

Making the Invisible Visible!

The Significance of an Integrated Data Management System for Persons with Disabilities at National Level

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Disability groups have for decades, advocated for the rights of persons with disability in the Philippines. Their work has provided great contributions in integrating and embedding disability-inclusion in development. These can be seen in the numerous policies, mechanisms and mandates for mainstreaming accessibility, adapted programs, and affirmative action measures for participation. The tagline “*Nothing about us, without us*” has been a powerful message throughout the advocacy, and still holds true for the sector today.

The advocacy towards disability-inclusion has extended to disaster situations. Indeed, while persons with disability are considered as vulnerable due to the environmental, social, communication, and attitudinal barriers that they face in society, they become even more vulnerable in times of disaster. They are known to be disproportionately affected by disasters as they face higher risks, and experience particularly high rates of mortality during these events¹. Likewise, they are often excluded in disaster response support and services such as food distribution, medical care, shelter and water, sanitation and hygiene (WASH) facilities².

Recognizing the devastating effect disasters have on vulnerable groups such as persons with disability, disaster risk reduction and management (DRRM) measures in the recent years have become more integrated and holistic. DRRM has taken on a disability-inclusive perspective which integrates the principles of participation, twin track approach (adapted and mainstreaming approaches), comprehensive accessibility and universal design, “build back better”, non-discrimination, and coordination and collaboration in DRR. Furthermore, disability-inclusive disaster risk reduction and management (DiDRRM) poses that a community cannot truly gain disaster resilience without the inclusion and meaningful participation of the most vulnerable.

In the national law for DRRM or the Philippine Disaster Risk Reduction and Management Act of 2010 (Republic Act 10121), such principles are reflected in explicit mandates for removing barriers that deprive persons with disability opportunities to participate in and to access DRR responsive services and programs. It assumes that the sector has existing and evolving capacities and can greatly contribute to building community capacity to respond to disaster risk³.

The first five years of its implementation have demonstrated the efficiency of the community-based approach in disaster risk reduction. Experiences have brought insights on effective approaches and strategies in reducing the vulnerabilities and increasing the capacities of communities. Likewise, it produced important lessons in inclusivity which were integrated into the law’s first sunset review on from 2015-2016⁴. Almost at the same time, the Sendai

¹UNISDR. (2013). Involving persons with disabilities in disaster risk management builds stronger resilience. Retrieved from: <http://www.unisdr.org/archive/35249>

²CBM. (2012). Inclusion Made Easy: A Quick Program Guide to Disability in Development. Retrieved from: https://www.cbm.org/article/downloads/78851/CBM_Disability_Inclusion_-_Disaster_Management.doc.

³Republic Act 10121. Retrieved from: http://www.ndrrmc.gov.ph/attachments/article/45/Republic_Act_10121.pdf

⁴Government of the Philippines. (2015). SURGE calls for inclusiveness in DRR law sunset review, OCD leads RA 10121 sunset review. <https://reliefweb.int/report/philippines/surge-calls-inclusiveness-drr-law-sunset-review-oed-leads-ra-10121-sunset-review>

Framework for Disaster Risk Reduction (SFDRR) 2015-2030 was adopted in March 2015 and was applauded for how it affirmed and upheld principles of inclusivity, accessibility and universal design. Together, both acted as an impetus for DRR actors to intensify efforts for inclusive DRR in the country. The official adoption and use of the *Lahat Handa* Manual by the National Disaster Risk Reduction and Management Council (NDRRMC), Office of Civil Defense (OCD), and local governments for inclusive community-based DRRM is one of the many emerging efforts that adhere to the principles of disability inclusion.

Disability-inclusion and disaster resilience, both as cross-cutting themes in development, hold much potential as drivers of development. Together as policy and as a practice in disaster risk reduction, could truly save lives and build back better.

In working towards DiDRRM in the country, there is a need to draw out the context, distinct experiences, and perspectives of persons with disability in disasters. There is much to collect from their meaningful experiences as persons with disability who hold specific vulnerabilities as well as valuable, inherent, and evolving capacities. Building a picture of the current context of DiDRR will provide a springboard for identifying changes in policy and practice for disability inclusive disaster risk reduction management in the country.

A. Overview of the sector: Persons with disabilities

Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) describes persons with disabilities as “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”⁵.

Globally, 15 percent of people are estimated to be living with disability, two to four percent of which have severe disabilities.⁶ Numbers are believed to be higher in developing countries, where worsening inequalities exacerbate conditions for persons with disability.⁷ Poverty is said to be both a cause and an effect of disability, making the proportion of persons with disability highest among the poor.⁸ Older people, women and children who belong to underprivileged ethnic groups are most likely to live with disability; and women and girls are more at risk to physical and sexual abuse and exploitation.⁹

Indeed, persons with disability are often left unseen, unheard and unaccounted for,¹⁰ making them one of the most marginalized sectors in society. They struggle daily with multiple and

⁵UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html>

⁶ World Health Organization (2011). World Disabilities Report. Retrieved from: http://www.who.int/disabilities/world_report/2011/world_report_disability_easyread.pdf?ua=1

⁷Handicap International and French Development Agency (2012). Disability and Development. Retrieved from: http://www.hiproweb.org/fileadmin/cdroms/Handicap_Developpement/www/en_page21.html

⁸ Ibid

⁹ Handicap International. (2016). cited Lancet (2012), “global women population have some form of disability and are twice as likely to be affected by violence than their peers without disabilities”

¹⁰Dr. Emma Calgaro, et. al. (May 2015). Global Resilience Challenge Problem Statement: Disability and Disasters: Empowering people and building resilience to risk. Retrieved from: http://www.globalresiliencepartnership.org/assets/downloads/GRP-DisabilityandDisasters_ProblemStatement.pdf

interconnected barriers to basic services, opportunities, self-reliance, independence, and participation. Deeply embedded cultural beliefs, politics and governance, and utilization of limited resources are some of the root causes of discrimination and inequality, manifest in the practices of individuals and institutions, and are reproduced systemically.

Given estimates, at least 15.5 million people are living with disability in the Philippines.¹¹ Half of these are women and most are children and adolescents. About seven out of ten persons with disability are believed to be from rural areas.¹² However, the real number and diversity of persons with disability have not been reflected accurately in the country's data collection systems. The national census from 2010 only reported the sector to be less than two percent of the population, while the recent 2015 census entirely excluded the sector.¹³ Such practice has dire consequences on the persons with disability's inclusion in state programs, plans, and projects; and to an extent, reflect government accountability to the sector. To be seen, disability education must be central across different actors, and the state must systematize and standardize practice in data collection to reflect the real number of the sector.

With no reliable data to account for persons with disability, basic social services are less likely to reach persons with disability. In the Philippines, only one out of ten Filipinos with disability is able to access programs and services. Employment opportunities and social services for persons with disability are either scarce or absent¹⁴ as the sector is largely underserved by government agencies, and struggles with basic access to disability cards, health care, and education. As of 2009, only two percent of children with disability access Special Education (SPED) programs.¹⁵ Women and girls who care for persons with disability and women with disabilities are also more likely to take on the burden of care and household work. But social protection programs have yet to reach the sector and their carers or life intermediaries in a way that effectively transfers risks. In some cases where services do reach them, these are likely to be of low quality and are not responsive to their specific needs. To respond to the institutional discrimination and make state programs and services responsive to the needs of the sector, a multi-approach of changing cultural beliefs and practices at the individual, institutional, and systemic levels must happen.

Despite existing norms that respect, protect, and fulfill the rights of persons with disability in the country such as the Magna Carta for Persons with Disability (RA 7277), its recent amendment (RA 9442) as well as other related laws such as the Magna Carta of Women (RA 9710) and the national declaration of 2013-2022 as the 'Decade of Persons with Disability', the sector remains

¹¹Government of the Republic of the Philippines - Department of Social Welfare and Development. 2015 Listahanan (National Housing Targeting System), Table 5. Number of poor households by type of disability. Retrieved from http://listahanan.dswd.gov.ph/download/reports/profile_of_the_poor_/source%20table%200082912.pdfData reports that among the poor, 15% are in rural areas (2 percent more than in urban areas; most proportion of persons with disability among poor are in Cordillera Administrative RegionAR at 32.4 percent.

¹²Asian Development Bank (2005). Disabled People and Development: Philippines Country Report. Retrieved from: <http://library.pcw.gov.ph/sites/default/files/disabled%20people%20and%20development.pdf>. cited government estimates at 70% of persons with disability are in rural areas. DSWD 2015 Listahanan statistics show that 60% of the total persons with disability in the country are in rural areas.

¹³Philippine Star. Jake Soriano (23 Nov 2015). Census Leaves persons with disability's angers Disability Council. Retrieved from: <http://www.philstar.com/headlines/2015/11/23/1525063/census-leaves-out-pwds-angers-disability-council>

¹⁴Asian Development Bank (2005). Disabled People and Development: Philippines Country Report. Retrieved from: <http://library.pcw.gov.ph/sites/default/files/disabled%20people%20and%20development.pdf>.c The document describes basic social services and the access of persons with disability.

¹⁵As of 2009, only 2 percent of children have been reached by SPED, as mentioned in: Government of the Republic of the Philippines - Department of Education (2009). Department Order 72, series of 2009 - Inclusive Education as Strategy for Increasing Participation Rate of Children. Retrieved from: <http://www.deped.gov.ph/orders/do-72-s-2009>

largely unheard of in deciding over matters that affect their lives. In formal participation, only about 22 percent of registered persons with disability voters were able to cast their votes in the 2013 elections. Numbers fell further to 14 percent in the 2016 elections.¹⁶ Moreover, while DPOs have been formed in recent years and have advocated for the sector's rights, an enabling environment to meaningfully participate in governance has yet to be realized across the country.¹⁷ To raise voices and be heard, contributions must be made in strengthening the sector and in engaging the state to create mechanisms, adhere to practices that build inherent and evolving capacities of the sector, and enable meaningful participation.

B. Disability-Inclusive Development

A rights-based approach for disability-inclusion in development has been advocated for by disability groups and allies in the past decades. Unlike previous approaches—the charity and medical models that treat the sector as passive recipients of support and services; the economic model which aims to increase productivity; and the social model that focuses on environmental barriers that cause disability—the rights-based approach fully recognizes persons with disability as an active actor in the fulfillment of their rights. Empowerment is central in this approach, where actions must be aimed towards how the sector gains power to challenge discrimination and inequality, promote self-reliance and independence, and define development for themselves.

Another focal concept in disability-inclusive development is inclusion, which has been defined as “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”¹⁸.

C. National Frameworks

Even prior to international frameworks such as the UNCRPD, the Philippines has over the years, proven that the disability sector should be valued as members of the greater society, with equal rights and privileges with that of persons without disabilities. For instance, a present mechanism at the national level is the National Council for Disability Affairs (NCDA), which acts as the national policy formulation agency of the country on disability in development. It monitors policies on the sector's rights and is mandated to coordinate with other government agencies and drive them towards disability-inclusive development. At the local government level, the Persons with Disability Affairs Office (PDAO) is mandated to implement and formulate plans, programs and policies for the welfare of persons with disabilities.

¹⁶ Philippine Star, Maria Feona Imperial and Lala Ordenes (February 16, 2016). Fewer registered persons with disability voters for 2016 elections. Retrieved from: <http://www.philstar.com/headlines/2016/02/16/1553628/fewer-registered-pwd-voters-2016-elections>

¹⁷ Asian Development Bank (2005). Disabled People and Development: Philippines Country Report. Retrieved from: <http://library.pcw.gov.ph/sites/default/files/disabled%20people%20and%20development.pdf>.

¹⁸ Handicap International. (2014). Empowerment and participation: Good practices from South & South-East Asia in disability inclusive disaster risk management. Retrieved from http://www.preventionweb.net/files/38358_38358hiempowermentandparticipationi.pdf

There has also been a number of disability-related laws in the country. Those that link to disaster risk reduction management are policies on accessibility (BP344), institutional mechanism for PWDs programs and services (RA10070), incentives (RA9442), and economic independence through employment and opportunities (RA10524; EO417).

Disability-Related Laws and Policies

Magna Carta for Persons with Disability

The Magna Carta for Persons with Disability or Republic Act 7277 has been the most important legal basis for persons with disability in the country, as it provides a clear and comprehensive input on the rights and privileges of persons with disability. This has been adopted to ensure their rehabilitation, self-development and self-reliance, thereby achieving the necessary skills and capabilities to take an active part in their community.

Following RA 7277, there are also existing legal instruments focused on accessibility (BP 344), institutional mechanism for persons with disability programs and services (RA 10070), incentives (RA 9442), and economic independence through employment and opportunities (RA 10524; EO 417).

Accessibility

The Batas Pambansa 344 or more commonly known as our Accessibility Law was passed more than three decades ago, with the aim of enhancing the mobility of persons with disability by requiring certain buildings, institutions, establishments and public utilities to install facilities and other devices that enable free movement of persons with disability. The law promotes equal rights of persons with disability and persons without disabilities in accessing physical infrastructure. Significantly, this act becomes more relevant during disaster situations, in which everyone's safety and security is threatened and ease of access of evacuation routes and exit points are life-saving. This includes employing measures to increase accessibility in evacuation centers, such as ramps and railings, tactile paths, ropes and guides, blinkers and light-assistive devices, audio-assistive measures, and signage or visual aids, among others.

Institutional mechanism for persons with disability programs and services

RA 10070 aims to establish institutional mechanism to ensure the implementation of programs and services for persons with disability in the province, and city/municipal level. This is an amendment of RA 7277, which focused on strengthening livelihood opportunities, health, physical fitness and the economic and social well-being of persons with disability through the establishment of Persons with Disability Affairs Office (PDAO). This is also a mechanism in ensuring the active participation of the disability sector in various undertakings of their respective local government unit.

In terms of how this policy influences DiDRR, it is deemed significant that the concerns and issues of the sector, especially during and post disaster situations, are well taken cared of. This ensures that programs and services relevant to the sector increase their capability to prepare for a disaster through trainings and planning. During response, this mechanism will also ensure that

the needs of the sector will not be disregarded, especially issues concerning protection, safety, and security. Moreover, this institutional set-up is relevant in post-disaster situations, to ably assist the disability sector in recovery and rehabilitation efforts, through livelihood opportunities, education, shelter, and access to various resources.

Incentives and Anti-Discrimination

RA 9442 is also one of the amendatory outcomes of the Magna Carta for Persons with Disability, centering on the sector's privileges and incentives. This mandates all service providers to give at least 20% discount to every person with disability, in different businesses such as food, healthcare and medicine, accommodation, recreation, transportation, and education. Aside from incentives, this also provides tax considerations to their primary carers and prohibition of verbal and non-verbal ridicule and vilification against persons with disability.

Realizing the essence of this law in promoting DiDRR, it is noteworthy to uphold these privileges and incentives even in actual disaster situations. Through these provisions, the sector's purchasing power is increased, which is deemed significant in the continuance and promotion of their well-being in the aftermath of disasters. On the other hand, the prohibition of ridicule and vilification also help stop discrimination towards the disability sector as data showed that bullying and discrimination of persons with disability aggravates during actual and post disaster conditions.

Economic independence through employment and opportunities

RA 10524 or more commonly known as "An Act Expanding the Positions Reserved for Persons with Disability" stipulates equal opportunity for employment and remuneration for work of equal value of persons with disability. Apart from providing the sector with greater opportunity to work in the government through mandating that one percent of employment positions shall be reserved for the sector, this law also champions the integration of the persons with disability in the mainstream society.

Another law which promotes economic independence to the sector is EO 417, enjoining Government Owned and Controlled Corporations to support the persons with disability sector, through purchase of their products, technical training advancements, and microfinance assistance mechanisms. The relevance of this law poses one of the possible solutions to address economic marginalization of the sector, especially since there is a high concentration of persons with disability involved in self-employment through micro-small-medium enterprises. This will facilitate sustenance of persons with disability's initiatives to empower their members and strengthen their organizations, which can lead to the creation of better disaster recovery and rehabilitation strategies for persons with disability.

Disability-inclusion in Disaster Risk Reduction: Republic Act 10121

Republic Act 10121 or the Philippine DRRM Act of 2010 is a law mandated to strengthen disaster risk reduction and management in the country. It states among its policies aims to address the root causes of vulnerabilities to disasters, strengthen the country's institutional capacity for disaster risk reduction and management, and build the resilience of local communities to disasters including climate change impacts. Moreover, it aspires to develop and strengthen the capacities of vulnerable and marginalized groups to mitigate, prepare for,

respond to, and recover from the effects of disasters. In declaring such, it acknowledges persons with disability as active players and contributors in resilience building.

In accordance with RA 10121's mandates, the National Disaster Risk Reduction and Management Plan (NDRRMP) provides the legal basis for policies, plans and programs to deal with disasters. The NDRRMP lays out four thematic areas that are envisioned to lead to safer, adaptive, and disaster resilient Filipino communities towards sustainable development:

- a. Disaster Prevention and Mitigation: the outright avoidance and lessening or limitation of adverse impacts of hazards and related disasters.
- b. Disaster Preparedness: the knowledge and capacities developed by governments, professional response and recovery organizations, communities and individuals to effectively anticipate, respond to, and recover from, the impacts of likely, imminent or current hazard events or conditions.
- c. Disaster Response: the provision of emergency services and public assistance during or immediately after a disaster in order to save lives, reduce health impacts, ensure public safety and meet the basic subsistence needs of the people affected.
- d. Disaster Rehabilitation and Recovery: measures that ensure the ability of affected communities/areas to restore their normal level of functioning by rebuilding livelihood and damaged infrastructures and increasing the communities' organizational capacity¹⁹.

The law is currently subject to an amendment. This is to address its gaps and improve current practices on DRRM.

The Need for Accurate Data to Achieve Inclusion and Visibility

National information on persons with disability is vital in gaining a complete understanding of the sector, and in determining how best to address their needs and tap their capacities. In times of disaster, accurate information about persons with disability is needed for proper provision of goods, facilities, and services. Indeed, in ensuring DiDRRM, as targeted by Goal 7 of the Incheon Strategy, precise data is necessary in providing timely and appropriate support to persons with disability in responding to disasters. However, the country's data collection systems have not reflected accurate counts of persons with disability, thereby serving as a source of their exclusion.

While there are many efforts in counting at the national and local levels, the consultations conducted by the Center for Disaster Preparedness showed that these do not use the same tool nor are regularly used for local planning in DRRM. The lack of accurate counts and information on the sector locally and nationally also prevent DRR practitioners from reasonably estimating the proportion of the population who have disabilities. It is then imperative to streamline, standardize and make registry accessible to persons with disability, especially for poor persons with disability who live in remote and conflict-sensitive areas. This can help generate data that can inform disaster risk reduction planning, implementation and monitoring and evaluation.

At the heart of changes that must happen to achieve DiDRRM is meaningful and significant participation of persons with disability. The UNCRPD upholds the full participation and inclusion

¹⁹ Republic Act 10121. Retrieved from http://www.ndrrmc.gov.ph/attachments/article/45/Republic_Act_10121.pdf

of the sector in society. Yet in the country, participation of persons with disability in policymaking bodies, especially at local DRR councils is rare. Apart from social isolation and low awareness on disability, such practice is said to be linked to a lack of understanding of local DRR councils on the imperative to involve vulnerable groups in decision-making. The cost of persons with disability's absence in DRRM councils mean generic plans, poor budget allocations and implementation. DRRM mechanisms offer an opportunity to drive the participation of persons with disability and facilitate their empowerment. Its mandates should help change the existing culture of shame and discrimination and reduce persons with disability and other marginalized and vulnerable group's disaster risk. Thus, it is evident that disability-inclusion must be integrated in all thematic areas of disaster risk reduction and management to be able to achieve full and equal human rights for persons with disability.

The goal of the *Integrated Data Management System project* is to promote the inclusion of persons with disabilities in planning, budgeting, and other development processes of LGUs and agencies particularly in DRRM. Its measure of success is the percentage of city/municipal offices that commit to using the database in developing their annual plans and programs particularly in DRRM. The intended outcome of the project is for the LGUs to have increased capacity to capture specific information on persons with disabilities in their locality. The measure to achieve this is through the percent increase in number of persons with disabilities recorded in the municipal database and the increase in the number of types of information regarding persons with disabilities available through the municipal database.

Target users of the tool are national agencies, local government units, DPOs, civil society organizations, and other key institutions. The data gathering tool and the database will aid these agencies and organizations in enhancing risk assessment tools and systems to address the needs of specific disabilities in all phases of DRRM²⁰. These goals and outcomes are in line with enhancing the participation of persons with disabilities who are among the most marginalized sectors in the world. The Caraga region will be targeted as the pilot site for the proposed project, as it belongs in the Mindanao island group, wherein several regions and provinces experience poverty and a multitude of natural and human induced hazards. Strategically, municipalities in the region have already established offices to serve persons with disabilities from various age groups and genders. CDP's existing linkages in the region will help make the implementation of the pilot more effective.

The database can also be used during capacity building activities in Community-Based Disaster Risk Reduction and Management, particularly during the Community Risk Assessments (CRA). The database can be used to further develop certain risk assessment tools, like the Elements-at-Risk tool, which determines the resources, capacities, and vulnerabilities of a community. Information collected from the CRA process is the foundation of a community's disaster risk reduction and management plans. More comprehensive data on persons with disability will ensure that local development and DRRM plans will cater to the specific needs and concerns of the sector and reinforce a community's preparedness and response capacities.

In ensuring the sustainability of the data gathering tool and database, CDP strengthens its linkages with local service providers such as the Municipal Health Office and Municipal Social Welfare and Development Office to ensure that the tool developed is user-friendly and can be adopted into the existing data management systems. Through continuous consultation with local DPOs, CSOs, community councils, and other vulnerable groups, CDP hopes to foster

²⁰ The phases of DRRM are: disaster preparedness, prevention and mitigation, emergency response, and recovery and rehabilitation

ownership with local partners, thereby ensuring the tool and database's usability and sustainability.

The data base uses the Kobo Collect which is an open source Android application used in primary data collection of challenging environments. Ultimately, the intended output is the establishment of a comprehensive data management system for persons with disabilities at the municipal and city levels. Such initiative is definitely replicable and scalable at national level.

The data gathered through the mobile application, specifically the number of persons with disabilities present and concentrated in specific areas, the kinds of disabilities they have, disaster risk reduction and management information, and other pertinent details gathered through the tool, such as age, gender, etc. can be used by various duty-bearers for the better provision of resources for persons with disabilities.

The data can be used by the Municipal Health Office for the provision of Persons with Disabilities ID; for the Social Welfare and Development Office to provide specific social services; for the Provincial/Municipal/City/Barangay Disaster Risk Reduction and Management Councils' database in tracking down vulnerable groups in Community Risk Assessments, evacuation, rescue, response, and other DRRM activities; and for civil society organizations who may need the data to implement projects together with persons with disabilities.

Identification of persons with disabilities enables them to have greater access to basic social services and other resources that are specific to their needs, including medical attention, community-based rehabilitation (CBR), as well as education. Capacitating the duty bearers and service providers on the usage of the tool and mobile application will allow them to access data on persons with disabilities immediately. This can radically change the face of service delivery for persons with disability, as the first of its kind is created and available for free and open access.

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