Empowerment and participation

Good practices from South & South-East Asia
in disability inclusive disaster risk management

Disability
inclusive
DRR
Network
for Asia and Pacific

HANDICAP
INTERNATIONAL

Aktion
Deutschland Hilft
Bündnis deutscher Hilfsorganisationen

Abbreviations

ADH	Aktion Deutschland Hilft - Germany's Relief Coalition
BPBD	Badan Penanggunaggan Bencana Daerah - District/Province Disaster Management Agency (Indonesia)
CBDRM	Community-based disaster risk management
CRA	Community risk assessment
CSO	Civil society organisation
CSMC	Cyclone shelter management committee
DCP	Disability creation process
DiDRRN	Disability inclusive Disaster Risk Reduction Network
DIPECHO	Disaster preparedness programme of the European Commissions's Humanitarian Aid department (ECHO)
DPO	Disabled persons' organisation
DRM	Disaster risk management
DRR	Disaster risk reduction
EWS	Early warning system
IEC	Information, education, communication
NGO	Non-governmental organisation
NTT	Nusa Tenggara Timur (a province in the eastern part of Indonesia)
RRAP	Risk Reduction Action Plan
SUBU	Scale Up, Build Up (DRR project in the Philippines)
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

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Good practices from South & South-East Asia in disability inclusive disaster risk management.

This report presents selected good practices from South and South-East Asia that highlight how persons with disabilities can participate in and contribute to efforts in disaster risk management. The good practices were collected through an online screening survey amongst DiDRRN members. In addition, field research was conducted in Indonesia and the Philippines.

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Table of contents

Executive summary

As the good practices in this report illustrate, the inclusion and active participation of persons with disabilities in disaster risk management can come a long way: as they got engaged in community and higher-level advocacy meetings, the women and men portrayed in this paper have shed the stigma of mere recipients and become valued contributors to risk reduction efforts. Empowered, their dedication has become palpable: through their contribution to better risk management, their lives have been transformed, perceptions changed, and risks reduced.

The paper begins by laying out why disaster risk management (DRM) and the participation of persons with disabilities matters. Despite being a vulnerable group at high risk of being affected by natural and man-made hazards, the specific needs, concerns and capacities of persons with disabilities are often 'invisible' and not appropriately integrated into DRM set-ups.

Although much has been achieved over the past decade regarding the participation of persons with disabilities in DRM - notably the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the formation of the Disability inclusive DRR Network (DiDRRN), the creation of several guidelines and adoption of national policies, there is still a fair way to go on the road towards realizing the vision that the risks of persons with disabilities are reduced to the same level as those of anyone else.

Participation is the key: once integrated into DRM efforts, persons with disabilities can ensure that their specific concerns are appropriately addressed. Aside from reduced risk, there are also numerous other benefits that in sum can transform and improve the lives of men, women and children with disabilities.

How, then, can this participation be facilitated? Following a brief review of the 'twin-track approach' - and basic considerations on participation of persons with disabilities in **section A**, this report addresses this question in its main part through the presentation of good practices from South and South-East Asia.

These practices were identified through an online screening survey amongst DiDRRN members, submissions by partners based on a detailed template, as well as through interviews and field research in Indonesia and the Philippines.

Reviewing these good practices, three main recommendations emerge towards the facilitation of persons with disabilities, presented in **section B**.

The first recommendation concerns **the enabling of persons with disabilities to take up active roles as DRM actors** (section B, chapter 3). Two practices from the Philippines and Nepal highlight how through initial encouragement, training and coaching, men and

women with disabilities have not just participated in DRM efforts and taken steps to enhance their personal resilience, but actually moved further by actively contributing to enhance the lives and reduce the risks of their entire communities. In the process, they have not just become 'visible', but valued and respected members of their communities.

The second recommendation highlights the **engagement of persons with disabilities in community-based DRM efforts** (section B, chapter 4). Good practices from the Philippines, Bangladesh, Vietnam and Indonesia show that actual participation can come through various channels and forms. The hosting of a radio program by persons with disabilities is an innovative and effective way to disseminate key DRM messages to a wide audience. The practice from Indonesia, meanwhile, makes the point that disability-inclusive DRM should be approached not head-on, but rather from a functional perspective (focus on high-risk groups) - especially where levels of stigmatization run high. It also argues for synchronization between community-level implementation and policy-making, pointing out that both elements are needed to create effective and sustainable results.

Finally, the third recommendation is about **extending the leverage through joint advocacy efforts towards inclusive DRM** (section B, chapter 5). By looking at practices from the Philippines and Indonesia, it is illustrated that building on existing networks and resources, forming of coalitions of like-minded organizations, soft diplomacy and trust-building are all key ingredients to successful advocacy. Preparedness for long-term engagement and anticipation of setbacks are additional elements.

By presenting and analyzing good practices from South and South-East Asia, the main part of this paper serves to extend existing knowledge, allowing practitioners to replicate and adapt approaches and lessons learnt. Given the positive and at times surprising outcomes, they also serve as an encouragement to persons with disabilities themselves.

In **section C**, the report provides fifteen practical recommendations that are based on good practices and that run in support of the enabling, engagement, and extension of leverage for the participation of men, women and children living with a disability in disaster risk management. A summarized version is presented on the following two pages.

The report concludes that when working towards disability-inclusive disaster risk management, *processes* and *outcomes* are intimately linked to each other. The key resources for success in this field are already there - not only the several manuals and technical advice, but more crucially, persons with disabilities themselves. *Their* participation is the ultimate key.

List of recommendations		
What?	**Why?**	**How?**
A. ENABLE participation of persons with disabilities to take up active roles as DRM actors		
A.1 **Thoroughly collect information** on disability.	In order to appropriately plan concrete disaster risk management actions in a given area, it is crucial that information is obtained about the number of persons with disabilities, their specific impairments, interests, capacities, risks and needs, as well as their supportive environment (families, neighbours).	1. Develop a questionnaire that elicits the key information you need (see template in the guideline of Malteser International). 2. Ask village stakeholders to fill in questionnaires. 3. Meet these stakeholders (including people with disabilities and their family members) to collect and double-check 4. Analyze information and highlight special points for consideration for further steps.
A.2 **Empower** persons with disabilities by informing them about their rights and roles in DRM, by building their confidence and by training them appropriately.	Due to exclusion and stigmatization, many persons with disabilities tend to shy away from (and have little experience in) speaking for themselves at public meetings, and may not be aware of their rights and possible roles in DRM. Therefore, they need to be informed about such rights and roles. Their confidence and capacity needs to be reinforced prior to their engagement in the community - without such preparation, efforts towards inclusion are likely to fail.	Visit persons with disabilities and their families and explain why DRM matters and how they could make a difference. Encourage them to get involved and suggest possible roles. Spend time with them enquiring about their capacities, needs and concerns. Then deliver training sessions to persons with disabilities that help develop and practice public speaking and representation.
A.3 **Include family members and caregivers** of persons with disabilities.	Family members and caregivers need to be included for three reasons: a) their involvement tends to make persons with disabilities more comfortable, b) they often have their own specific concerns, and c) they often support the evacuation and protection of persons with disabilities. Their involvement must not replace the participation of persons with disabilities themselves.	Involve caregivers throughout the entire process; listen to their specific concerns, highlight the benefit of their involvement, and suggest possible roles in community-based efforts. Value their contributions to care and the wider community.
A.4 Identify and **address barriers** to participation.	An obvious point worth highlighting: in order to be able to participate in meetings, persons with disabilities must be able to access meeting venues and have assistance available if required. Social or attitudinal barriers to participation also need to be identified and addressed.	Consider what it takes for a person with a disability to get engaged - can he or she easily attend a meeting, drill, or advocacy events? Ensure that those activities are accessible when selecting venues and arrange assistance as required (e.g. translators for deaf persons). Identify and address other barriers to participation.
B. ENGAGE persons with disabilities in DRM efforts		
B.1 **Discuss** with persons with disabilities **adequate roles in DRM** that consider their specific strengths and impairments.	Not everybody is good at everything - whether they have an impairment or not. Therefore, it it important to discuss with persons with disabilities potential DRM roles that they would feel comfortable with - what functions can someone best assume, given individual strengths and challenges. Aim to recognize, incorporate and build their potential. Inadequate roles may overwhelm persons with disabilities and be detrimental to their effective participation. Avoid stigmatized roles.	Ask each person with a disability what concrete role he or she feels comfortable playing in a village's DRM set-up. For instance, a person with a mobility impairment may be unsuitable in search and rescue but formidable at arranging emergency shelters or in advocacy.
B.2 Identify, select, train and **engage 'thought leaders'** amongst people with and without disabilities.	The ability to build up confidence and capacity is limited - not everybody has the charismatic leadership qualities required to argue and convince others. Efforts are most effective if (potential) 'thought leaders' can be identified and their capabilities reinforced - who in turn can convince others. 'Thought leaders' are required *both* for community-based efforts and for advocacy.	Amongst all community members (wider community and pre-trained people with disabilities), some people will demonstrate leadership qualities as they speak up, argue their case, and convince others. Select those persons, develop their skills further and engage them in the ongoing process towards reinforcing disability inclusive disaster risk management.

What?	Why?	How?
B.3 **Approach** disability inclusion **tangentially** instead of head-on.	Especially in areas where stigmatization of persons with disabilities is pronounced, it may be counter-productive to approach the issue of disability directly. Instead, discuss risk reduction more generally and approach disability inclusion 'through the back door' - e.g. by asking about who is at the greatest risk.	Consider that community members may have several urgent needs and that disability inclusiveness may not be at the top of their agenda, in particular where stigmatization is strong. Therefore, address the 'common denominator' first and then approach disability from a functional perspective. As the community identifies people with disabilities as a high-risk group, what can be done and what can they do to reduce their risk?
B.4 **Drive a synchronized approach** between higher levels (policy) and lower levels (implementation).	Both the levels of policy (e.g. district) and implementation (community) need to be addressed if efforts in inclusive DRM are to be sustainable - stand-alone approaches are doomed to be short-lived. Community-level mechanisms require both back-up for larger disasters as well as ongoing financial support.	Drive your efforts towards disability inclusive DRM through two parallel and inter-linked channels: Involve policy-makers in community implementation, and facilitate feedback from communities to policy-makers. Restrict the role of external organisations to facilitation and advice, and let the linkage between communities and policy-makers develop autonomously.
B.5 Fully **engage** all key **stakeholders**, including representatives of vulnerable groups as well as service providers .	Although multi-stakeholder dialogues can be time-consuming, it is crucial that all key players "pull on the same string" - without such a unified effort, DRM is less effective and systematic.	Conduct a thorough stakeholder mapping to ensure that no key stakeholder is omitted, and to identify possible roles. Invite all stakeholders and involve them in an ongoing manner.
B.6 **Consider radio programming** as an effective channel for the promotion of disability inclusive DRM.	The involvement of people with disabilities in radio programming can be hugely effective: highlighting their own experience, they are credible promoters of inclusive disaster risk management to a wide audience.	Identify possible radio stations for programming on disability inclusive disaster risk management. Then identify and train suitable persons with disabilities as anchormen or women. Thoroughly prepare programme content that delivers key messages and is presented in an interesting manner. Coach the new anchor persons (consider co-anchors) and identify sources of funding.
C. EXTEND the leverage through joint advocacy efforts towards inclusive DRM		
C.1 Build on existing networks and **form coalitions** between like-minded organizations.	Advocacy is most effective if coalitions between like-minded organizations can be built and maintained - such a coalition yields greater leverage on government counterparts than separate and un-coordinated efforts.	When advocating for policy changes towards disability-inclusive disaster risk management, involve existing partners (such as like-minded CSOs, DPOs, INGOs) and assess whether other stakeholders may be interested to expand a coalition. Agree on a common objective prior to launching advocacy efforts.
C.2 Persons with disabilities should directly **represent themselves**.	Direct involvement of persons with disabilities helps change mindsets of government counterparts and tends to be more effective than indirect representation by others.	Follow the steps described above under 'inclusion' and encourage persons with disabilities to speak for themselves in advocacy efforts, laying out the greater effectiveness and likely change of perception amongst counterparts.
C.3 **Plan** for the **long haul**.	Advocacy takes time to be effective: Consensus need to be built between key players, policies devised, translated into practice, tested and possibly amended. One should be ready to accompany this process for several years, in particular when advocating for policy changes on the national level.	Plan strategically and beyond the lifespan of most projects. While advocacy can be effective over short time spans on the community level, consider successive projects with an overlapping focus in advocacy, and/or plan projects with a duration of at least three years for higher levels.
C.4 **Anticipate** and reduce the risk of **set-backs**.	A common set-back is related to staff turnover: if key government players are replaced (e.g. after local elections), advocacy efforts may need to be renewed.	Always base your efforts on a range counterparts (not just the head) amongst stakeholders -this will reduce the risk of advocacy outcomes being lost due to staff turnover.
C.5. **Pursue soft diplomacy** and trust-building.	A diplomatic approach that argues and demonstrates the case for disability inclusive DRM is more likely to succeed than a confrontational stance. Gaining the trust of government counterparts and building close relationships is crucial.	Build trust with counterparts, for instance through informal relations, learn and understand their viewpoints, backgrounds and interests. Rather than focussing on past mistakes or omissions, focus on shared objectives.

Introduction

When disaster strikes a community, everyone is affected in one way or another. Villagers may be injured or even lose their lives, see their houses and assets damaged or destroyed, and their livelihoods undermined. The recovery can often take several years, as people rebuild their livelihoods. Disaster risk management (DRM) is about reducing vulnerability and reinforcing resilience - the ability of communities to anticipate, reduce the impact of, cope with, and recover from the effects of adversity without compromising their long-term prospects. DRM efforts need to be inclusive and should not leave aside community members based on age, gender, disability or other factors. Many national and international laws and conventions recognize the equal rights of persons with disability in disasters. In its Article 11, the UN Convention on the Rights of Persons with Disabilities (UNCRPD) states the right to protection and safety in the event of a disaster.

Persons with disabilities nonetheless often remain excluded from DRM policies and practices, even though they are particularly vulnerable to disasters. Often hampered by stigma and a view that they are merely at the receiving end of charitable efforts, many persons with disabilities are not involved in community affairs. Their reduced social participation represents a barrier to their participation in DRM activities and their basic access to information and other services. Their living conditions and poverty often exacerbates their vulnerability to disasters while reducing their capacities to cope with such events.

During a crisis, persons with disabilities are often 'invisible' to relief operations, as they are not included in assessments, relief and evacuation measures. The response to their basic needs is often not adapted and their specific needs are ignored. The environmental disruption created by a natural hazard can represent an added barrier to their survival, security and access to assistance: the loss of a caregiver, a mobility aid, destroyed roads are cases in point. Persons with disabilities are also at higher risk of abuse and violence and they see their physical and psychological health affected by disasters, with the aggravation or creation of new temporary or permanent impairments.

While much has been achieved against this background, the path towards full adoption of disability inclusive disaster risk management is still long. Today, persons with disabilities are slowly starting to be considered in DRM activities. Yet, to a considerable extent, their voices remain unheard, as few persons with disabilities are directly engaged through active roles in the DRM process. This paper aims to contribute to the greater participation of persons with disabilities in disaster risk management by showing encouraging practices.

Much remains to be done. Indeed, inclusive DRM materializes only when the views of persons with disabilities are being heard and taken into account - shaping the evolving practices under disaster risk management set-ups. To that end, persons with disabilities should, just like any other member of the community, be able to discuss and contribute, taking active roles and responsibilities towards reduced disaster risk for all.

Highlighting good practice

By highlighting some of the progress achieved towards the participation of persons with disabilities in disaster risk management, this collection of good practices from South and South-East Asia aims to motivate and encourage DRM policy-makers and practitioners, and provide guidance as to how greater inclusiveness and participation can be attained. Initiated by the Disability Inclusive DRR Network for Asia and the Pacific (DiDRRN), this paper was produced by Handicap International with the financial support of Aktion Deutschland Hilft, Germany's Relief Coalition.

Map of South and South-East Asia: Locations of presented good practices

Good practice 3.2 (page 11)
NEPAL
Good practice 4.5 (page 20)
BANGLADESH
Good practice 4.7 (page23)
Good practice 4.4 (page18)
VIETNAM
Good practices
4.1 (p. 13) 4.2 (p. 15),
5.1 (p. 26), 5.3 (p.29)
THE PHILIPPINES
Good practice 3.1 (page 9)
INDONESIA
Good practice 4.6 (page 21)
Good practice 5.2 (page27)
Good practices
4.3 (p. 16), 5.3 (p.29)

The collection of good practices was guided by the definition of criteria to correctly identify good practices, showing examples of participation of persons with disabilities in disaster risk management. In a first step, Banyaneer, the consultancy recruited for the production of this paper, conducted an online screening survey amongst DiDRRN members. In a second step, the consultants invited selected respondents to provide more detailed information in a good practice template.

The good practice stories presented in this paper were thus produced with the contribution of DiDRRN members such as ASB, CDD, Handicap International, and Malteser International. Furthermore, the consultants visited central and eastern Indonesia as well as the central Philippines to identify additional good practices from Handicap International.

The paper is structured in three sections that illustrate general recommendations towards greater participation of persons with disabilities. *Section A* provides the background on disability inclusive disaster risk management and reviews existing guidelines as to how the participation of people with disabilities in disaster risk management can be facilitated.

Section B contains the actual good practices, structured in three separate chapters that illustrate general recommendations towards greater participation of persons with disabilities. Each practice highlights the involvement of individual persons as well as groups, describes the initial setting, the achievements, and the lessons learned from the practice. Each practice concludes with a box with key insights. The final *section C* presents the key recommendations that can be drawn from the good practices and that are geared to inform future programming.

SECTION A | **BACKGROUND**

1. Inclusive disaster risk management

1.1 Disability and inclusion

Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that:

> "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments (including visual, speech, and hearing impairments) which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".[1]

To understand all processes involved in creating situations of disability, the "Disability Creation Process"(DCP) uses the expression "disabling situation" to emphasize the fact that disability is not a state but indeed a situation. This situation results from the interaction between personal and environmental factors, that, for a given social role, can facilitate a person's participation, or create a situation of disability.

Studies show that because of their disabilities, persons often do not receive the needed health care, they are less likely to attend schools, to be employed; they are often unable to participate in the community and likely to face severe poverty.[2]

One of the seven guiding principles of the UNCRPD is the full and effective inclusion in society. Inclusion means respecting the full human rights of all persons, acknowledging diversity and ensuring that everyone can actively participate in development processes and activities, regardless of age, gender, disability, state of health, ethnic origin or any other characteristics.

Inclusion is not just about "involvement" or "integration" but about upholding rights, recognizing specific needs and barriers to inclusion, and taking steps to address these issues.

Barriers refer to physical or invisible obstacles that prevent a person with disability from accessing or fully participating in "life activities". There are a number of different types of barriers such as *physical barriers*; this refers to barriers preventing access to the built and physical environment; *social and cultural barriers* including negative behaviours such as prejudice, pity, over-protection and stigma. Finally, *institutional barriers* refer to policies, legislation and institutions which do not adequately support the rights of everyone in the community.
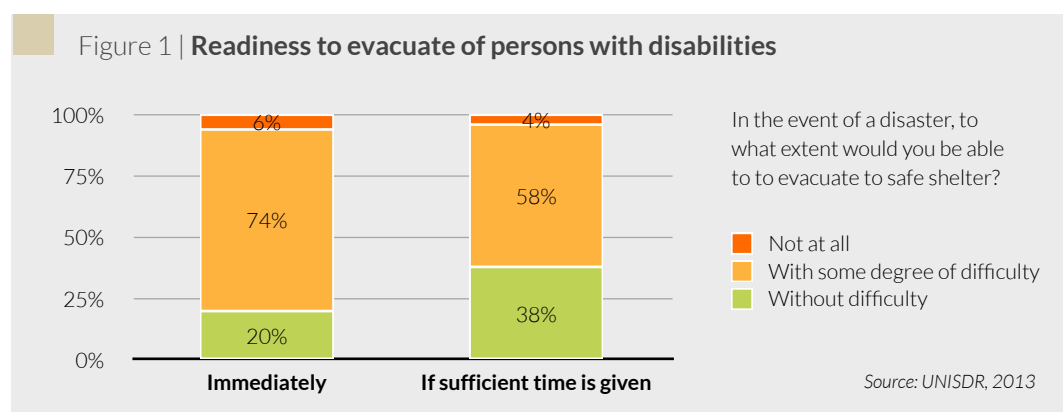
1.2 Disability and disasters

Natural disasters such as earthquakes, floods and cyclones have a huge impact on human infrastructure, lives and livelihoods. Persons with disabilities are amongst the most vulnerable of groups in society. An estimated 15% of the world's population lives with some form of disability. These women, men and children are at particular risk from disasters.

A 2013 survey[3] amongst 5,450 respondents with disabilities from 126 countries illustrates why persons with disabilities are injured or lose their lives at disproportionately high rates[4]: as they are rarely consulted about their needs, preparedness, relief and recovery efforts often take these needs into account.

Figure 1 below shows that in the event of a sudden disaster, only 20% of respondents say they could evacuate immediately without difficulty, while the majority would have some level of difficulty or not be able to evacuate at all. If sufficient time was given to evacuate, 38% say they could evacuate without difficulty - still a minority of all respondents. The fact however that the percentage of those who say that they could evacuate without difficulty if

1. See UNCRPD *http://www.un.org/ disabilities/default.asp?id=261*

2. See WHO (2010): World Report on Disability *http://www.who.int/disabilities/ world_report/2011/report/en/*

3. See UNISDR's Global Survey of Persons with Disabilities (2013) *http://www.unisdr.org/archive/35032*

4. Considerable evidence from specific disasters shows that persons with disabilities are disproportionally affected by disasters. For instance, data from the 2011 East Japan earthquake indicate that the mortality rate was 0.8% amongst the overall population but 3.5% for persons with disabilities (UNESCAP 2012).

Figure 1 | **Readiness to evacuate of persons with disabilities**

In the event of a disaster, to what extent would you be able to to evacuate to safe shelter?

- Not at all
- With some degree of difficulty
- Without difficulty

Source: UNISDR, 2013

sufficient time was given almost doubles underscores the importance of early warning systems that reach all members of the community, regardless of mobility or communication challenges.

The survey also highlights that 71% of respondents have no personal preparedness plan. Only 31% always have someone to help evacuate, while 13% never have anyone to help them. Just 17% of respondents were aware of a disaster management plan of their community, out of which a mere 14% had been consulted on these plans. At the same time, 50% say that they wish to participate in disaster risk management (DRM) efforts.
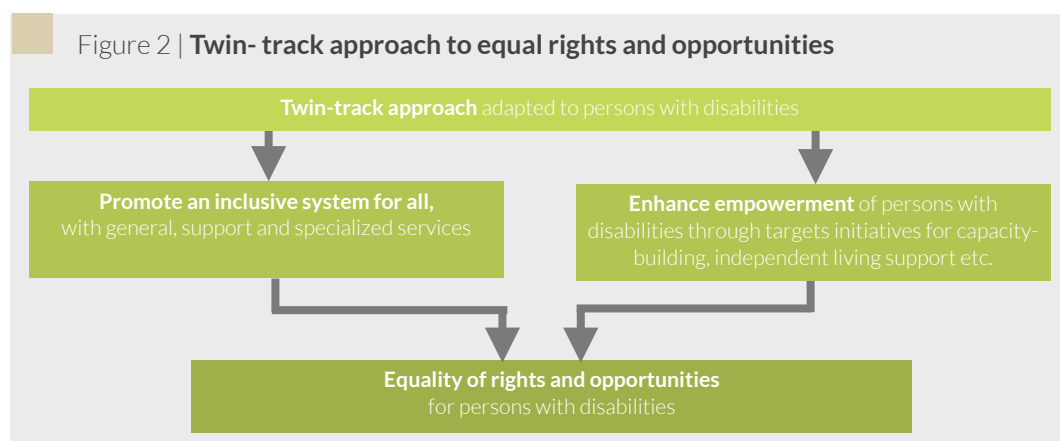
The survey findings underline two points that many practitioners of disability-inclusive DRM argue for. *First*, as they are amongst the most vulnerable groups affected by disasters, disaster risk management must include and address the specific capacities and needs of persons with disabilities. *Second*, in order to do so most effectively, the men, women and children living with a disability must participate and have a role in these efforts.

1.3 Key principles to inclusive disaster risk management

Generally speaking, inclusive DRM implies that all marginalized and excluded groups are stakeholders in DRM processes; it ensures that persons with disabilities are recognized as equal members of society like any other members of society - irrespective of their impairment or any other status such as age, race, color, sex, language, religion, political opinion, national, or ethnic origin.

How can inclusive disaster risk management be facilitated? A key principle in this regard is to pursue the twin-track approach, which aims to address the needs and rights of persons with disabilities in development and as well as providing more focused activities aimed specifically at empowering persons with disabilities to participate.[5]

Figure 2 illustrates these two lines of action. On the left-hand side, the focus is on making general services accessible to all by removing barriers, putting support mechanisms in place while providing specialized services that address specific needs to ensure equality of

Figure 2 | **Twin- track approach to equal rights and opportunities**

Twin-track approach adapted to persons with disabilities

Promote an inclusive system for all, with general, support and specialized services

Enhance empowerment of persons with disabilities through targets initiatives for capacity-building, independent living support etc.

Equality of rights and opportunities for persons with disabilities

5. The twin-track approach was conceptualized by the UK's Department for International Development (DFID) as a model to facilitate the full participation of women in development. It is presented here to promote the full participation of persons with disabilities in disaster risk management.

opportunity. In disaster risk management, this implies for instance that early warning systems, safety shelters as well as search and rescue services are accessible to all without barriers. Furthermore, specific services need to be developed to address the additional needs of persons with disabilities in the event of a disaster.

On the right-hand side, emphasis is on the empowerment of individuals to support independent living, greater self-determination and greater involvement. For inclusive disaster risk management, this means that persons with disabilities are empowered to participate in all DRM activities and decision-making. Their capacity to participate and act effectively in the event of a disaster should be reinforced through targeted training and skills building, provision of assistive devices, rehabilitation and other relevant measures.

This twin-track approach recognizes that effective inclusion of the women, men and children living with a disability in mainstream services does not replace the need for an inclusive system for all, where mainstream, support and specialized policies co-exist.[6, 7]

2. Participation of persons with disabilities

Inclusive disaster risk management adapts key principles of inclusive development based on three principles: *non-discrimination*, *accessibility* and *participation*.

Non-discrimination is related to the concept of equal opportunities, taking into consideration that people with disabilities do not have the same starting point. Inclusive DRM, therefore, has to ensure that no DRM action will contribute to creating new barriers for people with disabilities. An essential implication of non-discrimination is to systematically consider *accessibility* issues. Inclusive DRM implies that the physical environment, transportation, information and communications used in the context of DRM must be accessible to people with disabilities on an equal basis with others. Finally, the key principle with which this publication is concerned is *participation* and active involvement. It is particularly important to overcome isolation and invisibility of people with disabilities. For DRM this means that people with disabilities need to be integrated in planning and implementation processes.

Participation of persons with disabilities is an over-arching principle of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Article 4.3 in particular highlights that participation of representatives is an obligation of states for any decision that affects the lives of persons with disabilities.

Participation can be understood at three levels, which all are necessary and complementary to each other[8]:

- Participation of persons with a disability in **decisions affecting his/her individual life** - for instance, determining the place where he or she wants to live, expressing preference between different options for rehabilitation, and

- Participation of persons with disabilities as **representatives of users of services** in the governance of service providers, for instance to claim for new types of services, express quality expectations, and highlight particular concerns; and

- Participation of persons with disabilities to **influence decision-making processes**, policies and practices, for example. to advocate for a disability law or new accessibility standards.

Persons with disabilities cannot participate effectively in disaster risk management efforts unless they are given the support they need in advance as well as during decision-making processes. Without active and effective participation of persons with disabilities, DRR efforts are not inclusive. Participation therefore is the cornerstone of inclusive disaster risk management. It is both an end in itself as well as a means to an end, that is, reduced disaster risk for all.

6. The toolkit for practice in South Asia lists as key principles for disability inclusive DRM:
   - Commit to being disability inclusive
   - Establish a base of information on disability in the community
   - Reduce barriers to inclusion in CBDRM activities
   - Tackle attitudinal barriers

   For further information, see Handicap International (2012): Disability Inclusive Community Based Disaster Risk Management. A toolkit for practice in South Asia. *http://disabilityindrr.org/resourcespage/*

7. Several other guidelines and papers for inclusive DRM exist, such as:
   - Arbeiter-Samariter-Bund and Handicap International (2011): Mainstreaming Disability in Disaster Risk Reduction. A Training Manual and Facilitation Guide.

   - Malteser International (2013): Manual on Disability Inclusive Community-Based Disaster Risk Management. *http://www.didrrn.net/home/files/9014/0057/9145/EN_TL_Disaster_Risk_Management_2page.pdf*

   - Handicap International (2011): Support to Organisations Representative of Persons with Disabilities. Policy Paper.

   - Handicap International (2012a): Making it Work: Good practices for disability-inclusive development.

   - Handicap International (2012): Disability Inclusive Community Based Disaster Risk Management. A toolkit for practice in South Asia.

   - CBM (2013): Disability Inclusive Disaster Risk Management. Voices from the field & good practices.

8. See Handicap International (2011); p.18.

SECTION B | **GOOD PRACTICES**

3. Enabling persons with disabilities to take up active roles as DRM actors

The first of the three levels of participation concerns its very basis: persons with disabilities need to be enabled to take up active roles as actors in disaster risk management. This includes collecting data on disability, empowerment, informing persons with disabilities about their rights as well as the risks they face, and the role they could and should play in disaster risk management, encouragement, training and coaching, and the removal of physical, social, attitudinal and political barriers to participation.

This chapter presents two related good practices and shows remarkable outcomes. For Mila Baretto, a mobility-impaired mother of four from the southern Philippines, a training course on disability-inclusive disaster risk reduction was truly inspiring: having learnt about the rights of persons with disabilities and encouraged and supported by local government officials (whom she met at this course) as well as of Action Against Hunger and Handicap International, the usually shy woman became a staunch promoter of disability-inclusive DRM. Not only did she carry out steps to see her household better prepared for disasters, she also engaged in her community and beyond. Now the President of a reactivated Federation of Persons with Disabilities, she demonstrates outstanding dedication for the rights of her peers.

Meanwhile, in Nepal's westernmost district of Kanchanpur, the good practice of Handicap International and local DPOs illustrates the role of confidence-building and coaching for persons with disabilities. As they have raised their specific concerns and as these have been addressed, persons with disabilities feel less vulnerable, knowing that both mutual support between villagers and external assistance in case of frequent floods has been enhanced.

The two practices illustrate that disability itself is not an insurmountable wall to participation - rather, by giving them access to information, ensuring their recognition of themselves as DRM actors, and building their confidence after years of discrimination and exclusion, persons with disabilities can become very active and dedicated members of their communities who are valued and respected.

As this chapter and the good practices in subsequent chapters demonstrate, men and women with disabilities, once empowered, do not stop at securing and enhancing their own lives, but show care and commitment to other community members - both in disaster risk management as well as in other key concerns, such as improved livelihoods..

3.1 The Philippines: Outstanding commitment to inclusive DRM

As President of a local DPO, Mila Baretto supports other persons with disabilities, and managed to improve disaster preparedness across her region. Mila, 44 years old and mother of four, tells her story from Cotabato in the southern Philippines.

Mila Baretto, President of the Arakan Federation of Persons with Disabilities - Cotabato, southern Philippines.
Photo: Handicap International

Mila attended a training on disability-inclusive disaster risk management in late 2012. Conducted by Handicap International and Action Against Hunger (ACF) as part of the Scale Up, Build Up (SUBU) project, the training course targeted community members as well as representatives of local government agencies. Inspired by the course and supported by the Municipal Social Welfare and Development Officer, the Municipal Disaster Risk Reduction Management Office and ACF, Mila reactivated the Arakan Federation of Persons with Disabilities, which had been set up in 1996 but had been dormant over the past years.

"To date, 20 out of 28 barangays[9] in our area have PWD presidents who contribute to regular meetings", says Mila. "We coordinate with the local government, join municipal activities like celebrations, fiestas, or planning days, and do what we can to ensure that people with disabilities are involved in efforts towards greater preparedness."

Leadership and engagement...

Mila goes on to explain, "as the President of the Federation, I acted as trainer on disaster risk reduction. I also helped people with disabilities get registered, and completed the census or registry for them to be provided with identification (ID) cards. This helps them to enjoy privileges

such as discounts in transportation, medicine, and food. I also regularly visit each barangay and ensure that meetings between people with disabilities are conducted." Although Mila explains this in a very ordinary way, the accomplishment is quite extraordinary.

The job of registering people with disabilities is the responsibility of the Department of Social Welfare - but the department is under-staffed and the registration would have taken years to complete. Mila took it on herself to visit 20 of the 28 barangays, reaching some very remote areas. Overall, she was successful in registering 750 people with disabilities in just four months. She completed this task as a volunteer, with limited mobility, and with a family to look after. She even covered the transport costs herself.

...and its impact

When asked what has made her activities successful, Mila answers without hesitation: "The setting up of our organisation and advocating for what is due to us has made us successful. We are already enjoying a portion of the one percent from the municipality's development fund. In the past, this fund was only accessed by senior citizens, but now we have accessed the fund too. Aside from our engagement in disaster risk management, our organisation now has a livelihood project

9.   Barangay is a local term describing a sub-district in the Philippines.

for each person with a disability in her area, it has also helped the region become more informed and able to plan for and with persons with disabilities in times of emergencies. Mila lists this as an important factor for any community. "It is important to complete a census of people with disabilities in each community because this will be the basis of any planning for disasters."

In terms of the greatest change she has seen from her role in mainstreaming disabilitiy into DRR, Mila thinks carefully and responds: "Through these activities I became confident. I can now talk with professionals and government officials. I am not ashamed to deal with them although I did not even finish my education. Government staff attend to our needs when we go to their respective offices. I also see other people with disabilities who involve themselves in public affairs. We now are not only at home, we are out in the community."

Another salient change is that the local government has involved persons with disabilities in their planning processes. "Now the government involves us in planning", say Mila. Furthermore, "after typhoon Yolanda (known as Haiyan outside the Philippines), our members went from house to house to ask for relief goods for the Yolanda survivors. We feel that our group is always being helped and now we also want to help other people."

A reversal of roles

Mila has observed a reversal of roles with her local government in some respects. Instead of asking them for help, she has been assisting them in their duties.

She recalls, "whenever I do business related to our sector with government offices, they tell me: 'Mila, you are helping us, you are helping the government do its duties. You lighten our jobs!'" Mila herself wonders why this reversal has happened. She admits, "I think the government should complete its job and help us too, but anyway, that is how it is! On the other hand, I feel good that we help the government, and that we do something for others not only for ourselves." However, Mila is not yet satisfied with her organisa-

tion's activities as they are, as she looks ahead to further goals. "I want to learn computer skills so that I can make reports. This will speed up all our transactions with the government too", she says.

Challenges

Mila's role in leading the Arakan Federation of Persons with Disabilities has not come without its challenges. She explains, "I help my family to earn a living like tending our animals, and helping on our farm. I also am responsible for household chores. My time for these jobs was reduced because I needed to serve people with disabilities." This has been a difficult balance for Mila. Another challenge has been around funding. Mila lists, "I need to train the officers in disaster risk reduction, in relief, in livelihood. Me and other volunteers also have no transportation allowance. I live far away from the municipal centre but I have to pay for my own transportation for meetings and activities. There is a need for more capacity building."

Lessons

Due to the training from the SUBU project, "I learned about our rights and privileges", says Mila "I also learned that that there is a one percent of the municipal budget which we can use. I am also now clear that people with disabilities should be involved in all disaster planning!", she says firmly. Importantly, she says she has learnt that it is important to speak up: "we should express our needs and we should talk about these needs in front of other people in the community."

Recommendations

Mila wants to share recommendations for others working for persons with disabilities. "We need to work hard because it is difficult to start any organisation.

From my experience, it is hard to organise. I have also had people saying things against me, and met some discrimination - some people cannot understand, but I just go on. I have to do this so that other people with disabilities can also help themselves. We need to decide things on our own because this is our right." she says emphatically.

"We need to decide things on our own because it is our right."

Mila Baretto

➔ Insights

- Disability inclusion can go a long way: as this story illustrates, it can transform the roles of people with disabilities from being sidelined to taking leadership responsibilities in disaster risk management.

- Building the confidence of people with disabilities is key to unleashing this potential.

- Empowering persons with disabilities allows them to be aware of their own risks and encourages them to take roles and responsibilities in DRM for their own safety.

3.2 Nepal: Disabled Persons Organizations' empowerment in disaster preparedness

In Nepal's westernmost district of Kanchanpur, floods cause regular disasters that put a particularly heavy burden on people with disabilities. Initiated by a project that was able to build on existing resources and experiences, persons with disabilities contributed to making a positive difference.

Following work on disability-inclusive DRM in other areas of Nepal, Handicap International initiated a DIPECHO-funded project in Kanchanpur in 2012. With inclusive DRR training manuals and IEC material already existing, the ability to re-deploy staff from past projects, and the support of a local rehabilitation centre and DPOs, the opportunity for replication and refinement of past practices was evident.

An inclusive approach

The project started off by reinforcing the capacities of local DPOs, which had no prior experience in inclusive disaster risk management. Coached by disability workers from earlier projects in other areas, these DPOs then facilitated two types of activities: on the one hand, they sensitized the wider community about the rationale for including people with disabilities. On the other hand, they visited people with disabilities to address the barriers to inclusion and to build the confidence of persons with disabilities.

Only afterwards did the DPOs launch vulnerability and capacity assessments (VCA) that included vulnerable groups such as persons with disabilities, women, children and elderly persons. Villagers then formed Community Disaster Management Committees (CDMC), who in turn used the VCA findings to prepare action plans for preparedness and mitigation measures.

Persons with disabilities who were members of the CDMCs also lobbied at the district level for budget allocation for people with disabilities, in line with Nepal's government norms. More generally, DPOs collaborated with government agencies to facilitate links between district-level agencies and village-based committees.

Results: greater confidence and resilience

The communities' efforts led to a number of improvements: as persons with disabilities spoke up for themselves and contributed to planning, the relations between people with disabilities and other villagers began to alter. Villagers recognized the

capabilities of people with disabilities and became aware of their specific needs, while persons with disabilities felt more empowered. Nembati Rana, a woman with a physical impairment, says: "We have been homeless three times because flood washed away our home and all household resources. After being part of the VCA, I realized my vulnerability to floods as well as my capability to cope with them. Now that my voice is being heard, I feel empowered and take part in the village's risk reduction activities."

With contingency plans in place and mitigation measures completed, communities as a whole see themselves as more hazard-resilient. Not only has mutual support between villagers been strengthened, the greater connectedness to outside actors such as DRM actors, the Nepal Red Cross and DPOs also means that external assistance can be obtained more easily when needed.

Replicability

One year after the initial VCA, the CDMCs took part in a refresher training - and demonstrated that they were able to replicate the process in adjoining communities. With both local capacities (CDMCs, DPOs) as well as a Local DRM Planning guideline (which describes most tools and has been endorsed by government) in place, much of the groundwork for the replication of similar efforts in inclusive disaster risk management in nearby hazard-prone areas is complete.

"Now that my voice is being heard, I feel empowered and take part in the village's risk reduction activities."

Nembati Rana

➜ **Insights**

• Building on existing resources (DPOs, guidelines, staff) and addressing gaps is an efficient and effective way to carry out disability-inclusive disaster risk management.

• Efforts in DRM should address both the individual and community level as well as the enabling environment (DPOs, DRM actors) to enhance effectiveness, sustainability, and replicability.

• Families and caregivers of people with disabilities should be included in all efforts, as they increase confidence level of persons with disabilities and will often play a supportive role in evacuations.

4. **Engaging** persons with disabilities in DRM

Photo: Brice Blondel

The second level of participation concerns the actual engagement of men and women living with a disability in disaster risk management efforts. Seven good practices from across the region show that while such engagement can take various forms, the results are far-reaching. For instance, a case from the Philippines illustrates how well-prepared radio programmes presented by persons with disabilities can be a useful tool to spread key messages on disability-inclusive disaster risk management.

The experience in Vietnam's central province of Quang Nam demonstrates another way how persons with disabilities can make a difference on a wider scale: following the local set-up of community-based disaster risk management systems, they shared their experience and raised specific concerns when contributing to the creation of a national manual - a guideline that is now being used across the country.

Meanwhile in northwestern Bangladesh, the efforts towards inclusive flood risk management point to community-internal aspects that are worth considering - the crucial points of identifying and engaging 'thought leaders' and showing the real-term benefits of inclusive DRM to the wider community.

The final practice in this chapter follows that strain, as it argues that disability should not be approached head-on but rather indirectly, highlighting both high-risk groups and overall benefits on inclusive DRM from a functional perspective. This practice from the Indonesian province of West Java also makes a point in promoting a 'synchronized approach': in order to render community-based DRM efforts effective and sustainable, they need to be underpinned by advances at the policy level.

4.1 The Philippines: Promoting safety and risk reduction over the radio

A Philippine civil society organisation (CSO), Simon of Cyrene, trained men and women with disabilities to anchor a weekly radio program in the rural areas in the central Philippines. Through the program, they disseminate key messages on disaster risk reduction and disability inclusion to villagers. Vicente "Vic" Balonso is one of the Bicol region radio announcers.

Following a stroke, Vicente 'Vic' Balonso became an anchorman for a DPO-supported radio program, championing inclusive DRR. He since became the President of the local Federation of PWDs. *Photo: Samadhi Marr, Banyaneer*

Vicente "Vic" Balonso is 61 years old and a field officer for the Municipal Agriculture Office in Santo Domingo. "I had a stroke in 2005: I was on duty at a farmers meeting and when I woke up, I was already in the hospital. At the time I felt that it was the end of the world but I recovered through faith and determination. I was determined to help myself and I went to therapy and changed my diet. After coming out of the hospital, for six months I enjoyed a wheelchair, I liked being pushed around for a while!" he jokes.

However, after six months he had to return the wheelchair - which spurred him on to try to walk. "I tried my best to walk, for six months I used a cane to walk and then I went back to work. After a further six months I threw the cane away and learned to balance for myself" he says. Now Vic is the President of the association of persons with disabilities in Santo Domingo, and last year he was elected President of the their Federation, a DPO that promotes inclusive DRM and the rights of people with disabilities, and provides assistance across 23 barangays.

Living with hazards
Vic outlines that his community faces several risks. "In our municipality of Santa Domingo, there are many risks. We are just under the gaze of the Mayon volcano

and we also get a lot of typhoons in this area. Through my work with the farmers I know that the upland farmers sit at the foot of the Mayon volcano which regularly has ash fall and sometimes eruptions, and the lowland farmers are on the coast and face typhoons. All across our region people face landslides."

Radio broadcasting
Through Vic's association with *Simon of Cyrene* he picked up the extra job of radio broadcaster, delivering information about persons with disabilities and connected issues in Santo Domingo. "My passion is helping farmers not to use chemicals on their crops and to use organic methods. My other passion is helping to prevent illnesses and accidents so we don't get any more unnecessary members of our PWD club", he laughs.

"In 2011 I was invited to a training with *Simon of Cyrene* to learn about radio broadcasting. Ten people with disabilities attended and *Simon of Cyrene* brought participants from all over the region. I learned many things from the training but the most important was self-confidence."

He explains: "You see, if you are going to talk about something on the radio, you have to know the topic well and be totally confident. We started to broadcast to our area about different topics concerning

people with disabilities. *Simon of Cyrene* helped prepare the information to present each week. We broadcast every Friday for one hour. I had a school teacher as a co-anchor. We often did a question & answer (Q&A) format with him asking questions.

After a few shows I asked my co-anchor: 'how do you know we have any listeners?' So on that program we gave out my cell phone number so that listeners could call in for questions. After that announcement we had two callers with questions. I joked with my co-anchor that at least we knew we had two listeners!" he smiles cheekily. Eventually, he found out that "we had listeners across all 23 barangays. I heard that in all the barangays, maybe only two or three people had a radio, so others would go to their place to listen to the program."

Promoting safety and risk reduction

"Also, I attended a DRR training with *Simon of Cyrene* and coordinated the mapping of people with disabilities in each barangay. From my own experience, I knew that these people are more at risk during calamities." explains Vic. "I myself had to be evacuated once. In 2006, there was an eruption and my father rushed me to an evacuation centre by truck. I was lucky! However, the evacuation center was difficult to live in. For example, the water faucet was so far for me to get water. The building itself was flat and so it was pretty accessible for me, my main problem was water. For others in a wheelchair it was not very accessible."

"On the radio program we discussed a number of topics related to disasters. We spoke about climate change, about the role of the barangay officials during a disaster, and advised what people with disabilities should do in an emergency."

"We advised them to wait at a designated spot for evacuation. We told people about the three-signal system that is used in this area – and what to do at each signal" says Vic. "As for the volcano eruptions, we have a resettlement area for those barangays that are in the danger zone. Some barangays are located right at the foot of the volcano, so we prioritise them for evacuation."

Impact of the radio program

During his time presenting the radio program, Vic noted positive results in his community. "One person with disabilities had no disability ID card but he heard about the ID card system on the radio; we helped him to get a card, which gave him many privileges, like discounted transport, medicine and groceries. We also referred a lot of people to go to the right office to access community rehabilitation services", Vic adds. "During the time of the radio program there was an increase in requests of people with disabilities for ID cards and I think this was due to the program", he says.

When asked about the program's most significant change, Vic thinks carefully and comes up with two responses. "*First*", he says, "we gave really important information. Not just to people with disabilities but to all community members. We talked about prevention of illness and accidents that can lead to physical impairments to prevent getting any more people getting disabilities. *Second*, for me personally, I learned so much about each topic, I had to study and be ready to answer questions from my co-anchor. I had to have confidence. I told myself 'you can do it – just try'. If I had no confidence I would not have been able to deliver the topic well."

Radio programs: a model for inclusive DRM

Vic recommends radio programming to other areas in the Philippines and beyond. "With radio you reach a wide audience, people should do it - it is good. Train people with disabilities to anchor the show, it was important that I was a person with a disability as I could share my own personal experiences of having a disability" he says. "I have seen that people are more aware in my community since the radio program started."

The radio program ended this year but Vic relays, "we are always welcome at the station so we can start again whenever we want to. We are waiting for more support to run the shows."

When I first had the stroke, I thought it was the end of my life. But now I feel I can help others and promote better disaster preparedness."

➜ Insights

- Radio programs can be an effective tool to disseminate key messages in inclusive disaster risk management

- Persons with disabilities participating in DRM awareness-raising activities contribute not only to raise awareness about DRM but also about the existence and rights of different members in a community, including persons with disabilities.

- Presenters need to be well trained and coached, and programs adequately prepared to build audience.

- Funding for ongoing programming needs to be secured to ensure sustainability.

4.2 The Philippines: Persons with disabilities help develop disability-inclusive early warning system

Guruyan is a barangay in rural Philippines that sits under the gaze of an active volcano. Most of the barangay residents are rice farmers. As a pilot barangay for the Scale Up, Build Up (SUBU) project, Guruyan has been involved in a number of DRR activities over the last two years.

In a community meeting at Guruyan while sipping a fresh coconut, the barangay captain Roger Guel lists the risks for his fellow residents: "Here we are only five kilometres away from an active volcano and so we are at risk of eruptions and ash fall. We also face typhoons, floods and erosion/land losses."

The community is positive about the lessons they have learnt through the SUBU project. "We have changed since this project - we are able to identify vulnerable people who are at risk of disasters and we give people with disabilities, elderly and children priority in evacuations", says the captain. A fellow villager, Rudy Godalle - himself physically impaired and member of the DRR committee, adds: "we have learnt protection of the environment, we have planted bamboo and trees to try to stop further erosion."

Inclusive early warning
The village's early warning system (EWS) works both with sound and visual signs: The first warning (five bell rings/blue flag raised in the village centre) calls for being alert, the second (ten bell rings/yellow flag) means villagers should get ready to evacuate, and the third warning (continuous bell ringing/red flag) signals "evacuate now".

As there are several residents with hearing impairments, villagers have been assigned to warn them in case they do not see the flags. Barangay captain Roger says not without pride: "it was our idea in the community to use the flags, those who cannot hear can see the flags and know what is happening."

Changes
Rudy, whose arm is impaired, points to other changes: "another change we have seen is the improvement of knowledge within the community. People now recognise persons with a disability like me, and we have gained respect in their eyes."

"Now they know that we have rights and that we should be respected. Also, they are aware that buildings should be more accessible and have good door designs." he

Rice farmer Rudy Gudalle (60) working on his field at the foot of an active volcano.   *Photo: Samadhi Marr, Banyaneer*

says. "Following our engagement, we are now given priority in a disaster; earlier, we didn't know any of this, we didn't even know what to do ourselves, we would just wait for others, for news of calamities and what to do."

A real-life test-run
When typhoon Haiyan (locally known as Yolanda) approached the Philippines in late 2013, Guruyan was in its target zone. "Everyone was vigilant", recalls Rudy. The community called all the DRR committee members, activated all volunteers and alerted the community. They had a stock pile of rice, food and medicines ready to distribute if needed.

Rudy said during that time, most persons with a disability had already evacuated themselves. "Being part of the committee, I also helped evacuate people" he says. Although Yolanda eventually spared Guruyan, the 'real-life drill' indicated that the new system was effective.

Advice for other communities
Rudy and Roger recommend key points to other barangays who want to improve their disaster preparedness: "from our experience, an accurate survey is needed in the beginning to know who is at risk and where they are." A community drill was another important feature: "we are a

"Being part of the committee, I also helped evacuate people."

Rudy Gudalle, farmer with a disability

large barangay with seven sub-barangays, and we did this drill process seven different times."

Another idea that worked for them was conducting research on nearby social organisations that could assist if needed. "We researched and created a social census map which is important as we identified organisations that can help us after calamities" they explain. Other villagers add that "we also identified resources we have in this community, like who are the midwives etc."

Rudy, who is proud to have been invited to represent people with disabilities, says "we made a historical timeline of past disasters and from the past we learned a lot about the nature of those disasters. For example, if there is a typhoon, we know

what part of the community is probably the safest. Also, if there is ash fall from the volcano, we now know to wear protection masks. Earlier, we didn't know this and how bad it was for our health!"

→ Insights

- The participation of people with disabilities in DRM results in solutions suitable for all, as this case of an inclusive early warning system (EWS) shows.

- Participation can transform the lives of people with disabilities: greater confidence yields respect and recognition - the benefits include better disaster preparedness and resilience, along with enhanced mutual support within communities.

4.3 Indonesia: Persons with disabilities drive risk reduction efforts

When Maria Sanam, a 51-year old woman with a disability, became a member of the newly established disaster management team, it transformed her life - and made her village Binaos a more inclusive and better prepared community.

Maria recalls her early involvement as a Village Disaster Management Team (TSBD) member in her West Timor village. "I received an invitation to a community meeting. At first, I hesitated whether I should attend the meeting. Those days I spent most of my time at home. I grew up with the feeling that I am physically disabled, and was not confident to be in a social event like that, let alone to participate in a discussion. I was afraid people would not listen to me," says Maria.

Soon Maria and other TSBD members participated in the training provided by CIS Timor, a local CSO supported by Plan International. She learned about DRM and the rights and possible roles of people with disabilities.

Maria Sanam (51), a dedicated member of the Village Disaster Management Team in Binaos, West Timor. *Photo: Dewi Sitompul, Banyaneer*

Maria took up the role as coordinator for persons with disabilities within the village's team. "We mapped where vulnerable people live, and appointed TSBD members to evacuate vulnerable people during disasters" says Maria. The team also educa-

ted their families and local communities about specific needs of people with disabilities when disaster strikes. Maria has been a TSBD team member for more than one year, and with her newly acquired skills on inclusive DRR, Maria got involved in identifying evacuation routes, participated in relief distribution during a recent fire, and promoted inclusive DRR to fellow villagers.

The connecting door
Her involvement in the team has led her to meet other people with disabilities. Maria says that there are four of them, two of whom are children. "It was a great relief for us to be able to meet, since we all lived in isolation. Now we are not only connected to each other but also to our community", says Maria.

Now, Maria is not only talking about inclusive DRR issues in her village. She realizes that people with disabilities are often seen as a burden to their families, as many cannot contribute to the household income.

Therefore, she encourages her friends with disabilities to learn new skills to improve their livelihood. She says: "I feel that we need to help each other. I encouraged them to produce something, something that can create income… Now one of my friends produces sweepers from coconut lids. He can't sell them to the market because he can't walk, so I help him with that."

Improved disaster preparedness
Maria says that through her participation in the TSBD team, she learned how to prepare for disasters and how to help others. The community as a whole has benefited, as persons with disabilities take on active roles and are regarded as contributors. "One of my friends, who has a speech disorder, evacuated the elderly in his household during the recent fire. That was something new we had not seen before."

Nahor Tasekeb, the head of the village, agrees: "This is a big change. Before, he was the one who needed help when

disasters happened, but now he can save others." Tasekeb adds that people with disabilities are involved in preparing the new village development plan - and steps towards inclusive DRR such as protecting water sources and making them more accessible, tree-planting, and emergency drills, are now included in the draft plan. Maria explains that for evacuation drills, "we use different signs to alert people about disasters, for example using colourful flags and sounds to alert people who cannot hear and cannot see clearly."

Lessons learnt
"When starting a disability inclusive DRR program, first set up a database about people with disabilities, assess their needs, and communicate with them", advises Maria. "Slowly they will come out and participate, if you involve them and provide them with continuous capacity-building."

Based on her own experience, she adds: "It takes time but eventually they will be confident enough to participate." Harris Oematan, vice director of CIS Timor, adds that it is truly difficult to get all persons with disabilities to participate in village efforts. He observed that their families and the community as a whole had the belief that people with disabilities were cursed - they were not seen as equal to others. But as many people with disabilities came out into the spotlight and learned how they could contribute, the perceptions of community members has changed.

Maria, meanwhile, has further plans: while she is happy about the fact that she could gain access and become a valued part of the community who is better prepared for disasters, one of her main concerns is how her group can be financially independent. She emphasizes: "This issue is the main concern of us people with a disability."

Encouraged by her success in the past, she feels that she needs more skills to improve her livelihood, and wants to work to enhance that of her friends with disabilities.

→ Insights

- Involving a person with a disability in DRM efforts encourages others to join as well.

- Create a database of persons with disabilities and assess their needs regularly, in particular after disasters.

- Set up an early warning system that can be used by the entire community, for instance by using sounds and colourful flags.

- Provide support towards the empowerment of persons with disability through their own group - this will not only enhance their participation but also enable them to live financially independently.

4.4 Vietnam: Empowered, persons with disabilities engage for enhanced preparedness

Despite many persons with disabilities being respected war veterans, impaired people in Vietnam tend to be viewed as victims in need of special assistance. When Malteser International and local DPOs launched a DRM project in the country's central province of Quang Nam, that perception began to change. Rather than being an afterthought to overall planning, persons with disabilities spoke up and contributed to a new DRM system that includes better disaster preparedness for all members of target communities. A new manual has been created in the process, providing step-by-step guidance for disability-inclusive DRM in Vietnam and beyond.

Nguyen Van Quang, Head of the Dien Ban DPO, shares disability inclusive CBDRM activities to DPO members.
Photo: Nguyen Thi Cam Nhung, Malteser International

Just south of the city of Danang, Quang Nam province lies in Vietnam's central area that is frequently hit by typhoons, storms and floods. During the war, the province saw some of the heaviest fighting; high numbers of persons with disabilities are testimony to this past.

As Malteser International prepared a new project for community-based disaster risk management (CBDRM), it collaborated closely with the disabled persons' organisations (DPOs) that had been just been established under the 2011 disability law. Together with Malteser International, the DPOs facilitated a thorough assessment of people with disabilities and their specific needs.

Twin-track approach
They then followed a twin-track approach: recognising prevalent stigma as well as a reluctance of many persons with disabilities to express specific concerns, the DPOs first worked exclusively with

persons with disabilities (and their families) and built up capacity and self-confidence. Only afterwards did the project launch the second track, the overall assessment of disaster risks and the development of village disaster risk management plans. Persons with disabilities - 2,443 of whom were trained and 273 selected as representatives in DRM committees - were now confident to raise specific concerns and to contribute to the overall implementation.

Confident engagement
As Nguyen Van Quang, Head of the Dien Ban DPO, says: "Earlier, we did not dare to to call the President of the commune's People's Committee to talk. Now, we can come to the People's Committee and discuss our business with him face to face." The result for the people in Quang Nam is both greater inclusion of people with disabilities as well as better preparedness, anticipation and response of floods and storms.

"Now I can sleep well because I know someone will help me evacuate if there is a risk of a flood. It is like having life insurance."

Vo Van Dung, An Lac village

The likely impact of the CBDRM project extends beyond Quang Nam: Conceptualised as a pilot project, the lessons drawn from the central province were used in the development of a manual for disability-inclusive CBDRM. As part of this process, persons with disabilities contributed to several Hanoi-based workshops and managed to show that they were not so helpless 'victims' that they had been perceived of.

The manual will be used in the implementation of Vietnam's strategy to develop community-based DRM in the country's 6,000 most hazard-prone communes ('Project 1002').

Whereas initial plans had no provisions whatsoever for disability inclusion, the broad engagement and sense of ownership amongst DPOs, the Ministry of Labour, Invalids and Social Affairs (MoLISA), the National Disaster Management Committee and the Steering Committee for Flood and Storm Control (SCFSC) allows for the proper adoption of the manual's concrete guidance.

➔ Insights

- The thorough assessment of people with disabilities' needs and capacities is crucial

- Twin-track approach: work with persons with disabilities and reinforce their confidence, while working with the whole community at the same time

- Persons with disabilities need to represent themselves to argue their case and change perceptions

- The level of openness and stigma towards persons with disabilities plays a role in eventual outcomes

➔ **Manual on disability-inclusive DRM**
http://www.didrrn.net/home/index.php/resources/

4.5 Bangladesh: Changes in roles and perceptions for greater disaster preparedness

Based on the banks of the mighty Brahmaputra river, the villages in Sreepur, a union in Bangladesh's northern district of Gaibandha, have to cope with floods regularly. Through a disaster risk management project, villagers have become better prepared for these annual events. Persons with disabilities played a key role, and are being recognised as valuable contributors rather than as recipients of charitable efforts.

To most people in rural Sreepur, poverty is a daily challenge. When floods inundate or wash away their homes, hard lives become even harder, but despite the high frequency of floods, disaster risk management focused on response rather than preparedness. Persons with disabilities were considered recipients, yet, the baseline survey for a project run by local organisations Centre for Disability in Development (CDD) and GUK with the support of CBM indicated that only 11 % of them had actual access to emergency relief supplies, while most were without an independent income and relied on the support of their families. Poverty, disability, stigma and poor accessibility rendered persons with disabilities amongst the most vulnerable.

Approach

The project selected the six most hazard-prone of Sreepur's nine wards; in each of the six wards suitable community facilitators were selected and trained in disability inclusive DRM. School teacher and social worker Nurul Amin Mondal Rujjhas was one of them - with his charm, openness and ability to listen to diverse needs, he went to the households of persons with disabilities, encouraged them to express their concerns and take an active stance in the community.

Following this facilitation and confidence-building, persons with disabilities joined newly formed Ward Disaster Management Committees (WDMC). The WDMCs consist of 25 members, at least two of whom are persons with disabilities and seven of whom are women.

Backed by CDD and GUK, WDMCs conducted community risk assessments and led activities to develop overall plans for community risk reduction specific contingency plans for various hazard scenarios. WDMCs also advocated for the inclusion of persons with disabilities at the Union Disaster Management Committee (UDMC), and shared their experiences and concerns at higher-level forums.

WDMCs feature task forces for (a) early warning, (b) search, rescue and evacuation, (c) first aid, (d) damage assessment,

(e) water and sanitation, and (f) shelter management. Persons with disabilities took roles that they were best suited for. Persons with mobility impairments were in charge of shelter management so that they did not have to leave evacuation shelters. All WDMC members were trained for their various functions in task forces.

Results

The three most significant changes induced by the project concern greater disaster preparedness, a change in the perception and role of persons with a disability, and better linkages between wards and union-level DRM actors.

In April 2011, after the project had concluded, a fire broke out in one of the wards. Whereas this had normally caused panic, the WDMC responded very quickly, fought the fire and prevented significant property damage. After the fire, the WDMC collected money from the community and helped affected families rebuild and recover.

Aside from more organised and systematic response (tested in mock drills), WDMCs also promoted steps in risk reduction and disability inclusion through courtyard meetings, street theatre performances, billboards, posters and brochures.

Through their active engagement, the perceptions of persons with disabilities have begun to change, as they are now seen more as valuable contributors rather than the recipients of charitable action. Their contribution as well as the overall performance of WDMCs has been recognised by the UDMC, which allocated funding to facilitate the sustainability of WDMCs.

Lessons learnt and recommendations

Given years of exclusion and discrimination against them, it was difficult at first to encourage people with disabilities - women in particular - to take up public roles. Other barriers also had to be taken into account: accessible meeting venues had to be found, while deaf people needed family members as interpreters. Considering that there is a long list of development priorities, project efforts could not

Nurul Amin Mondol sharing his ideas during the capacity-building training of the local Ward Disaster Management Committee.
Photo: CDD

just focus on disability inclusion but had to bring demonstrable benefits to wider communities as well - in this case, better disaster preparedness for the entire community. In order to get the community on board, it made sense to identify and engage 'thought leaders' - influential people who can convince and motivate others to get involved.

The key lesson from the project is that only a multi-faceted approach that addresses these points effectively can generate the intended changes. For the sustainability of these changes, it is crucial to get government DRM actors on board, both to provide long-term funds and backup to local DRM efforts when needed.

➔ Insights

- Identify and engage local 'thought leaders' who can convince others of the merit of disability inclusive disaster risk management

- Ensure that clear benefits can be demonstrated to and understood by the wider community

- The confidence and capacity of persons with disabilities to speak during meetings shall be reinforced to facilitate their involvement in disaster risk management.

4.6 Indonesia: Women cadres drive inclusive DRM in Ciamis

"Passing several islands with one stroke of the paddle" - an Indonesian proverb signaling great effectiveness - comes to mind when looking at recent DRM efforts in the West Javanese district of Ciamis. As a result of these efforts, children with disabilities have taken up schooling, women have become engaged as cadres, while community resilience and disability inclusion have been reinforced. Notably, the collaboration between various government agencies improved, allowing DRM efforts to be integrated into long-term planning.

Ciamis' northern sub-district of Panawangan is exposed to earthquakes and landslides. With high rural poverty rates, many men and women leave their families behind to seek work in other parts of Indonesia or overseas. In 2008, when Arbeiter-Samariter-Bund (ASB) started working here, persons with disabilities were 'invisible' - they were not engaged in community affairs, children with disabilities were largely kept out of school, and the only local DPO that existed had very limited reach and capacity.

Furthermore, disaster risk management was largely *reactive* (response) rather than *proactive* (prevention and preparedness). Finally, issues concerning persons with disabilities were the prerogative of one government agency (Department for Social Affairs, DinSos), while DRM was that of another (the then newly established District Disaster Management Agency, BPBD). With interdepartmental links under-developed, this did not bode well for inclusive DRM.

Approach
Building on experiences and resources from previous projects in other areas, ASB launched a three-dimensional approach that included a) the establishment of a DRR information delivery mechanism (based on women cadres), b) advocacy, networking and planning with government agencies, and c) the facilitation of community-based planning and implementation.

With the support of Australian Facility for Disaster Reduction (AIFDR) and in cooperation with the University of Sydney, the capacity of local or nearby chapters of the DPOs PPCI (Indonesian Association of People with Disabilities) and Gerkatin (Movement for Indonesian Deaf People's Welfare) have been reinforced. Concerning government agencies, ASB contributed to government efforts to set up a DRR Forum at the district level, which includes 39 members (twelve of which form a working group) from 23 agencies.

Throughout this Forum, three types of plans were devised - a district disaster management plan (overall policy framework), a district disaster management action plan (identifying resources and responsibilities to implement the policy), and contingency plans for specific disaster scenarios.

Regarding communities, ASB and the government selected Panawangan sub-district and worked in all of its fourteen villages. They selected and trained 76 women as cadres and DRR master trainers, who delivered practical information to reduce risks (such as safe room settings, drills) to 100 children with disabilities out of school as well as 895 neighbours and family members of children with dis-abilities. Members of DPOs trained in previous projects elsewhere (Deaf Art Community, Yogyakarta) supported this process. Community members with disabilities played a crucial role in planning activities and exercises.

Results
The multi-pronged approach paid off, as the efforts led to several changes in perceptions and behaviour. Government actors now understand the need to address high-risk groups such as people with disabilities in overall DRM efforts, and have collaborated well between departments. Dicky Erwin Juliady, Head of the district's BPBD, says: "Alongside including non-government actors, it is necessary for BPBD to engage at the policy level with other government institutions, in charge of health, education, and social affairs."

Women have become formally established as key actors in DRM. Community efforts have reduced exclusion and prejudice, as people with disabilities contributed to DRM practices and policies.

Out of 101 children with disabilities that were out of school, 44 have now started schooling, with all those remaining being enrolled or on waiting lists. Furthermore, 383 neighbours formally committed themselves to assist children with disabilities when needed. For the first time, a person with a disability became a member of the district's DRR Forum.

Children and women listen carefully as one of the female cadres delivers information on disability-inclusive disaster risk management. *Photo: ASB*

Lessons learnt and recommendations

With the efforts in disability inclusive disaster risk management being hugely successful, what can be learnt from this practice? A recent review of the project's most significant changes, conducted by community members and the government, draws up several recommendations.

With regard to the *interaction with the government*, three points are made. *First*, it suggests that the involvement of all relevant government stakeholders is crucial. In this context, the creation of a smaller core drafting team (consisting of 12 of the 39 members of the inter-departmental project team) proved effective. The inclusion of planning and finance departments is seen as critical.

Second, the full integration of all DRR plans and documents into overall development plans is important to ensure that plans are actionable and equipped with necessary long-term funding. Without such integration, it is unrealistic to expect that government agencies would be able to allocate the resources required for the implementation of plans.

Third, the review finds that full coverage of an administrative division (in this case, a sub-district) is preferable to the targeting of just one or two villages in an administrative area. Full - rather than partial coverage - allows the government to act at the policy level, while at the same time providing resources and examples that can be drawn upon to guide policy formulation and institutionalization.

Concerning *community engagement*, ASB and the government identify three success factors. *First*, they suggest that disability inclusion should *not* be approached head-on within communities. Rather, the approach should come from a DRR perspective to draw on common experiences and then approach disability from the perspective of functioning - for instance by asking the question as to who had problems evacuating in the last earthquake. This avoids facing prejudicial pre-conceptions and has proved to be very effective.

Second, they find that key DRR messages should be delivered in a simple and relevant manner - focusing on practical actionable steps rather than complex technical details.

Third, the team sees the engagement of women cadres as a key to the overall success: although DRM tends to be seen

"We persons with disabilities need to prove that we're not just objects, who can only beg and expect sympathy from others. We are subjects, the actors behind DRR activities."

Dodo Zakaria (37),
member of the Ciamis DRR Forum

> *"Great practice in DRR is only possible if all stakeholders work together."*
>
> *Dicky Erwin Juliady*
> *Head of Ciamis BPBD*

as a male domain, it was found that women were consistently more active in community-based activities in areas such as health, early childhood learning and family welfare. The team recommends: "Pay particular attention to who in the communities is best suited to delivering DRR information, and then train these people appropriately. Selection should be based on merit" - rather than on traditional roles.

An *overall lesson learnt* is that the synchronization of community-level engagement and district-level planning is key to the institutionalization and sustainability of disability-inclusive disaster risk management.

When implementing disability-inclusive DRM, two further learning points are identified. Although desirable, one should recognize that not all persons with disabilities will be able to evacuate in cases of disaster. Therefore, active and positive engagement of families and neighbours is essential in order to provide assistance as needed.

A critical pre-condition for implementing disability-inclusive DRM is the openness of DRM actors to overcome the common misconception that engaging with disability is technical and resource-intensive. The practical necessity is to recognize that resources exist locally - that is, people with disabilities themselves.

➜ Insights

- Efforts at the community level should be synchronized with those at higher planning levels (policy, frameworks) to facilitate effectiveness and sustainability

- Giving roles and responsibilities to persons with disabilities at both levels (community and policy) is crucial in this regard

- For policy development, bring all key stakeholders together; in particular, include planning and finance departments

- Aim for full rather than partial geographical coverage of an administrative area to allow for better government planning

- Tackle disability inclusion tangentially and not head-on to avoid facing prejudicial preconceptions

- Selecting community facilitators based on merit - who is most suitable and committed?

- Include families and caregivers of people with disabilities in planning and implementation of risk reduction efforts

4.7 Bangladesh: Participation key to success in greater accessibility

In Bangladesh's southern district of Chittagong, cyclone shelters have provided emergency shelter for decades. Yet, persons with disabilities hardly ever used them due to their limited accessibility. After upgrades advised by persons with disabilities, this has changed: during the 2013 Mahasen cyclone, persons with disabilities sought shelter and found facilities suitable to their needs.

Throughout community risk assessments (CRA) in early 2011, communities in Chittagong's Sitakunda sub-district identified a key problem with existing cyclone shelters: access roads, water points, toilets, and power switches were unsuitable for most people with disabilities.

As a result, PWDs and their families had been reluctant to evacuate and did so at the last minute or not at all - leaving them at substantial risk from cyclones. Therefore, they devised Risk Reduction Action Plans (RRAP) that sought to improve shelter conditions and utilization.

From planning to action
Supported by Handicap International, communities got together with DPOs and key government actors and formed Cyclo-

ne Shelter Management Committees (CSMC). DPOs selected representatives in these committees; at least 10% of CSMC members are persons with disabilities. The CSMC visited accessible cyclone shelters in other areas and explained the need for upgrading to the local government.

They oversaw the renovation process, which included the construction of ramps, accessible toilets and water points. Handicap International also trained CSMC members on disability inclusive DRM, who have since met every month to coordinate awareness-raising and preparedness efforts. For instance, the committee ensures that equipment is stockpiled and ready to use in the shelters, and that volunteers are adequately trained.

The new ramp at the Mahanagor cyclone shelter gives people with disabilities better access and led to higher evacuation rates of people with disabilities during cyclone 'Mahasen' in 2013. *Photo: Handicap International*

Better shelter use, greater inclusion

The investments into accessibility have yielded results rapidly: as cyclone Mahasen approached Sitakunda, people evacuated physically impaired relatives early. Tanjina Akter, mother of 16-year old and wheelchair-bound Sharmin, says: "During the last major cyclone in 2007, I waited until the last moment to see if I could avoid carrying Sharmin to the shelter - it was so difficult! This time, I took her to the shelter in her wheelchair - it was much easier."

Aside from the better access, the process had another positive outcome: persons with disabilities spoke for themselves, and the communities around the four upgraded cyclone shelters changed their attitudes towards persons with disabilities, treating them with greater respect.

Success factors

Shafiqul Islam, Handicap International's DRM coordinator, sees several key factors behind the project's success: as it was based on the needs of persons with disabilities as expressed by them, the local CSMCs drove the process, and local administrators got 'on board' following advocacy efforts. Developing close working relationships with key counterparts, such as the members of the Union Parishad and communities was vital - as Shafiqul says, "informal meetings beside workshops and planning meetings helped to develop mutual trust."

Finally, the existing working relationships of HI's local partner Young Power in Social Action (YPSA) with the communities were a favourable pre-condition.

Lessons learnt

When replicating accessibility-related work in other contexts, Shafiqul suggests that three groups must be firmly embedded into the planning process: "*First*, people with disabilities themselves and their families must be part, as nobody else can define their actual needs.

Second, key government partners need to be involved - they need to give permission for upgrading and be convinced of the benefits.

Third, the overall community should contribute by establishing the CSMC - without the community, the investments are not sustainable."

➔ Insights

- Nobody can define the needs of persons with disabilities better than they (and their caregivers) themselves - their participation is a key to success in greater accessibility.

- Government actors as well as the wider communities need to be involved in planning and implementation, both to obtain approvals and to ensure adequate maintenance. Inclusive Cyclone Shelter Management Committees are appropriate set-ups in this regard.

5. **Extending** the leverage
through joint advocacy efforts towards inclusive DRM

Photo: Brice Blondel

The final of the three levels of participation concerns advocacy. Successful advocacy for inclusive DRM can extend the leverage of usually local efforts, and the involvement of persons with disabilities is crucial in experience-based advice on new or revised policies and plans.

We first look at a Philippine DPO that was able to build on existing networks from decades of work in promoting rights of persons with disabilities when embracing advocacy of inclusive risk management.

The second good practice - from the Indonesian province of Yogyakarta - shows how a group of DPOs, CSOs and INGOs was able to form a coalition that pulled on one string when advocating for policy changes towards inclusive DRM. The practice argues that such collaboration as well as 'soft' diplomacy and readiness to engage for the long haul are crucial elements of successful advocacy.

The chapter concludes with a look at government perspectives. Portraying two government officers who started as counterparts of civil society advocacy, they have since become both partners as well as champions for participation and inclusive DRM within their departments. The portraits serve as a reminder of the importance to understand the perspective, interests and challenges of counterparts. By building trust and good working relationships, government partners can become the internal advocates that are vital for the successful of eventual outcomes.

5.1 Philippines: Disabled Persons' Organization builds advocacy network for DRM

Since its foundation in 1982, the Philippine DPO Simon of Cyrene has been promoting the rights of persons with disabilities in the central region of Bicol. Having worked closely with various government departments through the years, the organization had a solid network to build on when it started working on disability-inclusive disaster risk reduction (DRR) in 2011.

Program manager Erynn Jaucian explains the move to DRR: "We saw the need for DRR because in the Bicol region we are extremely prone to disasters - and during community assessments for various programs we had seen the needs. Furthermore, in our experience barangays did not have proper lists or maps of people with disabilities. So after a disaster, people with disabilities were often housed in evacuation centres that were not accessible, with no appropriate toilets or water facilities."

Advocacy - building on a network

Through *Simon of Cyrene's* 32 years of experience working with local government counterparts for their community-based rehabilitation programs, they were in a good position to collaborate with local partners for inclusive DRR. *Simon of Cyrene* immediately started to advocate for representation of people with disabilities on the City/Municipal Disaster Risk Reduction and Management Councils. So far, two municipalities have persons with disabilities on their councils.

Along with advocating for representation, they also undertook training and orientation of local government units on disability issues and inclusive DRR. The *Simon of Cyrene* staff say that normally this would have been a difficult task, however they already had a good understanding of their local government units and had established relationships. Furthermore, as Erlynn Jaucian adds, "we also had an ally in the Community-Based Rehabilitation coordinator within the government. Our daily work is together and this government coordinator knows all the workings of her department, the

local government dynamics, budgets and how to approach things in the proper way."

Staff agreed that the representation of people with disabilities in the C/MDRRM councils is important. They meet each quarter and persons with disabilities present news on accessibility and they often request more people to be included and involved in trainings.

Ate Cora Llarena, *Simon of Cyrene's* DRM and Mental Health Manager, reports that they are effective representatives: "they are confident to represent the sector at the council. They are aware about current concerns and know how to assert their rights". These representatives are core leaders within DPOs. Program staff explain that DPOs are very active in the region due to the large community based rehabilitation program of *Simon of Cyrene*. These DPOs are funded through the local government allocation to the elderly and persons with disabilities.

Most significant changes

There have been many positive outcomes of this advocacy according to *Simon of Cyrene* staff, the most significant they agreed on is increased awareness and visibility. Erlynn Jaucian states: "now the local government is aware of DPOs and people with disabilities; they have become more visible to the local government". DPOs now have one-year plans, which they submit to the local government units to receive their funding allocation.

A two-way learning process

Another good practice that *Simon of Cyrene* has started is coordination with the Albay Public Safety Emergency and Management Office (APSEMO). Since the collaboration started, *Simon of Cyrene* staff say that APSEMO now knows how to support persons with disabilities in disaster response and are able to look out for their concerns.

Erlynn explains: "It is a two-way learning process: we learn how to improve disaster management in our programs from APSEMO and we share our knowledge and

"People with disabilities were simply not visible during times of disaster."

Erynn Jaucian

expertise on the needs of people with disabilities, explaining how their needs are different from other community members. Also during disasters we co-ordinate relief efforts and they invite us to be a part of their training."

Challenges

Nonetheless, it was all but smooth sailing for the recognition of persons with dis-abilities in the DRR sector within the government. "One particular issue we have to deal with", says Erlynn, "is the constant change in local government every three years after elections. This often means that our advocacy has to start from the beginning after elections, as we have to re-sensitise newly elected government officials."

Furthermore, the organisation still en-counters "indifference from some local government units in including people with disabilities in DRM initiatives." They also see that some rescue staff are not trained to handle the needs of people with disabilities during disasters.

Simon of Cyrene staff thus plan to start training government rescue teams on working with persons with disabilities in times of disasters. Ate Cora Llarena explains: "We have seen many cases of rescue workers not able to work with people with disabilities appropriately and sometimes causing more harm or injuries! We had a case with someone who was visually impaired and the rescuer was not able to communicate with him properly or lead him safely in the evacuation. Also, the rescue teams always use pick-up trucks for evacuations which are too high for many people with disabilities to use."

"Just a simple step system or ramp from the pick-up would make things so much better in times of rescue", argues Erynn.

Simon of Cyrene will continue to coordina-te with local government units to improve inclusive DRM efforts in the Bicol region. Their vision is to provide water safety training for persons with disabilities and to advocate for greater access to water transport in the island regions.

➜ Insights

• Building advocacy efforts on existing networks with government counterparts represents a great opportunity.

• Learning can be mutual - as the described case of APSEMO illustrates.

• Endurance is required in the face of setbacks and challenges.

• Advocacy efforts need to be renewed after the replacement of government counterparts (e.g. after elections).

5.2 Indonesia: Joint advocacy for a disability inclusive DRR policy

In the Indonesian province of Yogyakarta, six organisations have joined forces to advocate for new regulations on inclusive disaster risk management. Ari Kurniawan, a senior trainer with the CSO Ciqal, is at the forefront of these efforts.

In early 2006, a strong earthquake struck the city of Yogyakarta and neighbouring areas. Five thousand people died. Thou-sands more were disabled as a result. In order to ensure that the needs and capacities of persons with disabilities would be integrated into disaster risk management, several organizations have joined forces.

"Together we can"
Following Indonesia's ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2011, six of them (Arbeiter-Samariter-Bund and Han-dicap International as well as local CSOs Ciqal, SIDRAP, BPCI, Gerkatin and Pertuni) joined a task force to draft a provincial regulation on disability inclusion.

The regulation was signed in 2012 and will take effect in 2015, following a period of awareness-raising and preparation. While contributing to this process, the coalition of organizations has also enga-ged with various departments at the district level (e.g. social affairs, public works, education); as a result, four out of seven districts in the province have crea-ted complementary district-level regu-lations.

The subject of policy making
Ari Kurniawan, master trainer of local CSO Ciqal, says that despite Indonesia's ratification of the UNCRPD and other recent successes, Indonesia still has a lot of 'home work' to accommodate the rights of people with disabilities - in particular

Ari Kurniawan of the Indonesian CSO Ciqal. *Photo: Ciqal*

the rights to get equal access to social and physical services. Mr Subroto, the head of the social rehabilitation section of Yogyakarta's provincial department for social affairs, agrees. In terms of DRR, he adds that many public servants still have limited understanding of the needs of persons with disabilities, while his government also lacked an adequate database of persons with disabilities. "Because of these factors, the needs of persons with disabilities during disasters are often ignored, which in turn makes them more vulnerable", Subroto says.

So the translation of the rather general provincial regulation into more detailed frameworks on disability inclusion - currently in process - was important. Both Kurniawan and Subroto see progress: "The more we meet through various meetings", says Subroto, "the less we use terminologies that are degrading to persons with disabilities and the more we become aware about specific rights and needs."

Subroto recognizes: "When drafting a policy, one should know who will be affected by that policy. If it is persons with disabilities, they should be involved in the draft making; if they are not involved, the policies will not meet their needs."

Challenges

Mr Kurniawan appreciates how well the task force has been coordinating with government officials. However, the coalition's efforts were not without challenges: "Despite the increased awareness about

persons with disabilities, BNPB (the country's national DRM agency) did not properly address disability during last year's commemoration of the National Disaster Risk Management Day." Overall, the issue of disability inclusion remained on the sidelines of most DRM initiatives - as a result, many needs of persons with disabilities were not met.

Mainstreaming disability inclusion into DRM

In terms of disaster response Kurniawan sees a change of practices. His NGO Ciqal - supported by Handicap International - advocates other NGOs to mainstream disability and vulnerable people inclusion. As a master trainer in disability inclusive DRM, Kurniawan has trained many participants (government officials and NGO staff in Indonesia and Timor Leste), and sees greater sensitivity.

He recalls: "When the earthquake struck Yogyakarta in 2006, not much attention was given to persons with disabilities. During the 2012 eruption of nearby Mt Merapi volcano however, the emergency response was more appropriate to the needs of persons with disabilities." Now shelters were equipped with ramps, accessible toilets for disabled people set up, and trauma healing activities provided to children at evacuation camps.

"In the past, it was almost impossible for people who use wheelchairs to go to the city hall", Kurniawan says. "But with our regular meeting at city hall, now they have built a ramp so the building is accessible. It is a small change but it means a lot for us." In the recent election, the election committee also provided braille ballot papers for people who have vision impairments, while some election sites had been equipped with ramps. "I am happy to see these positive general changes", relays Kurniawan.

With regard to DRM, he is also glad to see that the provincial regulation is signed - yet, "it will probably take the government another two years to implement it. In fact, disability issues are not the sexiest among government priorities. In the end, this regulation will only be meaningful if the government allocates funding to support persons with disabilities." The job for

"You have to understand your counterpart's viewpoint."

Ari Kurniawan,
Ciqal master trainer

him and his colleagues at the multi-stakeholder task force is far from over - and they will continue to strive for making disability inclusion a practical reality.

Lessons learnt on the long road of advocacy

Kurniawan shares four aspects that he learned in recent years: "*First*, it takes time and strong will on the long road of advocacy. The more we speak about it the more the government listens to us." *Second*, he thinks that the formation of coalitions of like-minded organizations is crucial - "together we can", Kurniawan says. *Third*, he believes that the support from international actors plays a role - with ASB and Handicap International in

the process, "both communities and government staff tend to pay more attention." *Finally*, he urges that all channels should be used for advocacy. "Speak at mosques and churches, at social events. Visit schools, go to the villages and explain the issue."

Kurniawan is confident that this advocacy effort can be replicated in other provinces. "The key to success", he says, "is the ability of stakeholders to work together."

Rather than using harsh criticism of the government's lack of support towards people with disabilities, he believes in soft diplomacy. "You have to understand your counterpart's viewpoint."

➜ Insights

- Building local coalitions of like-minded organizations is crucial

- Formal regulations, once signed, need to be explained and 'translated' into practice

- Time and endurance is required for advocacy efforts

- Soft diplomacy and constructive dialogue is more effective than confrontation. Good working relationships with government counterparts are required.

5.3 Indonesia and the Philippines: Government champions embrace participation for inclusive DRM

Convinced that the engagement of persons with disabilities in DRM is crucial, two government officials in eastern Indonesia and the central Philippines championed disability-inclusive DRM, and helped to bring about significant results.

A few years back, neither Tini Thadeus nor Justin Derayunan had heard about disability-inclusive DRM. Justin, who became the Disaster Risk Reduction Officer of Tarangnan municipality in the Philippines in 2012, says that while he knew the Disaster Management Law and had been aware of a law on persons with disabilities in disasters, "in my experience this law was never discussed publicly or within the government."

Tini meanwhile, the Head of the recently established disaster management agency (*Badan Penanggulanggan Benacana Daerah*, BPBD) of the Indonesian province Nusa Tenggara Timur (NTT), says that prior to project efforts by the AID consortium, a coalition of international and local NGOs, the inclusion of persons with disabilities "was not an issue."

While efforts in both countries were initiated by NGO networks (in the Philippines, several organizations had collaborated in the Scale Up, Build Up (SUBU) project), both Tini and Justin took up, championed and advanced disability-inclusive DRM.

From counterparts to partners

Tini proudly recalls how he and other members of the province's DRR forum presented the experiences from disability-inclusive DRM projects to the provincial parliament, calling for the allocation of funding to continue and expand such efforts. "Afterwards, the parliament indeed gave us the money", he says proudly.

This allowed BPBD to replicate externally-funded interventions in four of the province's 22 districts to several others. With

the government's budget allocation, BPBD currently pursues such efforts in Sumba Barat Daya, Maumere and Alor districts.

Over in the Philippines, Justin was also successful in obtaining government funds. "Without funding, disability-inclusive DRR is not easy to implement", he says. "But allocating a budget for persons with disabilities is way out of my jurisdiction. Although I knew that persons with disabilities needed to be included in DRR and that we needed funds for this, I couldn't just simply write that into my budget." Thus, he navigated through go-

vernment departments and argued his case. "I talked to so many people. It took time, but in the end I got results."

Justin looks satisfied as he shows the respective allocation in the 2013-14 budget. Now he can continue and extend disability-inclusive DRM to more of the 41 barangays in his municipality.

Change through participation

While the two local governments' budget allocations stand out, both Justin and Tini say that through the involvement of men and women with disabilities themselves, the strong support from NGOs and DPOs, and their own internal advocacy, the views of many government colleagues had changed. "Change is sometimes intangible", says Tini, "but there is a clear change of mindsets amongst government officials and parliamentarians."

Lisbeth Manurung, the BPBD officer who acts as focal point for persons with disabilities, adds that her agency has mainstreamed disability inclusion into its overall dissemination strategy. This means that key messages are disseminated at workshops, seminars, trainings - to district disaster management agencies, government departments, individual communities and the public at large.

Back in the Philippines, DRR officer Justin says that "now the local government discusses how to look after and involve vulnerable people during disasters." He personally sat down with persons with disabilities to develop a more effective and inclusive flood warning system.

Building bridges

To a significant extent, the success that Justin and Tini were able to achieve is built on the internal championing that they pursued as a follow-up to advocacy of and collaboration with NGOs and DPOs.

In Timor, the members of the AID consortium - Plan, CARE, Handicap International as well as four local CSOs and DPOs - had been promoting disability-inclusive DRM since 2011. Tini appreciated their efforts and says that he quickly understood the matter. "One of the strong points was the joint advocacy from a range of actors that

Tini Thadeus (above), Head of the disaster management agency BPBD in Indonesia's Nusa Tenggara Timur province, and Justin Derayunan jr (below), Disaster Risk Reduction Officer of Tarangnan municipality in the central Philippines, have become champions for disability-inclusive disaster risk management.
Photos: D. Sitompul, S. Marr/Banyaneer

"One of the strongest points was the joint advocacy from a range of actors that included persons with disabilities."

Tini Thadeus
Head of BPBD, NTT province

included persons with disabilities", says Tini. "Advocacy will be more successful if you work together", he says. "If you work alone, not much is going to happen."

According to him, persons with disabilities themselves play a crucial role, both in advocacy and in convincing communities. "To mainstream inclusive DRR in the community, one has to approach the key people", he says. "In NTT people still hold up traditional values; one has to talk to the elders, the informal leaders. If you can convince them and they approve of the general ideas, it will be easier to get to the wider community."

Having persons with disabilities involved in this process, who "could talk about their own experience, helped a lot in that process."

➔ **Insights**

- For advocacy to reach intended outcomes, it is important to find champions within government to drive processes further. As they are familiar with internal structures, procedures and networks, they know "who to talk to".

- Government counterparts have to become partners - good collaboration with civil society actors can help them prepare and argue their case when convincing government colleagues.

- The engagement of persons with disabilities in these efforts is vital, as they can speak from experience and thus can contribute to new or amended policies and plans..

SECTION C
THE ROAD AHEAD

6. Recommendations

. . . .

The good practices in this paper include practical advice as to *what* should be done *why* and *how* - in order to facilitate greater participation of persons with disabilities in disaster risk management. Drawing from these good practices, we present fifteen practical recommendations below, grouped under the three main points enable, engage, extend. Having the user in mind, each recommendation answers the *why* and the *how* questions, as well as references to related good practices.

A. ENABLE participation of persons with disabilities to take up active roles as DRM actors

A.1 Thoroughly collect information on disability.

Why? In order to appropriately plan concrete disaster risk management actions in a given area, it is crucial that information is obtained about the number of persons with disabilities, their specific impairments, interests, capacities, risks and needs, as well as their supportive environment (families, neighbours).

How? 1. Develop a questionnaire that elicits the key information you need (see template in guideline of Malteser International). 2. Ask village stakeholders to fill in questionnaires. 3. Meet these stakeholders (including people with disabilities and their family members) to collect and double-check 4. Analyze information and highlight special points for consideration for further steps. *(See practice 4.4 from Vietnam)*

A.2 Empower people with disabilities by informing them on their rights and roles in DRM, by building their confidence and by training them appropriately.

Why? Due to exclusion and stigmatization, many persons with disabilities tend to shy away from (and have little experience in) speaking for themselves at public meetings, and may not be fully aware on their rights and the possible roles they could and should play in DRM. Therefore, they need to be informed on such rights and roles. Their confidence and capacity needs to be reinforced prior to their engagement in the community - without such preparation, efforts towards inclusion are likely to fail.

How? Visit persons with disabilities and their families and explain why DRM matters and how they could make a difference. Encourage them to get involved and suggest possible roles. Spend time with them enquiring about their capacities, needs and concerns. Then deliver training sessions to persons with disabilities that help develop and practice public speaking and representation. *(See practice 3.2 from Nepal)*

A.3 Include family members and caregivers of people with disabilities.

Why? Family members and caregivers need to be included for three reasons: a)their involvement tends to make persons with disabilities more comfortable, b) they often have their own specific concerns, and c) they often support evacuation and protection of persons with disabilities. Remember that their involvement must not replace the participation of persons with disabilities themselves, but rather be an additional measure.

How? Involve family members and caregivers throughout the entire process; listen to their specific concerns, highlight the benefit of their involvement, and suggest possible roles in community-based efforts. Value their contributions to care and to the wider community. *(See practice 4.7 from Bangladesh)*

A.4 Identify and address barriers to participation.

Why? An obvious point worth highlighting: in order to be able to participate in meetings, persons with disabilities must be able to access meeting venues and have assistance available if required. Social or attitudinal barriers to participation also need o be identified and addressed.

How? Consider what it takes for a person with a disability to get engaged - can he or she easily attend a meeting, drill, or advocacy efforts? Ensure that those activities are accessible when selecting venues and arrange assistance as required (e.g. translators for deaf persons). Identify and address other barriers to participation. *(See practice 4.1 from the Philippines)*

B. ENGAGE persons with disabilities in DRM efforts

**B.1 Discuss with persons with disabilities adequate roles in DRM
that consider their specific strengths and impairments.**

Why? Not everybody is good at everything - whether they have an impairment or not. Therefore, it it important to discuss with persons with disabilities potential DRM roles that they would feel comfortable with - what functions can someone best assume, given individual strengths and challenges. Aim to recognize, incorporate and build their potential. Inadequate roles may overwhelm persons with disabilities and be detrimental to their effective participation.

How? Ask each person with a disability what concrete role he or she feels comfortable playing in a village's DRM set-up. For instance, a person with a mobility impairment may be unsuitable in search and rescue but formidable at arranging emergency shelters or in advocacy. *(See practice 4.5 from Bangladesh)*

**B.2 Identify, select, train and engage 'thought leaders'
amongst people with and without disabilities.**

Why? The ability to build up confidence and capacity is limited - not everybody has the charismatic leadership qualities required to argue and convince others. Efforts are most effective if (potential) 'thought leaders' can be identified and their capabilities reinforced - who in turn can convince others. 'Thought leaders' are required both for community-based efforts and for advocacy.

How? Amongst all community members (wider community and pre-trained people with disabilities), some people will demonstrate leadership qualities as they speak up, argue their case, and convince others. Select those persons, develop their skills further and engage them in the ongoing process towards reinforcing disability inclusive disaster risk management. *(See practice 4.5 from Bangladesh and practice 4.6 from Indonesia)*

B.3 Approach disability inclusion tangentially instead of head-on.

Why? Especially in areas where stigmatization of persons with disabilities is pronounced, it can be counter-productive to approach the issue of disability directly. Instead, discuss risk reduction more generally and approach disability inclusion 'through the back door' - e.g. by asking about who is at the greatest risk.

How? Consider that community members may have several urgent needs and that disability inclusiveness may not be at the top of their agenda, in particular where stigmatization is strong. Therefore, address the 'common denominator' first and then approach disability from a functional perspective. As the community identifies people with disabilities as a high-risk group, what can be done and what can they do to reduce their risk? *(See practice 4.6 from Indonesia)*

B.4 Drive a synchronized approach between
higher levels (policy) and lower levels (implementation).

Why? Both the levels of policy (e.g. district) and implementation (community) need to be addressed if efforts in inclusive DRM are to be sustainable - stand-alone approaches are doomed to be short-lived. Community-level mechanisms require both back-up for larger disasters as well as ongoing financial support.

How? Drive your efforts towards disability inclusive DRM through two parallel and inter-linked channels: Involve policy-makers in community implementation, and facilitate feedback from communities to policy-makers. Restrict your role to facilitation and advice, and let the linkage between communities and policy-makers develop progressively.
(See practice 4.6 from Indonesia)

B.5 Fully engage all key stakeholders,
including representatives of vulnerable groups as well as service providers.

Why? Although multi-stakeholder dialogues can be time-consuming, it is crucial that all key players "pull on the same string" - without such a unified effort, DRM is less effective and systematic.

How? Conduct a thorough stakeholder mapping to ensure that no key stakeholder is omitted, and to identify possible roles. Invite all stakeholders and involve them in an ongoing manner. *(See practice 4.6 from Indonesia)*

B.6 Consider radio programming as an effective channel
for the promotion of disability inclusive DRM.

Why? The involvement of people with disabilities in radio programming can be hugely effective: highlighting their own experience, they are credible promoters of inclusive disaster risk management to a wide audience.

How? Identify possible radio stations for programming on disability inclusive disaster risk management. Then identify and train suitable persons with disabilities as anchormen or women. Thoroughly prepare programme content that delivers key messages and is presented in an interesting manner. Coach the new anchor persons (consider co-anchors) and identify sources of funding. *(See practice 4.1 from the Philippines)*

C. EXTEND the leverage through joint advocacy efforts towards inclusive DRM

C.1 Build on existing networks and form coalitions between like-minded organizations.

Why? Advocacy is most effective if coalitions between like-minded organizations can be built and maintained - such a coalition yields greater leverage on government counterparts than separate and un-coordinated efforts.

How? When advocating for policy changes towards disability-inclusive disaster risk management, involve existing partners (such as like-minded CSOs, DPOs, INGOs) and assess whether other stakeholders may be interested to expand a coalition. Agree on a common objective prior to launching advocacy efforts.
(See practices 5.1 from the Philippines and 5.2 from Indonesia)

C.2 Persons with disabilities should directly represent themselves.

Why? Direct involvement of persons with disabilities helps change mindsets of government counterparts and tends to be more effective than indirect representation by others.

How? Follow the steps described above under 'inclusion' and encourage persons with disabilities to speak for themselves in advocacy efforts, laying out the greater effectiveness and likely change of perception amongst counterparts. *(See practice 4.4 from Vietnam)*

C.3 Plan for the long haul.

Why? Advocacy takes time to be effective: Consensus need to be built between key players, policies devised, translated into practice, tested and possibly amended. One should be ready to accompany this process for several years, in particular when advocating for policy changes at the national level.

How? Plan strategically and beyond the lifespan of most projects. While advocacy can be effective over short time spans on the community level, consider successive projects with an overlapping focus in advocacy, and/or plan projects with a duration of at least three years. *(See practice 5.3 from Indonesia and the Philippines)*

C.4 Anticipate and reduce the risk of set-backs.

Why? A common set-back is related to staff turnover: if key government players are replaced (e.g. after local elections), advocacy efforts may need to be renewed.

How? Always base your efforts on a range counterparts (not just the head) amongst stakeholders, as this will reduce the risk of advocacy outcomes being lost due to staff turnover. *(See practice 5.1 from the Philippines)*

C.5. Pursue soft diplomacy and trust-building.

Why? A diplomatic approach that argues and demonstrates the case for disability inclusive DRM is more likely to succeed than a confrontational stance. Gaining the trust of government counterparts and building close relationships is crucial.

How? Build trust with counterparts, for instance through informal relations, learn and understand their viewpoints, backgrounds and interests. Rather than focussing on past mistakes or omissions, focus on shared objectives. *(See practice 5.2 from Indonesia)*

7. Conclusion
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When working towards inclusive disaster risk management, *process* and *outcomes* are intimately linked to each other. The key resources for success in this field are already there - not only the several manuals and technical advice, but more crucially, persons with disabilities themselves. *Their* participation is the ultimate key.

As powerfully demonstrated by the good practices in this report, men and women like Ari Kurniawan, Mila Baretto and Vic Balonso do not just make persons with disabilities less 'invisible'. They drive efforts to make communities safer and more resilient places to live, once their potential is unleashed - often hidden by decades of exclusion and stigmatization as a burden and as mere recipients of charitable efforts. In the process, the lives of persons with disabilities have been transformed, the perception of them amongst community members changed, and disaster risks reduced.

These encouraging practices highlight several aspects that need to be addressed in order to unleash this potential. Following the collection of data of persons with disabilities and their capacities, risks and needs, they need to be informed about their rights, about the risks they face as members of the community, and about the role they could and should play in DRM. Their confidence and capacity needs to be reinforced through encouragement, training and coaching. Family members and caregivers need to be included, barriers to participation addressed and 'thought leaders' identified.

Communities need to be sensitized to the benefits of inclusive disaster risk management. As argued in this paper, this is best done 'through the back door' - by discussing disaster risk in general and then turn to the question of high-risk groups. Once included, persons with disabilities can use and share their unique insights to develop risk management set-ups that ensure appropriate and inclusive systems and procedures.

Persons with disabilities are also effective advocates: speaking from experience and for themselves, they are able to convince government officials and other counterparts to adapt or create DRM policies and plans that are disability-inclusive. As like-minded organizations form coalitions, build relationships of trust and pursue 'soft diplomacy', their advocacy efforts are most effective.

In order to facilitate the effectiveness, sustainability and replicability of efforts in disability-inclusive disaster risk management, experience presented in this paper indicates that a synchronized approach should be driven: policy and actual implementation need to inform each other - neither a policy without concrete implementation nor stand-alone community action are likely to make a difference in the long run.

Thus, harnessing the potential of persons with disability both in advocacy as well as actual planning, implementation and monitoring of disaster risk management is vital to reduce the disaster risks for all.

"We need to decide things on our own because it is our right."

Mila Baretto
President of the Arakan Federation of Persons with Disabilities, The Philippines

"Now I can sleep well because I know someone will help me evacuate if there is a risk of a flood.

It is like having life insurance."

Vo Van Dung
An Lac village, Vietnam

"We persons with disabilities need to prove that we're not just objects, who can only beg and expect sympathy from others.

We are subjects, the actors behind DRR activities."

Dodo Zakaria
Member of the Ciamis DRR Forum, Indonesia

As the good practices in this report illustrate, the inclusion and active participation of persons with disabilities in disaster risk management can come a long way: as they got engaged in community and higher-level advocacy meetings, the women and men portrayed in this paper have shed the stigma of mere recipients and become valued contributors to risk reduction efforts.

Empowered, their dedication has become palpable: through their contribution to better risk management, their lives have been transformed, perceptions changed, and risks reduced.

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