to 90% of shelters in some communities and badly damaged schools and health facilities. Water sources in many communities in both rural and urban areas were damaged or contaminated (Department of Foreign Affairs and Trade 2017). Immediately after TC Pam, an El Nino event hit Vanuatu, resulting in widespread drought.

The situation and needs of people with disabilities following TC Pam were generally not captured in formal mainstream assessments led by the National Disaster Management Office. Where the needs of people with disabilities were identified, these were not prioritised during the response (Government of Vanuatu 2015); and some people with disabilities missed out on distributions altogether. Reflections on the response hypothesized that mainstream assessment methodologies and tools generally missed people with disabilities, and that agencies tended not to automatically include them in their efforts (Ministry of Justice and Community Services & CARE 2015).

More detailed information regarding the situation and needs of people with disabilities was required to support effective inclusion of people with disabilities in recovery activities. Vanuatu does not currently have reliable quantitative data on the prevalence, location and experiences of people with disabilities. In response, Oxfam in Vanuatu, Vanuatu Society for People with Disabilities (VSPD), Disability Promotion and Advocacy Association

(DPA), the Ministry of Justice and Community Services (MoJCS), Nossal Institute for Global Health and CBM Australia worked with key government organisations to undertake a disability situation and needs assessment in one affected island (Tanna), in order to meet this data gap.

## 2 Methods

This was a cross-sectional survey with nested case-control design which collected data on all people aged five years or older in randomly chosen households within 61 randomly selected clusters across Tanna, making up a representative sample of the population of Tanna. All adults were interviewed directly (where possible), and the parent/guardian of each child (aged 5-17) was interviewed on their behalf.

The survey questionnaire was a locally adapted version of the Rapid Assessment of Disability (RAD) questionnaire, originally developed by the University of Melbourne's Nossal Institute for Global Health and the Centre for Eye Research Australia (Huq et al 2013; Marella et al 2014, Marella et al 2015; Marella et al 2016). The RAD questionnaire asked about household and individual demographic information (including questions on disaster impact), then used a standard set of questions to identify people with disabilities.

Disability questions were different for adults and children. For adults, the RAD questionnaire contained the Washington Group (WG) Short Set of Questions on Disability (Washington Group on Disability Statistics, n.d.), which asked respondents how much difficulty they have in six different areas of functioning (seeing, hearing, walking, self-care, remembering/concentrating and communication). Anyone responding that they had 'a lot of difficulty' or 'cannot do at all' to any one question was considered to have disability. In addition to the WG questions, the RAD adult questionnaire used additional questions on depression and anxiety, use of hands and fingers, learning and appearance to identify people with difficulties in these domains that were also considered to have a disability. The RAD is therefore likely to identify more people with a wider range of disabilities than the WG short set questions alone.

For children, the RAD questionnaire used the draft UNICEF/WG Module on Child Functioning and Disability (UNICEF 2017). The module comprised of the following domains: seeing, hearing, mobility, self-care, fine motor, communication/comprehension, learning, remembering, emotions (anxiety/depression), controlling behaviour, focusing attention and concentrating, coping with change, relationships, and play. As in the adult version of the WG questions, any child who had 'a lot of difficulty' or 'cannot do at all' to any one question was considered to have a disability.

Adults and children who were identified as having a disability were then asked a further series of questions about their wellbeing, rights, and access to services. This latter category included items that explored access to DRR activities prior to the cyclone, access to response activities in the four weeks following Tropical Cyclone Pam, general services and community activities six months since the cyclone up until the time of the survey. If respondents reported any difficulty accessing any of these services, they were asked a follow-up question regarding the reasons for this.

For each adult and child with disabilities, another person living in the same community who was the same sex and approximate age - but did not have a disability - was also asked the same questions on wellbeing and access to services, to enable comparison of the experiences of people with and without disabilities.

The questionnaire was adapted, reviewed for cultural and technical appropriateness, piloted and translated in partnership with local stakeholders, including people with disabilities and people from Tanna. Interviewers were also selected from among people with disabilities, people from Tanna and people with links to local stakeholders. This strategy maximised the inclusive and relevant nature of the survey. Interviewers visited households personally, gained consent from participants and entered data onto digital tablets, using KoboToolbox software ([www.kobotoolbox.org](http://www.kobotoolbox.org)) to collect data and upload it a database for monitoring and analysis.

### 2.1 Stakeholder engagement and application of findings

This study was accompanied by a number of activities that sought to strengthen capacity of stakeholders to plan and implement disability inclusive DRR policies and practices in an evidence-based way. These three activities

included a training workshop focussed on measuring disability (held in Melbourne), three review workshops of interim results for stakeholder feedback and interpretation (held in Tanna, Port Vila and Melbourne), and two training workshops on disability inclusive preparedness for response.

Data analysis workshops drew together local stakeholders including people with disabilities to present interim findings from the survey. Trends that appeared to be emerging from the data were presented to stakeholders and their interpretation and responses to these results were derived in a participatory workshop. The feedback and interpretations, as well as narratives recording personal experiences, were transcribed and used to guide some aspects of the final analysis of the data, as well as the discussion and recommendations in this report.

The training workshops in Tanna and Port Vila offered an opportunity for key stakeholders in the humanitarian and disability sectors in Vanuatu to learn how to strengthen disability inclusive preparedness for response approaches, and observations and recommendations from the previous workshops. A key output from these workshops was a disability inclusive preparedness for response training package that is being developed and published for use by other organisations.

### 3 Results

The study surveyed respondents in 648 households across Tanna. A total of 1836 adults and 1330 children aged 5-17 were included in the final analysis, but only results from the adult survey are reported here. Women were 53.8% of adults, and 55% of adults were aged 18-35, consistent with Vanuatu's young, rapidly growing population.

About 1 out of every 21 adults (4.6%) had a disability, using the RAD definition. After adjusting for clustering effects, the prevalence of disability among adults on Tanna using the RAD functional definition was 4.63% (with 95% confidence interval of 3.76 – 5.69%). Calculation of adult prevalence using the WG short set of questions alone gave an estimate of 3.6% (95% CI: 2.8% - 4.5%).

There was no significant difference in disability prevalence between men and women, but disability prevalence increased significantly with age. More than half of all adults with disabilities (57%) were aged over 55, and their average age was 56.7 years.

Among adults with disabilities, the most common functional difficulty was with walking (36% of adults with disabilities), followed by difficulty seeing (34%), difficulty learning how to do new things (32%), difficulty remembering or concentrating (29%) and difficulty hearing (26%).

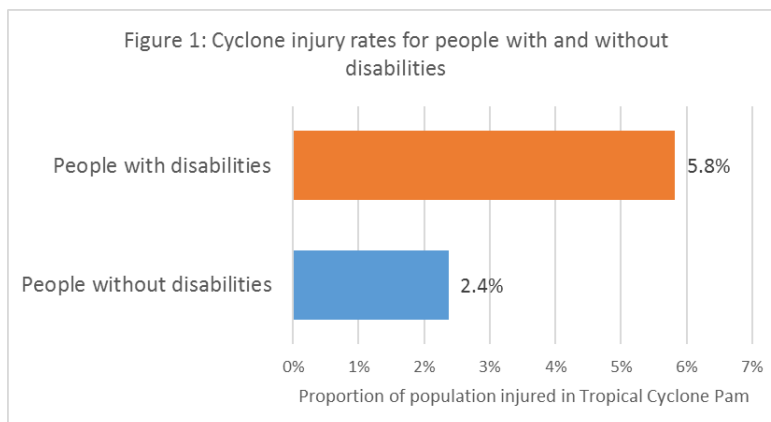
#### 3.1 Direct Impact of TC Pam

Almost all household representatives (92%) reported that their house was damaged during TC Pam, and 77% of households were self-assessed as uninhabitable.

79% of households evacuated during the cyclone; of those who did not evacuate, 64% said they had no need to evacuate and 29% said they had nowhere to go. This concurs with the poor access to evacuation shelters reported elsewhere in this survey.

This survey was not designed to record deaths on the island, but 47 adults and 23 children without disabilities, and 5 adults and 1 child with disabilities were reported injured during or in the immediate aftermath of the cyclone. The most common injuries were cuts and broken bones, and two respondents had sustained burns.

The injury rate among people with disabilities was 5.8%, which was significantly higher than the injury rate of 2.4% for people without disabilities. People with disabilities were 2.45 times more likely to have been injured in the cyclone than people without disabilities (95% CI: 1.04 – 5.77,  $p=0.040$ ). This difference was not significant when adjusted for age and sex. However, given the generally older cohort of people with disabilities, this does point to an increased risk of injury for people with disabilities during cyclones, most likely due to the disproportionate risk experienced by people with disabilities.



TC Pam was also responsible for disabilities: two adults with disabilities attributed their disability to the cyclone. In both cases the disabilities were due to vision problems caused by flying debris.

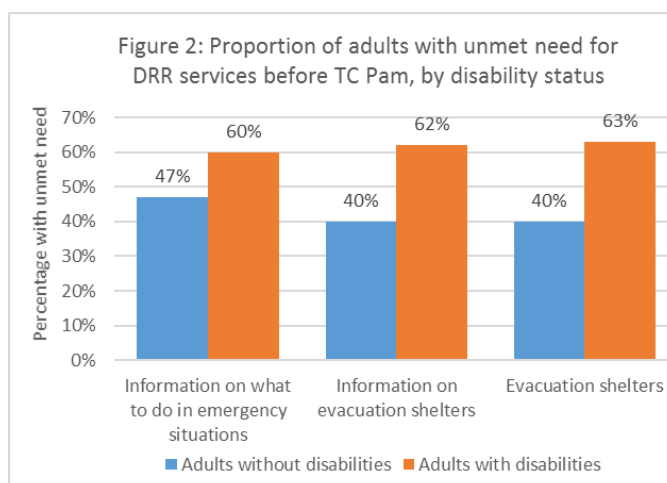
Thirteen adults (including six with disabilities by the RAD measure) lost their assistive devices during the cyclone, including glasses, walking sticks, crutches and a wheelchair.

### 3.2 Access to disaster risk reduction services prior to TC Pam

Adults with disabilities experienced poorer access to information on evacuation shelters, and to evacuation shelters themselves, than adults without disabilities. Fewer people (29% of cases - adults with disabilities - and 23% of controls – adults without disabilities) had an unmet need for information on the cyclone itself, possibly indicating that formal and informal early warning systems were the most effective DRR activity on Tanna.

Adults with disabilities were significantly more likely to have an unmet need for information on evacuation shelters (62% for cases vs 40% for controls,  $p=0.039$ ) and unmet need regarding access to evacuation shelters (63% vs 40%,  $p=0.032$ ).

These results imply that DRR coverage on Tanna prior to TC Pam was generally limited, and that evacuation shelters and activities promoting them were not adequately inclusive of adults with disabilities.



### 3.3 Access to services in the four weeks after TC Pam (response phase)

Access to services immediately after the cyclone was poor for most people, and not significantly different between people with and without disabilities.

Services with the highest level of unmet need for people with disabilities were health services (51%), women’s health services and products (65%), drinking water (42%) and emergency shelter materials (42%).

### 3.4 Access to services and community activities from TC Pam until the time of survey

Access to services and community activities continued to be poor for all adults in the 12-18 month period following the cyclone. This may partly reflect pre-existing availability of these services prior to the cyclone, but may also reflect longer-term impact of the cyclone.

There was no significant difference in access to services and community activities between adults with and without disabilities.

Levels of unmet need for medication (51% of cases, 59% of controls), health services (44% and 62%), safe drinking water (39% and 33%) and toilet facilities (33% for both) were particularly high.

Unmet need for disability-specific services, including rehabilitation services (60% of adults with disabilities), assistive devices (78% of adults with disabilities) and access to Disabled People's Organisations (82% of adults with disabilities) reflect the generally poor access to these services in most islands of Vanuatu.

### 3.5 Barriers to accessing services and community activities

Compared to their non-disabled peers, adults with disabilities more frequently reported that physical accessibility was a barrier to most services. The most common reasons for poor access to services for all adults was the absence of the service, or lack of information about the service.

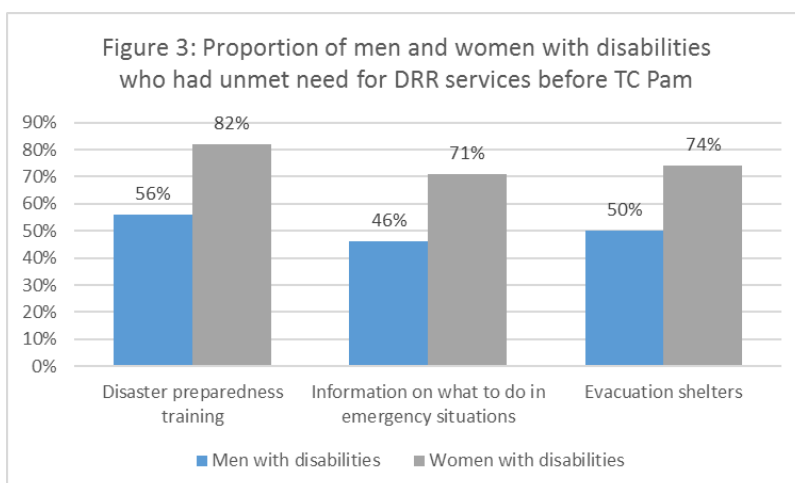
Adults with disabilities reported that accessibility of the built environment was a barrier to almost all services and activities, and for many services (shelter materials, food distribution, safe drinking water, toilet facilities, rehabilitation services, community consultations, social and religious activities, transport), it was the most frequently mentioned barrier.

### 3.6 Women and men with disabilities

Men and women were equally likely to have disabilities. Among adults with disabilities, there were no significant differences between men and women in terms of age, literacy, employment and household socio-economic status.

Women with disabilities were significantly less likely to have ever attended school. One third of women with disabilities (33%) had attended school at some point, compared to two thirds of men with disabilities (65%,  $p=0.004$ ). This is a far greater gender disparity than in the general population.

In comparison to men with disabilities, women with disabilities were significantly more likely to report unmet need for participation in DRR information/training sessions (82% vs 56% unmet need,  $p=0.013$ ), information on what to do in emergencies (71% vs 46% unmet need,  $p=0.021$ ), and access to evacuation shelters (74% vs 50%,  $p=0.030$ ). The disparities in access to information and training may partly relate to lower levels of education among women, and decisions about who is invited or allowed to attend training sessions.



Despite this disparity in DRR services, women were less likely than men to have been injured in the cyclone. The injury rate among men was 3.8%, compared to 2% among women, meaning men were 1.9 times more likely

to have been injured in the cyclone (95% CI: 1.07 – 3.34, p=0.027, adjusted for age). This may be due to gender roles leading to differences in where men and women were located when the cyclone hit, and in the activities they led during and in the immediate aftermath of the cyclone, leading to differential risk of injury.

## 4 Summary and Conclusion

In addition to experiencing similar limitations in access to services in the aftermath of TC Pam as everyone else, this study demonstrates that people with disabilities faced additional limitations in particular areas. These included limited access to information about evacuation, reduced access to evacuation centres themselves, and increased risk of injury. On top of difficulty accessing mainstream disaster preparedness and response services, people with disabilities also reported additional losses and unmet needs, including the loss of assistive devices, and minimal access to disability-specific supports such as rehabilitation services, assistive devices and Disabled People's Organisations. This led to increased risk of injury for people with disabilities.

This study indicates that in order for people with disabilities at the community level to have equitable access to safe evacuation shelters and services after a disaster, DRR processes need to be inclusive. This means that the particular diverse accessibility needs of people with different kinds of disabilities need to be taken into account, as well as lower literacy levels caused by limited access to education which was found to be commonly experienced by people with disabilities.

This research demonstrates that women with disabilities experienced particular exclusionary effects, including reduced access to DRR information and education sessions and evacuation shelters. Women with disabilities experience the burden of double exclusion related to their gender and their disability; their inclusion requires DRR programs to be intentionally geared to identify and address the barriers they experience.

This project concludes that in order to reach everyone, DRR efforts led by Government and Non-Government Organizations cannot be "one size fits all". DRR programs need to take into account individual community members and their particular strengths and needs, and tailor activities so that everyone is included. Efforts must be made prior to disasters occurring, to ensure that people with disabilities know where to go, how to get there, and how to access services, and so that all community members have the knowledge and skills to take responsibility for inclusive preparedness, evacuation and response before, during and following a disaster.

The twin track approach provides a useful framework for planning and implementing disability inclusive DRR strategies. It guides the mainstreaming of disability inclusion across existing DRR programs, while also acknowledging and addressing the particular needs people with disabilities have, for example rehabilitation, assistive devices and sign language.

Disaster responses are often planned based on information collected during assessments immediately following the event. Assessments following TC Pam did not systematically include questions or methodologies which collected reliable information about the particular needs of people with disabilities. This may be a causal factor for the exclusion found through this study. The identification of men, women and children with disabilities and investigation of their needs must be driven through stronger disability inclusive post-disaster assessment processes. This study found that the use of individual-level data collection may not be feasible in an assessment process which collects data at the household level; alternative, household level methodologies and tools must be tested for application following future disasters. This report provides an option for further exploration.

Since TC Pam, other disasters including cyclones have battered Pacific countries, making the recommendations arising from this study particularly important for all humanitarian stakeholders to consider and implement in the context of their disaster risk reduction programs.

Evidence from this study underpins the following recommendations, which are targeted at government and non-government humanitarian agencies in Vanuatu and other Pacific Island Countries.

- 1) Mainstream disability inclusion across DRR and response policies and practices:
  - a) Consult with men, women and children with a diverse range of disabilities and their representative organisations to identify differential risk and develop strategies which address barriers to meaningful

participation in disaster risk reduction initiatives. Particular attention must be paid to preparedness and the provision of accessible evacuation information, infrastructure built in accordance with design for all (universal design) principles, and strategies which ensure people evacuate safely with their assistive devices.

b) Strengthen Community Disaster Committees so that:

- i) Men and women with diverse disabilities are active participants, with opportunities to assume leadership roles in times of disaster preparedness, evacuation and disaster response.
- ii) Households and communities take responsibility for the identification and inclusion of people with disabilities in disaster preparedness activities, and safe evacuation of all men, women and children with diverse disabilities during times of disaster to ensure no one is left behind.

c) Prepare for disability inclusive disaster response by strengthening organizational capacity of all actors to work in a disability inclusive way, by training staff, consulting with people with disabilities, developing plans and tools and forming formal relationships with Disabled People's Organisations before a disaster.

- 2) Develop questions and methodologies which enable reliable identification of people with disabilities and their needs immediately following a disaster.
- 3) Identify and address the disability-specific needs of men, women and children with disabilities prior to and after disasters:
  - a) Prepare communities to enable safe evacuation of people with disabilities and their assistive devices.
  - b) Facilitate access to replacement assistive devices following a disaster by developing partnerships with government and non-government service providers.
- 4) Work in partnership with Disabled People's Organizations to prepare and implement disability inclusive disaster risk reduction and response activities, in accordance with the Convention on the Rights of Persons with Disabilities, and the Sendai Framework.
- 5) Acknowledging the specific challenges faced by women with disabilities following disasters, collaborate with women with diverse disabilities to develop and implement disaster risk reduction strategies which support their safety and inclusion:
  - a) Develop accessible, safe and private sanitation and accommodation facilities in evacuation shelters and buildings constructed following a disaster;
  - b) Implement education and skills development opportunities which include women with diverse disabilities;
  - c) Improve access to legal assistance and support from Disabled People's Organisations and women's rights organisations; and
  - d) Undertake further exploration of the gender based violence experiences of women with disabilities following disasters, and mainstream strategies to prevent and respond to these.
- 6) Ensure child-friendly disaster risk reduction, response and recovery initiatives are inclusive of children with diverse disabilities and their families.

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