



## Active Participation: Key to Inclusion

Testimonies from Humanitarian Workers with Disabilities



International  
Disability  
Alliance



**Cover image:**

**Typhoon Haiyan Philippines - Ageing and Disability Focal Points (ADFPs) in early 2014.**

**ADFPs aim to ensure that persons with disabilities and older people are included in emergency response. They do this by operating as specialised hubs, identifying the services that exist and the people with the needs and make the referrals. As well as improving the lives of the individual people and the families, ADFPs also raise awareness of disability inclusion among mainstream humanitarian organisations.**

**This image shows the ADFP Supervisor at the entrance to the ADFP in Concepcion during the emergency response after Haiyan.**

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CBM is an international Christian development organisation, committed to improving the quality of life of people with disabilities in the poorest communities of the world.

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## Foreword

Publications about humanitarian work and disability generally focus on how the exclusion of persons with disabilities from emergency aid increases casualty rates, psychosocial impact, and health issues. Not only are these negative effects directly impacting the individual people, but also they reduce the ability of their immediate families to cope and ultimately impede the recovery of society as a whole. Indeed, all of this is indisputable and the humanitarian community is becoming aware of it.

But this document, produced by CBM and the International Disability Alliance, goes one step further, and in doing so it will challenge preconceptions and change attitudes. By reading the first-hand accounts, we hear how persons with disabilities, not through any particular talent or skill but from unique knowledge gained through life experience, are ideally placed to provide insights, ideas

**Gordon Rattray (right) meeting Badsha Mia during a field visit to Gaibandha, Bangladesh.**



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and leadership, to supply essential data, and to fill the gaps in humanitarian response that cause this exclusion.

Manish, from Nepal, tells us about the challenges that people faced trying to access relief information after the 2015 earthquake. His organisation and colleagues from other Disabled People's Organisations (DPOs) produced radio slots and sign language for television bulletins. They also participated in training sessions with shelter stakeholders, and with support from our experience of past emergencies they ran focal points, identifying people and their needs and referring them to mainstream service providers.

Carlos, from Chile, echoes these experiences, talking about frustration in his early days in emergency response, but explains how; with experience and resources he and his colleagues are now well recognised and provide essential preparedness information for persons with disabilities and training for emergency responders on inclusion.

Succeeding these testimonies, the 'Charter on Inclusion of Persons with Disabilities in Humanitarian Action' provides an agenda to make humanitarian action address the rights of persons with disabilities and, at the time of writing, is being endorsed by humanitarian actors, from States to UN agencies and NGOs at all levels. Among the commitments, 'Participation' clearly spells out that persons with disabilities must be meaningfully involved in all phases of humanitarian action.

From my own experience of working in an emergency response unit, I see that the understanding of disability in humanitarian work is evolving. When persons with disabilities are seen not only as recipients of aid on an equal basis with others but are involved in relief efforts as active responders, their communities, and society as a whole, will benefit. This is the only way to achieve fully inclusive humanitarian action.

### **Gordon Rattray**

Emergency Communications Coordinator, CBM

## National Federation of Disabled Nepal



[www.nfdn.org.np](http://www.nfdn.org.np)

Manish Prasai is the administrative manager of NFDN, a national organisation, representing 300 DPOs across the five regions of Nepal.

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“We first had to save ourselves as we were all directly affected by the earthquake,” says Manish Prasai.

The 2015 earthquake that devastated Nepal was NFDN’s first experience of being directly involved in emergency response and, during the recovery phase, in advocacy for disability-inclusion.

“Once we could organise ourselves again in Kathmandu we started to try to contact our members,” says Manish. “It was chaotic, phone lines were down and communication was very difficult. Step by step we got information about the situation and many of our members told us about the difficulties they faced in accessing information about relief and distribution; there were so many terrible stories about destroyed homes, displacement and death, and our members losing their assistive devices,” continues Manish.

“ Strive to ensure that services and humanitarian assistance are equally available for and accessible to all persons with disabilities... **Charter 2.4** ”

Persons with disabilities often face additional challenges and can be more at risk during the aftermath of such a devastating earthquake. In Nepal, the rights of persons with disabilities are not very high on

the agenda of the government or the public services, and thus they still face stigma and discrimination, which will be reflected during an emergency response. This also implies that many persons with disabilities will not have received proper preparedness information, nor taken part in emergency training or received information on how to protect their own lives in case of a disaster.

**“Our very first response was to contact the national radio channel,” says Manish. “We didn’t know exactly what to do, but we thought that it was important to send out information via radio where we requested all emergency responders to make sure that all at-risk-groups, including of course persons with disabilities, also got immediate support. We also developed a rapid assessment questionnaire to make a quick survey among our members, to have a better idea of their needs.”**

Four days after the disaster, NFDN succeeded in arranging a first meeting with a number of humanitarian organisations, among them CBM, and proposed a partnership to address the inclusion of persons with disabilities in the emergency response. CBM immediately accepted the proposal and together the two organisations worked out a strategy to provide support in three of the most affected districts and at the same time set up Ageing and Disability Focal Points.

**“As this situation was new to NFDN and its members, CBM provided us with excellent information from their previous experiences, such as in the Philippines and Haiti,” explains Manish. “This really helped us to plan the work and especially how to organise the Ageing and Disability Focal Points.”**

The main objectives of CBM and NFDN’s collaboration were: 1) to collect and analyse information about persons with disabilities in the three districts; 2) to identify their needs and categorise and classify them in order to be able to link people with appropriate and available services and refer those that need more specific services; and 3) to set up referral mechanisms and district focal persons who could participate in cluster meetings.

**“Participating in cluster meetings in Kathmandu, with high level representatives of UN agencies and other humanitarian organisations was another new experience for us and it was**

not always easy to be heard in these cluster and response committees,” says Manish. “To begin with, we found the meetings a bit confusing and discussions were held in English language without translation. So, some of our focal persons had difficulties to follow and were not certain that their concerns raised, in local language, were actually heard. We learned a lot during this process.” He further adds – “the support of organisations such as CBM and Handicap International during these meetings was very helpful.”

Through the Ageing and Disability Focal Points, more than 3500 persons with disabilities and older people were identified and supported and more than 1000 were successfully referred to appropriate relief, such as food, shelter or medical attention.

“Many of the UN agencies and also the Nepalese government were not properly sensitised on disability,” summarises Manish. “For example, the recent guidelines produced by the International Federation of Red Cross and Red Crescent Societies (IFRC) on inclusive shelter management need to be used in practice; hardly anyone knew about them, and

**NFDN providing orientation session to its members in Makwanpur on how to run focal points and do advocacy during the emergency response.**



© NFDN



many shelters were not accessible to persons with disabilities. Secondly, our thinking has changed: disaster can no longer be an optional issue! All groups in society and individuals should have an emergency plan and a basic understanding of disaster and preparedness in order to react and respond safely. Finally, we also saw several positive outcomes at the end of this 10-month project with CBM. The post-disaster reconstruction plan has to be inclusive and we've seen some changes, for example among the local authorities in Kathmandu. After we made a presentation on accessible reconstruction they came back to us and asked us to work with them in the reconstruction plans and implementation."

## ONG Inclusiva Chile



[www.onginclusiva.org](http://www.onginclusiva.org)

Carlos Kaiser at the Expo Emergencia in Peñaflor municipality in 2013, where ONG Inclusiva was raising awareness on disability in emergencies and disasters.

© ONG Inclusiva

“Inclusion doesn’t work when people don’t understand what it means in practice,” says Carlos Kaiser, when being asked about how humanitarian actors and field workers can better ensure persons with disabilities’ access to relief and aid. Carlos is executive director of ONG Inclusiva in Chile, an NGO where persons with disabilities are leading the work.

“If they keep on looking at us as persons without abilities, we will always be marginalised,” he continues. “Inclusion starts with recognising everybody’s rights and moving away from a charitable way of looking at emergency response and disability.”

ONG Inclusiva was set up in the aftermath of the devastating earthquake that destroyed a large part of the central coast of Chile in 2010. When the discussions and planning on reconstruction started, Carlos, together with colleagues from the University Austral de Chile, realised the extent of the exclusion and invisibility of persons with disabilities during the immediate response phase - they had faced huge challenges in accessing even basic relief items and often their demands were not listened to because of negative attitudes and lack of knowledge on how to communicate with persons with disabilities.

“They look at us, persons with disabilities, as if we don’t have the same capacity as others”, says Carlos. He explains how this motivated him and his colleagues to develop a disability-inclusive reconstruction proposal, which was, to their surprise, widely accepted. This was the start of setting up ONG Inclusiva, which was officially registered in 2013.



Promote meaningful involvement of persons with disabilities and their representative organizations... and draw from their leadership, skills, experience and other capabilities to ensure their active participation in decision making and planning processes... **Charter 2.2**



“To put knowledge to the service of proper action,” continues Carlos, “means that we need to base emergency response on evidence and field workers need to be trained to provide relief according to standards. A country’s emergency response is influenced by the values and culture of that society. Therefore, ONG Inclusiva works in providing concrete guidance and training for emergency responders about diversity and how the capacities of persons with disabilities can be used to improve relief and protection in humanitarian action.”

In 2013, the ‘Manual on Inclusive Management of Emergencies: human rights of persons with disabilities in emergencies’ was published. This is a largely collaborative work among academics, PAHO/WHO and ONG Inclusiva, and provides guidance and clear advice for persons with disabilities and their families and for local and national authorities on how to be prepared for emergencies and to build disability-inclusive emergency response. Carlos is proud that the manual is now being used outside Chile, for example in Argentina, Spain and Uruguay.




**Launch of the Manual on Inclusive Management of Emergencies in Chile 2015.**

© ONG Inclusiva

“The World Conference on Disaster Risk Reduction in Sendai was a turning point in the field of disability rights at international level. Finally we have a framework that declares we also should be accounted for in data and statistics; until now we’ve been invisible,” says Carlos. “The Sendai framework



is an important step forward in terms of the inclusion of persons with disabilities in all levels of disaster risk management.”



Develop, endorse and implement policies and guidelines based on existing frameworks and standards, supporting humanitarian actors to improve inclusion of persons with disabilities in emergency preparedness and responses.

**Charter 2.3**



Carlos also talks about his personal frustration during the earthquake in Chile 2010 in not being able to provide immediate help and support for his people. A couple of years after the earthquake, and with the experience of developing the manual on inclusive emergency management, ONG Inclusiva decided to develop an example of building a safe, inclusive and resilient city: ‘Peñaflor Town Inclusive Safe Community: resilience for all’.

“Peñaflor is an atypical community where the authorities have a strong commitment to resilience,” explains Carlos. “With ONG Inclusiva’s practical approach to inclusion - from providing sign language training for first responders, equipping persons with disabilities with emergency kits and furnishing a stock of mobility aids in case of emergencies, to influencing the local council on safety and emergency - inclusion is becoming a daily practice.”

This example was also recognised internationally in 2014, when ONG Inclusiva was awarded a grant from the RISK award in Davos for its work in Peñaflor, which enabled them to develop the project further.

“The most important issue in making sure that emergency response is inclusive of persons with disabilities is the preparedness,” summarises Carlos. “Pre-assessment of the structure of the population, mapping of roads and infrastructure, and the emergency plans of public services such as hospitals and schools have to include and take into account the rights of persons with disabilities.”

## Disability Promotion & Advocacy Association of Vanuatu



“You are all included in the Disaster Risk Reduction plans claimed the participating organisations and national agencies on disaster management during a workshop we organised two years ago,” says Nelly. “But when we continued to discuss and dig into their understanding on how to include persons with disabilities before, during and after a disaster, we realised it was all just on paper.”

During the Cyclone Pam in 2015, DPA and its members experienced at first hand the challenges of both evacuating ahead of the cyclone and afterwards in accessing relief and information.

“Early warning mechanisms were not understood by some of our members and sometimes persons with disabilities were not even informed by their neighbours. This shows the urgency for both DPOs and our authorities to commit to actively include disability and persons with disabilities in planning, preparedness and response.” says Nelly.

After the disaster DPA gathered a lot of testimonies from persons with disabilities, describing their difficulties in evacuating, in accessing relief and about discrimination. DPA decided to carry out a more systematic assessment of all their members, so that they could



Condemn and eliminate all forms of discrimination against persons with disabilities in humanitarian programming and policy, including by guaranteeing protection and equal access to assistance for all persons with disabilities.

**Charter 2.1**



bring these results both to the cluster meetings and afterwards to the authorities for improving disaster relief and response.

**“One of our members, who is a wheelchair user, told us that the food distribution site was not at all accessible, it was totally chaotic,” says Nelly. He had to argue with the security guards to have a priority to receive assistance otherwise he would never have received food.”**

Nelly was supported to join some cluster meetings through the assistance of Oxfam. She says that this was a great learning experience but that it also showed her that persons with disabilities need more training on emergency response.

**“There were many expatriates from international organisations and you need to understand English, they do not always bring in translation. You need also to be well prepared, bring relevant data and dare to speak up!”**

DPA is now working on raising awareness both among their own members and relevant disaster management authorities on disability-inclusion in emergency preparedness and response. Together with the Pacific Disability Forum, a Disability-Inclusive Disaster Risk Reduction toolkit has been developed, and is currently used in Solomon, Vanuatu, Tonga, Samoa, Kiribati and Fiji across the Pacific Islands for various capacity building actions. A recent outcome of the project was the Post Winston Assessment in Fiji that was conducted by the Pacific Disability Forum and Fiji Disabled People’s Federation. The key findings from the assessment were shared widely with different national clusters with emphasis on the promotion and protection of the rights of persons with disabilities in Fiji.



DPA conducts training on how to support persons with disabilities in emergencies based on their experience during the Cyclone Pam in 2015.



© DPA

Nelly summarises the experience of DPA with some key recommendations.

“The most important thing is to actively involve persons with disabilities at all levels at the time of policy making and actions. After, what has been written in papers has to be implemented in reality; having very precise indicators on disability defined will support that. More concretely, during the emergency response, accessibility should be a key principle, starting with evacuation centres being fully accessible, to ensuring that communication and information about distribution or shelters can be accessed and understood by everyone.”

## International Deaf Emergency



[www.ideafe.org](http://www.ideafe.org)

Emmanuel Jacq (in the middle) together with a group of people during the reconstruction of houses in Haiti.

© IDE

“When we first came to Haiti after the earthquake in 2010, we met plenty of NGOs but none of them were actually thinking about the deaf population,” says Emmanuel, executive director of International Deaf Emergency (IDE), an international DPO. “I searched at international level but couldn’t find any organisation representing deaf people in emergencies, so that’s when we decided to create our organisation; to support the deaf and other persons with disabilities to be visible and have a voice in disaster and emergencies, where they have usually been invisible.”

During the emergency response in Haiti, which was initially chaotic and very difficult to manage according to Emmanuel, deaf people, as other persons with disabilities, were totally left out and had difficulties to access relief services. Lack of knowledge on how to communicate with deaf people was a main difficulty, but also the prevailing stigma and discrimination against persons with disabilities.

“Due to the severe impact of the earthquake and the enormous destruction, the desperation among people created fear and people were fighting to survive. In such a situation, persons with disabilities were extremely vulnerable, pushed away during food distribution or even had their food parcels stolen,” says Emmanuel.





Ensure that emergency and preparedness planning are designed to take into account the diverse needs of persons with disabilities.” **Charter 2.4**



In response to this situation, IDE supported the setting up of a fully inclusive tent camp in Port-au-Prince where 400 deaf people and their families could be temporarily settled together with other displaced families. This action was implemented in cooperation with the Red Cross, the French Embassy and Watermission International.

“We don’t aim to separate the deaf community from others, but because of lack of sign language interpreters among aid agencies and urgent needs among the deaf population for immediate relief, offering them this shelter enabled people to get urgent health services and also correct and updated information,” explains Emmanuel. “They also felt safe in this camp. It was shown afterwards that there was much less criminality and abuse in this camp compared to others, most probably because of the connection among people. Deaf people living in other camps also used this camp as a reference point.”

During the reconstruction phase, the Red Cross, who had taken over the management of the camp, decided to build more permanent houses. IDE then made sure that the cash-for-work programme was inclusive of deaf and deaf and blind persons as well as other persons with disabilities. Persons with disabilities are often excluded from such opportunities, due to misconceptions about their capacities.

“My first impression as a relief worker, also being deaf, was the striking way persons with disabilities united and worked together to overcome the challenges. They kept enthusiastic despite having lost everything. This motivated us to work further to build a bridge between aid agencies, governments and organisations of persons with disabilities. On the other hand I also faced difficulties due to communication barriers when meeting with aid agencies and donors. Luckily we have an overseas sign language interpreter.”

Emmanuel finishes the interview pointing out that there is a need to build capacities of persons with disabilities and help them self-



## Deaf people taking part of the reconstruction of houses in Haiti.



© IDE

organise, particularly deaf and deafblind people. Something as basic as education is still a challenge for many deaf, hard of hearing or deafblind children and illiteracy is high – many are not in school or don't even learn sign language especially in rural areas.

**"In Haiti there was no representative organisation for deaf people at national level in 2010, which is so important in order to be involved in, for example, Disaster Risk Reduction. IDE supported the set up of a national federation of deaf organisations that is now active since 2015. Increasing participation of DPOs in policy development and planning requires raising people's awareness about their rights and then training them on disaster preparedness, planning and response with adequate resources. So, we need to work both directly to raise people's voice during an emergency response but also work long-term to build capacities and raise awareness on the rights of persons with disabilities and how to make humanitarian action more inclusive," ends Emmanuel.**


## Charter on Inclusion of Persons with Disabilities in Humanitarian Action

- 1.1) We, the signatories of this Charter<sup>1</sup>, reaffirm our determination to make humanitarian action inclusive of persons with disabilities and to take all steps to meet their essential needs and promote the protection, safety and respect for the dignity of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.
- 1.2) We shall strive to ensure that persons with disabilities have access to humanitarian response, both in terms of protection and assistance, without discrimination, and allowing them to fully enjoy their rights. By this Charter, we reaffirm our collective will to place persons with disabilities at the centre of humanitarian response.
- 1.3) For the purpose of this charter, persons with disabilities include those who have long-term physical, psychosocial, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in, and access to, humanitarian programmes.
- 1.4) This Charter refers to all persons with disabilities, applies to all situations of risk and humanitarian emergencies and at all phases of a humanitarian response, from preparedness and crisis onset through transition into recovery.
- 1.5) We recognize that further progress towards principled and effective humanitarian action will only be realized if humanitarian preparedness and response becomes inclusive of persons with disabilities, in line with the humanitarian principles of humanity and impartiality, and the human rights principles of inherent dignity, equality and non-discrimination. We recall the obligations of States under international human rights law, in particular the Convention

<sup>1</sup> This document expresses our common political intention and intended course of action, however, it does not establish legally binding obligations to the States and other actors and does not affect the signatories' existing obligations under applicable international and domestic law.

on the Rights of Persons with Disabilities, international refugee law and further stress the obligations of States and all parties to armed conflict under international humanitarian law, including their obligations under the Geneva Conventions of 1949 and the obligations applicable to them under the Additional Protocols thereto of 1977, to respect and protect persons with disabilities and pay attention to their specific needs during armed conflicts.

- 1.6) With the intention of leaving no one behind, we reiterate our commitment to fully support the implementation of the 2030 Agenda for Sustainable Development as a core element in ensuring the inclusion of persons with disabilities. We highlight our will to translate into action the Sendai Framework on Disaster Risk Reduction and stress the necessity to support its implementation as an essential instrument to empower persons with disabilities and promote universally accessible response, recovery, rehabilitation and reconstruction.
- 1.7) We recall that persons with disabilities are disproportionately affected in situations of risk and humanitarian emergencies, and face multiple barriers in accessing protection and humanitarian assistance, including relief and recovery support. They are also particularly exposed to targeted violence, exploitation and abuse, including sexual and gender-based violence.
- 1.8) We recognize the multiple and intersecting forms of discrimination that further exacerbate the exclusion of all persons with disabilities in situations of risk and humanitarian emergencies and whether they are living in urban, rural or remote areas, in poverty, in isolation or in institutions, and regardless of their status, including migrants, refugees or other displaced persons, and that crisis often leads to further impairment.
- 1.9) We stress the importance of improving capacity building of national and local authorities and the broader humanitarian community on issues related to persons with disabilities, including though increased awareness and adequate




resourcing. We recognize that existing policies, procedures and practices on inclusion of persons with disabilities in humanitarian programs need to be strengthened and systematized. We further stress the importance of collection and analysis of disability data disaggregated by age and sex, as an important element in the design and monitoring of States' obligations, humanitarian programming and policy as a whole.

- 1.10) We recall that persons with disabilities and their representative organizations have untapped capacity and are not sufficiently consulted nor actively involved in decision-making processes concerning their lives, including in crisis preparedness and response coordination mechanisms.

**We commit to:**

## 2.1) Non-discrimination

- a. Condemn and eliminate all forms of discrimination against persons with disabilities in humanitarian programming and policy, including by guaranteeing protection and equal access to assistance for all persons with disabilities.
  - b. Facilitate the protection and safety of all children and adults with disabilities, recognising that multiple and intersecting factors such as gender, age, ethnicity, minority status, as well as other diversity and context-specific factors necessitate distinct responses and measures.
  - c. Pay specific attention to the situation of women and girls of all ages with disabilities in the context of situations of risk and humanitarian emergencies and further take all necessary action to empower and protect them from physical, sexual and other forms of violence, abuse, exploitation and harassment.
- 

## 2.2) Participation

- a. Promote meaningful involvement of persons with disabilities and their representative organizations in the needs assessment, design, implementation, coordination, monitoring and evaluation of humanitarian



preparedness and response programs and draw from their leadership, skills, experience and other capabilities to ensure their active participation in decision making and planning processes including in appropriate coordination mechanisms.

- b. Work to foster inclusive community-based protection mechanisms so as to better provide tailored and context specific response and strengthen the resilience of persons with disabilities, their communities, their families and caregivers.

### 2.3) Inclusive policy

- a. Engage with all relevant States, and other stakeholders and partners to ensure protection for persons with disabilities as required by international law.
- b. Develop, endorse and implement policies and guidelines based on existing frameworks and standards, supporting humanitarian actors to improve inclusion of persons with disabilities in emergency preparedness and responses.
- c. Adopt policies and processes to improve quantitative and qualitative data collection on persons with disabilities that delivers comparable and reliable evidence and is ethically collected, respectful of confidentiality and privacy. Ensure that data collected on persons with disabilities is disaggregated by age and sex, and analysed and used on an ongoing basis to assess and advance accessibility of humanitarian services and assistance, as well as participation in policy and program design, implementation and evaluation.

### 2.4) Inclusive response and services

- a. Ensure that emergency and preparedness planning are designed to take into account the diverse needs of persons with disabilities
- b. Strive to ensure that services and humanitarian assistance are equally available for and accessible to all persons with disabilities, and guarantee the availability, affordability and access to specialized services, including assistive

technology in the short, medium and long term.

- c. Work towards the elimination of physical, communication, and attitudinal barriers including through systematic provision of information for all in planning, preparedness and response, and strive to ensure the accessibility of services including through universal design in programming, policies and in all post-emergency reconstruction.

## 2.5) Cooperation and coordination

- a. Foster technical cooperation and coordination among national and local authorities and all humanitarian actors, including international and national civil society, UN agencies, the Red Cross and Red Crescent Movement, and representative organisations of persons with disabilities, to facilitate cross-learning, and sharing of information, practices, tools and resources inclusive of persons with disabilities.
- b. Foster coordination between development and humanitarian actors with a view to strengthening local and national service systems inclusive of persons with disabilities and capitalizing on opportunities to rebuild more inclusive societies and communities.
- c. Sensitize all international and national humanitarian staff, local and national authorities on the rights, protection and safety of persons with disabilities and further strengthen their capacity and skills to identify and include persons with disabilities in humanitarian preparedness and response mechanisms.



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CBM is an international Christian development organisation, committed to improving the quality of life of people with disabilities in the poorest communities of the world.

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