People with Psychosocial Disabilities in Disaster Events

The impact of exclusion from preparedness for people with psychosocial disabilities

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People with psychosocial disabilities are amongst those at highest risk during and after disaster events. This is for a range of reasons, including that people with psychosocial disabilities: experience significant human rights abuses in most settings; are subject to pervasive negative attitudes, marginalisation and are often excluded from Disaster Risk Reduction (DRR) activities and humanitarian responses.

The impetus for the Convention on the Rights of Persons with Disabilities (UNCRPD) was to shift societal norms from seeing people with disabilities as passive objects of care, towards inclusion as rights holders. Despite relative progress in this regard for people with disabilities, people with psychosocial disabilities continue to be detained in institutions and/or shackled or locked up in the community against their will on the basis of disability. They are often forgotten altogether during disaster planning or response, including during evacuation.

A further danger is that institutionalisation of people with psychosocial disabilities may rise after a disaster event. This is due to an ongoing lack of psychosocial supports and services provided in the community which are based on free, informed consent. There is an urgent need to address the barriers to inclusion of people with psychosocial disabilities.

Consultations with people with psychosocial disabilities

As part of the consultation into the report *Our lessons: An approach to disability-inclusive disaster risk reduction, March 2022*[1], interviews and focus group discussions were conducted to ensure that the perspectives of people with more marginalised disabilities, including people with psychosocial disabilities, were included throughout the report. In these specific focus groups and interviews, people with psychosocial disabilities related how they often feel unsafe and unsupported during disaster events - especially at the time of evacuation and whilst in evacuation centres.

The following discussion draws from these consultations and wider available literature to present key findings about the experiences of people with psychosocial disabilities during disaster events.

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People with psychosocial disabilities are not sufficiently included in planning, response, and recovery

People with psychosocial disabilities **are generally not involved in disaster event planning, response, and recovery** or in decision making processes, consultations, or policy meetings. This is based on an unfounded belief that people with psychosocial disabilities do not have decision making capacity or are unable to contribute. In some countries ***"persons with psychosocial disabilities are not identified as persons with disabilities, rather as persons with a medical condition alone and are stuck in institutions and will remain there for the rest of their life."***- FGD participant from Pakistan.

Disaster events can increase mental health issues

A disaster event can be especially difficult for people with psychosocial disabilities – initiating additional stress responses. **People with psychosocial disabilities reported experiencing much higher levels of stress and anxiety than prior to the disaster event**.

"People with psychosocial disabilities can often get heightened anxiety, particularly as it gets worse, some members get PTSD with Typhoons, they feel shelters are unsafe, people at the shelters don't understand disability and don't accommodate them." – FGD participant from Guam.

Forgotten: people with psychosocial disabilities in institutions

People with psychosocial disabilities in institutions are often not considered in preparedness measures. This means they can be left behind without the means to evacuate and survive the event, often leading to death.

"[A] lack of information during natural disasters to patients in St Giles [psychiatric] hospital is a cause of anxiety." – FGD participant from Fiji.

"Many people with psychosocial disabilities die in institutions during disasters, nobody notices it or helps them out of the situation. This is a situation in the whole of the Asia Pacific Region. Such institutions are prone to fire accidents and people are not rescued." – FGD participant from India.

Institutions have been associated with poor hygiene, and deprivation of basic needs including social distancing.[2] This has resulted in people with psychosocial disabilities being at greater risk of contracting and dying from COVID-19. Other than the many human rights violations that happen in institutions, people living in institutions have faced a lack of information or necessary resources to protect themselves from infection.

Use of detention and confinement as a standard response to gaps in disaster preparedness and inclusion

Evacuation of people with psychosocial disabilities is rarely properly planned - particularly regarding people who are in institutions and not considered as part of the general evacuation planning process.

"[There is a] lack of specific plan[ning]to evacuate persons with disabilities, particularly persons with psychosocial disabilities." – FGD participant from Indonesia.

In some community contexts, the use of confinement practices such as shackling remains common.

Together, this means that when it comes to evacuation time, **people with psychosocial disabilities are often left behind**.

"This we found due to many factors such as shackling, the evacuation team not sensitised to support in such situations, stigma and belief that persons with psychosocial disability are dangerous and they will hurt, lack of recognition as human beings." – FGD participant from Indonesia.

Where there have been stay at home orders introduced, such as during the COVID-19 pandemic, shackling has also been reported as a practice used by communities to respond to some people with psychosocial disabilities. Locked down communities have resorted to this practice due to stigma and fear, and lack of access to community mental health care, leaving people with psychosocial disabilities locked up without essential services and support.[3]

"The response and recovery do not include the specific services such as rehabilitation and health services including mental health service. This restricts a lot of people to cope and recover." – FGD Participant from Sri Lanka

Inappropriate supports available during response and recovery

Even when people with psychosocial disabilities can overcome the multiple barriers to evacuation during disaster events, they then face multiple barriers to safety and recovery: such as **evacuation shelters designed and staffed by people who have little understanding of the needs of people with psychosocial disabilities**.

Shelters are often overcrowded and can feel unsafe.

"I will not go to the shelter because I don't think it's safe. I have anxiety about being around people I don't know, and the crowding feels like I am 'smooshed', contained and it's a lot of anxiety around shelters…" – FGD participant from Guam.

Staff within shelters have limited training and often are unaware of issues related to any disability and in particular psychosocial disabilities.

"The issue is the lack of basic understanding by those who run the shelters because they are not certified to work with people with psychosocial disabilities. Inside shelters it's so cluttered that people using a wheelchair can't get around. We don't want to go because everything is so close together." – FGD participant from Guam.

Poorly designed shelters, and lack of policies and procedures are compounded by poor awareness and stigmatizing attitudes of staff. Active engagement of people with psychosocial disabilities in all disaster planning and preparation activities would better address these issues.

Barriers in disaster recovery phase

"Many persons with psychosocial disabilities are left out of relief recovery packages due to social stigma." – FGD participant from Nepal.

The barriers and challenges for people with psychosocial disabilities do not end after the disaster event, leaving them isolated and left behind without dignified services throughout the recovery phase.

"Mentally affected from the moment they prepare for the disaster through to after [the] disaster hits due to limited, if not no, recovery assistance from family members or outside circle." – FGD participant from Tonga.

Right to live independently in the community not respected in the context of disaster

Disaster recovery efforts often do not accommodate people with psychosocial disabilities to return to live independently in their community. Lack of preparedness and negative attitudes of service providers can lead to poor quality responses for people with psychosocial disabilities during the disaster recovery phase, in many cases resorting to institutions and other confinement practices. In research by the US National Council on Disability, with disaster affected communities, key informants noted that many survivors who had been living independently previously, were placed in institutions, and had not returned to their communities, while others reported people being threatened with restriction of civil liberties such as guardianship orders to force them into institutions.[4]

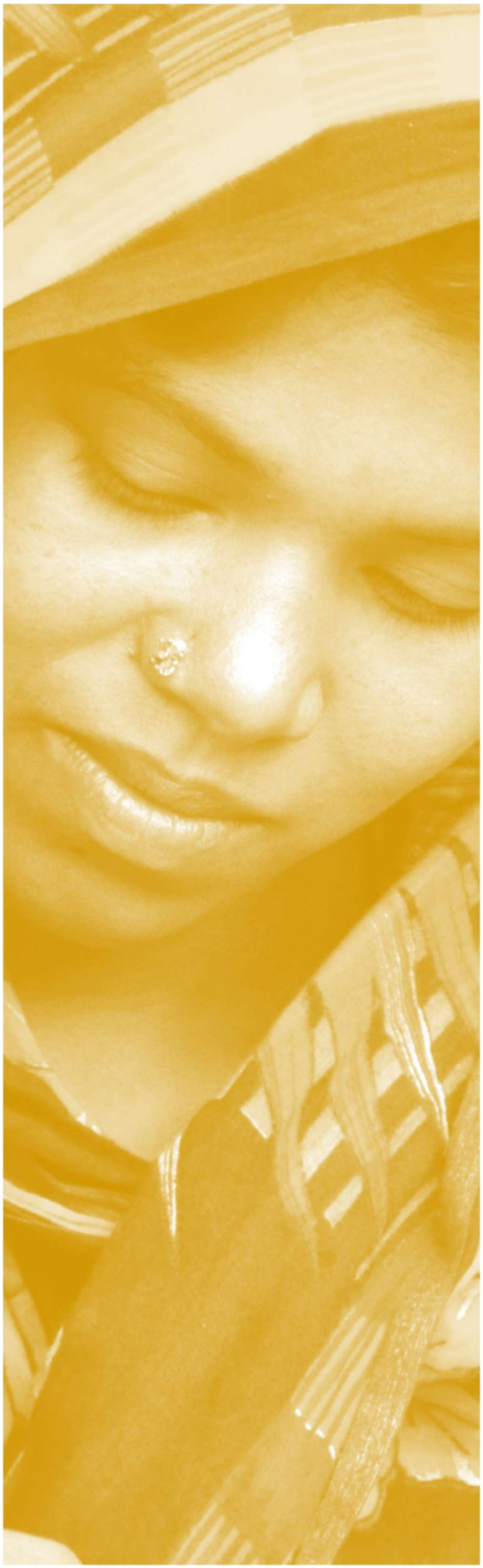
Unnecessary, protracted institutionalisation perpetuates the cycle of rights violations and poorer outcomes for people with psychosocial disabilities.

COVID-19 has been an important opportunity to highlight the need for guidelines to prevent institutionalisation of people with psychosocial disabilities, to speed up the task of de-institutionalization and has seen moves by the Committee of the United Nations Convention on the Rights of Persons with Disabilities to develop much needed *Guidelines on Deinstitutionalization of Persons with Disabilities, including in emergency situations.*[5]

"Due to stigmatisation, people with disabilities were already label[led] as useless and worthless human beings which cannot contribute any valuable assets to the community. Therefore, the people with disabilities were not invited or considered to be heard." – FGD participant from Tonga.

The involvement of people with psychosocial disabilities in disaster planning, response and recovery at all levels is critical to ensure an appropriate response.

Addressing barriers faced by people with psychosocial disabilities



The consultation found that an important reason that people with psychosocial disabilities are left behind in DRR and humanitarian response, is due to a **lack of awareness among all stakeholders**. This results in a lack of inclusion around the specific issues faced by people with psychosocial disabilities at all levels.

Efforts must be made towards de-institutionalization and development of adequate home and community-based supports and services which are pre-requisites for ensuring that people with psychosocial disabilities have dignified recovery from disasters and events. Thus, ensuring people with disabilities' right to full participation in society, to live independently and to receive empowering forms of support and assert control on the way they want to live and receive support, before, in the event, and after a disaster.

The findings of these consultations and others highlight the need for all stakeholders to commit to inclusion and to involve people with psychosocial disabilities and their representative organisations of persons with disabilities (OPDs) to understand their needs around information, accessibility and inclusivity of DRR, particularly in the planning stage and development of policies and procedures, so as to ensure that disaster response services and systems include them.

Governments, National Disaster Management Offices (NDMOs), INGOs, CSOs and OPDs, can better foster the inclusion of people with psychosocial disabilities in DRR efforts **by addressing the driving causes of social marginalisation.** This could be achieved through funding inclusive community initiatives for 'building back better', de-institutionalization, conducting community awareness-raising programmes to remove the stigmatisation, discriminatory attitudes, and social exclusion of people with psychosocial disabilities.

Funding Support should also be given for OPD engagement to make sure there is **representation of people with psychosocial disabilities who are fully involved at every stage from disaster event planning, response, and recovery**.

Funding would contribute towards the strong need **to improve rights-based practices around psychosocial disability** as part of an inclusive approach to DRR, including **preventing approaches that violate the CRPD such as institutional or coercive practices such as institutionalization, solitary confinement, use of physical restraints and shackling**. This would also involve advocating for the compliance of international human rights standards in the context of disaster preparedness, response, and recovery.[6]

Endnotes

1. CBM Inclusion Advisory Group, 2022, Our Lessons: An approach to disability-inclusive disaster risk reduction. Based on consultations with people with disabilities in the Asia and Pacific regions.

2. Human Rights Watch, 2020, Living in Chains Report https://www.hrw.org/report/2020/10/06/living-chains/shackling-people-psychosocial-disabilities-worldwide, p. 50.

3. Ibid.

4. Ibid., p. 21

5. Committee on the Rights of Persons with Disabilities, 2021, Regional consultations and guidelines on deinstitutionalization, Article 19. Annotated outline of Guidelines on Deinstitutionalization of Persons with Disabilities, including in emergency situations. Endorsed at the CRPD 25th Session. From: https://www.ohchr.org/en/treaty-bodies/crpd/regional-consultations-and-guidelines-deinstitutionalisation-article-19

6. UNICEF, 2019, Discussion paper: Rights based approach to disability in the context of mental health., p. 37.