POLICY BRIEF #1

MAKING THE COUNT MATTER:

THE IMPORTANCE OF DISAGGREGATED DATA FOR PERSONS WITH DISABILITIES

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EXECUTIVE SUMMARY

Climate change exacerbates existing social and economic inequalities, putting marginalized communities at greater risk to the impacts of climate change. Persons with disabilities are among those more severely affected because there is a lack of accessible solutions and services to address their diverse and unique needs and vulnerabilities. This can be traced to the lack of adequate and timely data on persons with disabilities to inform the development of adequate adaptation or response strategies, thus leading to inaccessible and even maladaptive solutions. While there are existing policies for the collection of such data in the Philippines, the country continues to grapple with improving data on persons with disabilities, encountering challenges across all phases from data governance, profiling, collection and reporting, to sharing and analysis. It is critical to strengthen enforcement of existing disability laws; develop and cascade a more appropriate, comparable, representative and disaggregated data structure and system to profile persons with disabilities in the country; and mandate their relevance and intersection in cross-sectoral issues, such as climate change and disaster risk reduction and management. This would help ensure that data is found useful and successfully integrated in development, climate change adaptation and disaster plans, and lead to more inclusive and accessible climate change and disaster risk management strategies.

KEYWORDS

Disaggregated data, Persons with disabilities, Climate change, Disaster risk reduction

INTRODUCTION

Persons with disabilities have been acknowledged as among the most vulnerable to the adverse impacts of climate change (Office of the High Commissioner on Human Rights, 2020; United Nations Department for Economic and Social Affairs, 2018). Despite accounting for approximately 15% of the global population, the sector remains invisible in laws and policies and overlooked in the provision of services, especially during humanitarian emergencies and disaster scenarios (UNDESA, 2018). A significant contributing factor to this is the limited amount of quality data on the sector, resulting in inadequate knowledge about the sector and their rights and needs.

UNDERSTANDING DISABILITY STATISTICS

The importance of developing "high quality, accessible, timely, reliable and disaggregated data" for decision-making was highlighted in the **2030 Agenda for Sustainable Development** (UN, 2015) and included among the **Sustainable Development Goals**, which called upon governments "to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts" (UN, 2023). The need for data is also enshrined in Article 31 of the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)** which mandates member states to "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" (UNCRPD, 2006). Despite these policies pushing for collection of data on persons with disabilities, there has been a continuing disconnect in the way countries define and collect data about the sector.

Persons with disabilities have long been understood through a medical perspective or "charity model" wherein disability is defined as impairments, directly or indirectly resulting from health or medical issues, resulting in the loss of certain functions. Over recent decades, the World Health Organization (WHO) and the UNCRPD have shifted to a social model of disability, wherein disability is conceptualized as the result of the interaction between individuals with health conditions with impairments and "various barriers that may hinder their full and effective participation in society on an equal basis with others" (WHO, 2002; UNDESA, 2018; UNCRPD, 2006).

In this social model, "disability" is not measured arbitrarily by the nature of the disability or health condition but by the degree of difficulty experienced by such individuals, as a result of barriers presented by unaccommodating or inaccessible physical, social and even political environments that may exist (Centre Team, 2019; WHO, 2002; UNCRPD, 2006). This shift in the framing of disabilities has set the stage for a more rights-based approach to disability-inclusion (Washington Group, 2023).

Various tools were later developed to provide guidance for countries in gathering data on the sector aligned with the social model of disability (UNDESA, 2018). The **Washington Group Short Set of Questions (WG-SS)**, which consists of six questions that identify functional difficulties across six functional domains on a spectrum of severity (from no difficulty to extreme difficulty), is one example that has been advocated as a means to gather internationally comparable data on persons with functional difficulties (WG, n.d.; Philippine Statistics Authority, 2019). Additionally, the **Model Disability Survey** (WHO, 2012) was designed to provide more detailed information regarding the difficulties experienced by persons with disabilities in their daily lives and additional insight regarding unmet needs, barriers, and inequalities that contribute to their quality of life.

DISAGGREGATED DATA IN CLIMATE CHANGE AND DISASTER RISK REDUCTION

Collecting data is highlighted most often in Climate Change (CC) and Disaster Risk Reduction (DRR) responses for the purpose of monitoring. Importance of data is well enshrined in the Sendai Framework for Disaster Risk Reduction (SFDRR) guiding principles, stating that DRR requires "...inclusive risk-informed decision-making based on the open exchange and dissemination of disaggregated data..." (SFDRR, 2015; Seglah & Blanchard, 2022). This sits alongside other guiding principles that highlight the importance of inclusion, participation and an emphasis on human rights, among others (SFDRR,

2015). The Age and Disability Consortium (2018) documented the use of tools like the WG-SS during disaster scenarios, which proved effective in identifying individuals needing more support and improving accessibility of post-disaster response and evacuation centers in a timely manner. Disaggregated data is essential during climate and disaster situations because it can help identify more appropriate CC or DRRM strategies that can result in lower casualties, better preparedness, and more effective outcomes for vulnerable and marginalized groups like persons with disabilities (Seglah & Blanchard, 2022). Conversely, the lack of or incomplete information on affected individuals has been known to lead to inappropriate or maladaptive strategies that can make their lives worse (Seglah & Blanchard, 2022). Whether in pursuit of climate and social justice or merely compliance with international mandates, high-quality disaggregated data is a necessity all countries must provide to meet the needs and rights of marginalized sectors like persons with disabilities.

DISABILITY DATA IN THE PHILIPPINES

The Philippine Statistics Authority (PSA) was established by virtue of **R.A. 10625 ("Philippine Statistical Act")** to serve as the central statistical authority mandated to produce data that would serve as the official and controlling statistics used by the government. The PSA conducts various surveys with the aim of providing useful information for the purpose of policy development and planning. Specific to collecting data on persons with disabilities, PSA has been inconsistent and has employed varying tools for data collection over the last few years.

The **2010 Census of Population and Housing (CPH)**[1] recorded 1.44 million persons with disabilities in the country, accounting for 1.57% of the total population at the time (Vera Files, 2015). The **2015 Census for Population (POPCEN)** was later criticized for having omitted persons with disabilities altogether, despite claims of having adopted the internationally recommended WG-SS questions (Vera Files, 2015). In the following year, the PSA released the **National Disability Prevalence Survey (NDPS)** which found that "12%

of Filipinos aged 15 and older experience severe disability" (PSA, 2019). In the latest **2020 CPH**, the PSA officially adopted the WG-SS, wherein it was able to account for 8.7% of the total household population or 8.4 million households with at least one (1) person declaring at least one functional difficulty (PSA, 2022).

The data gathered by the PSA is collected through enumerated surveys/interviews with responsible representatives of households that can provide the necessary information (PSA, 2022b). In addition to the national census, the PSA deployed a localized survey together with Local Government Units (LGUs), in accordance with **Republic Act No. 11315 ("Community-Based Monitoring System (CBMS) Act of 2018")**, which is a technology-based survey system that aims to collect local data to inform the strategic development of plans and development targets (Reyes, 2023). While this survey contains some questions on disabilities, it was mentioned as mandatory and has yet to be widely implemented.

Apart from data collection efforts of the PSA, there is also the **Philippine Registry for Persons with Disabilities (PRPWD)**, which is managed and maintained by the Department of Health (DOH), in coordination with the National Commission on Disability Affairs (NCDA), Department of Social Welfare and Development (DSWD) and the Department of Interior and Local Government (DILG). The PRPWD serves as the official national registry of the country, and provides the basis for various critical support services including healthcare, other financial benefits, and rights as stated in the **Republic Act No. 7277 ("Magna Carta for Disabled Persons")**. According to representatives from the National Council on Disability Affairs (NCDA), the PRPWD has only accounted for 900,000 individuals as of May 2023, which is closer to the estimates of the CPH conducted in 2000. The data in the PRPWD is gathered through local Persons with Disability Affairs Offices (PDAO), established by virtue of **Republic Act No. 10070 ("Magna Carta For Disabled Persons," as Amended, and For Other Purposes")** via the voluntary application process for persons with disabilities IDs that make them eligible for various benefits stipulated in **Republic Act No. 11228 ("An Act Providing for Mandatory PhilHealth Coverage for Persons with Disabilities")** and the Magna Carta, among others. The data from the PRPWD is protected under the Data Privacy Act and is therefore not available to the public. As such, the level of disaggregation of data in the PRPWD cannot be determined at this point.

Other government agencies have separate initiatives to gather population statistics. One referred to by disaster-related agencies is the **Listahanan Data (2015)**, gathered and managed by the DSWD. The project focuses on profiling poverty statistics, in which the disability sector constitutes 1.1% (320,922 individuals), and people with functional difficulties constitute 2.7% (700,000) (DSWD, 2015). This data is designed based on different and narrower parameters compared to the previously discussed databases, and yet, government agencies are mandated to use this particular dataset as the basis for providing social protection programs, in accordance with **Executive Order No. 867 ("Providing for the Adoption of the National Household Targeting System for Poverty Reduction...")**.

Given the data and statistical mechanisms that currently exist, it is evident that there is indeed data available on persons with disabilities. However, discrepancies in data gathered and its quality, gaps in implementation, among other issues, are still cause for concern. These gaps in data collection call into question the integrity of the data being collected, and consequently its usefulness as a basis for evidence-based decision making and inclusive action, particularly for climate adaptation and humanitarian responses.

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[1] Data from PSA census was available on their website until July 2023, however, it has since been taken down and is no longer readily available online through the relevant links.

Table 1. Differences between primary data gathering mechanisms on Persons with Disabilities

	Philippine Registry for Persons with Disabilities (PRPWD)	Census for Population and Households (CPH)	Community-Based Monitoring System (CBMS)
Methodologies	Applications from persons with disabilities, as supported through certification of disabilities issued by specialists or representatives of the city/municipality health office[2]; ongoing process of application	Enumerated survey/interviews with responsible representatives of households that can provide the necessary information; conducted every 10 years since 1980[3]	Enumerated survey/interviews with responsible representatives of households that can provide the necessary information; conducted every three years
Responsible Agency	Department of Health (DOH), National Council for Disability Affairs (NCDA), and Local Government Units (LGUs)	Philippine Statistics Authority (PSA) and field enumerators	Philippine Statistics Authority (PSA), Department of Interior and local Government (DILG), Department of Information and Communication Technology (DICT) Local Government Units (LGUs)
Terminologies	**Persons with Disabilities** "are those suffering from restriction or different abilities, as a result of a mental, physical or sensory impairment, to perform an activity in the manner or within the range-considered normal for a human being." **Types of Disabilities:** Visual, Deaf or Hearing, Intellectual, Learning, Mental, Physical (Orthopedic), Psychosocial, Speech & Language Impairment, Others (Cancer or rare disease)	**Functional Difficulties** "functional difficulties experienced by people may have been due to their health conditions" (e.g. injuries, mental or emotional problems, alcohol- or drug- problems, and other circumstances including pregnancy, age, stress, congenital anomaly or genetic predisposition) (PSA, n.d.) **Types of Functional Difficulties:** Seeing, Hearing, Walking or climbing steps, Remembering or concentrating, Self-caring or Communicating	**Persons with Disabilities/ Disabled persons** Same as the PRPWD

[2] [NCDA Administrative Order No. 001-2021](#)
[3] [Batas Pambansa Blg. 72](#) (" An Act Providing for the Taking of an Integrated Census Every Ten Years...")
[4] [See DOH Administrative Order 2017-0008](#), definitions adopted from the Implementing Rules and Regulations of RA 7277, RA 9442, and RA 1075

GAPS AND CHALLENGES IN DATA GATHERING PROCESSES

DATA GOVERNANCE

The lack of focus on data on persons with disabilities and their sub-groups is in direct violation of commitments made under the UNCRPD, and further makes meeting the right stipulated in the Magna Carta for Persons with Disabilities impossible to achieve. As discussed in the previous section, the varied methodologies and parameters currently being employed by the government has resulted in disconnected and inconsistent counts for persons with disabilities as a whole, and startlingly limited information about the sub-sectors, such as the d/Deaf community and people with other disabilities. As a result, this can lead to confusion in identifying the most appropriate types of data to guide decision-making under different scenarios.

Furthermore, when asked, most stakeholders associate this lack of data on persons with disabilities with poor data governance at the local level, either due to the frequently changing local administrations in three-year cycles[5], or a general lack of political will to allocate personnel and resources for the task. A study conducted in 2015 also noted that there are other issues such as "turfing between PDAOs and Social Welfare and Development Offices" and confusion regarding the need for a PDAO or merely a focal person, that may also be adding to the issue (Alampay, Crueg & Quebral, 2018). In 2021, the NCDA released a statement that only 50% of LGUs had successfully established a PDAO office leaving many LGUs without a focal office to coordinate with the sector (Rocamora, 2021). This is particularly concerning because the PDAO is the frontline agency tasked to manage data collection for the sector and represent their needs in critical decision-making bodies or processes[6]. Establishing the PDAOs and ensuring that they have the resources to deliver on their mandates are fundamental to securing more information about the sector.

DATA PROFILING

The R.A. 7277 ("Magna Carta for Disabled Persons"), among other laws, has yet to adopt the rights-based conceptualization of disabilities, as enshrined in the UNCRPD. As a result, many of the national datasets on the sector and their application at the local levels have used varying terms (e.g., disabled persons, persons with disabilities) and definitions (e.g., medical vs. social perspective) for persons with disabilities. It can also be observed that there are variations in the methodologies (e.g., enumeration with able household members, tech-based or virtual surveys, etc.) and parameters (e.g., 5 years old and above, 15 years old and above, from poor households, etc.) being used across databases. In reviewing local databases for persons with disability IDs, Alampay, et.al (2018) found that there was no standard structure or content across surveyed LGU. This begs the question of whether such data gathering efforts are indeed accurate in accounting for and characterizing the needs of persons with disabilities, particularly sub-groups like the d/Deaf community, and more so the data's usefulness in guiding decision-makers regarding the needs of such groups. For instance, going beyond the basic demographics, a critical concern of the d/Deaf is their literacy and signing competency levels, which can be directly associated with educational attainment and their access to education. Disaggregated data on educational attainment and literacy could provide actionable information to design strategic interventions and programs for the resilience of the sector.

DATA GATHERING AND REPORTING

For LGUs that are able to gather data on persons with disabilities, some challenges that are commonly encountered include the low participation rate of persons with disabilities with higher socio-economic status in local surveys, and the low application rate for persons with disabilities IDs due to experiences of discrimination or negative stigma associated with declaring their disabilities. The process of registering may also be too costly for some persons with disabilities, particularly for those with hidden or "non-apparent" disabilities from impoverished families that are required to submit medical certification[7]. Finally, challenges in data reporting include the lack of necessary equipment and access to the internet for the encoding and transmission of data to the centralized PRPWD. These issues are most prominent in far flung and rural areas.

DATA SHARING AND ANALYSIS

Gathering such data is not meant to be done merely for the sake of having data, but for its usefulness in guiding the development of national and local development plans. However, there is evidence that data sharing or the use of data on persons with disabilities across offices dealing with cross-sectoral issues, such as CC-DRR, is not being practiced. A review of current plans and policies such as the National Strategic Framework for Climate Change (NSFCC), the National Climate Change Action Plan (NCCAP), and the National Disaster Risk Reduction and Management Plan (NDRRMP), revealed that none of these major plans have integrated (or considered) statistics and information on persons with disabilities, beyond the mere mention that they are among the "vulnerable and marginalized communities". Despite the presence of data from the PSA and PRPWD as "official" sources for data on the disability sector, many government agencies indicate that they still use other sources of information, like the Listahanan database, which follows its own unique parameters and is not representative of the entire disability-sector population. At the local level, disability data is commonly overlooked altogether, as evidenced by guidance documents on the development of local climate change action plans (LCCAPs) and local disaster risk reduction and management plans (LDDRMPs)[8][9], which fail to include the sector through the PDAO, or even refer to data on persons with disabilities as a required consideration in the development of these plans. Beyond the realm of public governance, it should be noted that access to data on the disability-sector could help guide development action by other stakeholders. However, the data sources indicated in previous sections are not available publicly. While the NCDA houses various datasets on the disability sector in their website, the only one specific to the d/Deaf community are statistics of Deaf individuals fitted for hearing aids, which is a controversial intervention at best. The continuing oversight of the disability sector is in need of immediate remedies, as it has resulted in a lack of accessible, life-saving and disability-inclusive programs, to the detriment of the security and well-being of all persons with disabilities during high-risk disaster scenarios.

7 NCDA Administrative Order No. 001, Series of 2008.
8 DILG Memorandum Circular 2015-77. Guidelines on Mainstreaming Climate Change Adaptation and Disaster Risk
   in Local Development Plans
9 Enhanced LGU Guidebook on the Formulation of Local Climate Change Action Plan (Process Guide) Book 3

OPPORTUNITIES TO IMPROVE DISABILITY DATA AND ITS USE

A critical step towards improving disability data and its use in the country, is the updating of the Magna Carta for Disabled Persons and other disability laws, in accordance with the rights-based and social model of disabilities. Institutionalizing and standardizing the definitions and rights across all sectors, alongside the mainstreaming of more inclusive perspectives towards persons with disabilities, would change the landscape of governance for persons with disabilities for the better. Also critical to this would be the establishment of coordinating mechanisms across agencies and local offices to ensure the mainstreaming and utilization of disability data in all cross-sectoral issues; the same was recommended by the UNCRPD committee in 2018 (UNCRPD, 2018).

There is also a need for greater enforcement of the Magna Carta, as amended by Republic Act No.10070, which mandates the creation of PDAOs or a focal person for disability affairs in all local government offices. As the frontline agencies, they are best placed to address the needs of the disability sector within their respective jurisdictions, beginning with the development of updated databases on the community. Alongside this, it is essential to create an enabling policy environment for the allocation of resources and capacity building to enable the PDAOs to effectively execute their responsibilities.

Regarding the collection and management of data on persons with disabilities, more attention is needed to establish and cascade more appropriate, comparable and representative data profiling for persons with disabilities, with specific consideration of various sub-groups such as the d/Deaf. This could entail standardizing data points that must be gathered to adequately represent the sector and their needs; identifying more accessible data gathering methodologies; standardizing tools and frameworks for all databases; and ensuring that the data being gathered is vital for integrating across all development plans to inject greater inclusion for persons with disabilities. The UNCRPD Committee recommended that data on persons with disabilities should incorporate disaggregation by "sex, age, ethnicity, type of impairment, socioeconomic status, employment and place of residence, as well as data on the barriers that persons with disabilities face in society and their level of poverty" (UNCRPD, 2018).

Finally, refined data on the disability sector is key towards the development of more inclusive and accessible CC adaptation and DRRM strategies, which can spell the difference between life and death for persons with disabilities. It is critical to emphasize and institutionalize the importance of integrating disability data in all phases of CC and DRRM strategies, from risk and vulnerability assessments, climate and disaster planning, disaster response, post-disaster needs assessments, to recovery and rehabilitation. This would ensure that persons with disabilities are accounted for and adequately supported in situations of risk, in accordance with our commitments to the UNCRPD, UNFCCC, the SFDRRM, and even the SDGs.

Table 2. Summary of recommendations for enhanced and useful data on persons with disabilities

RECOMMENDATION	RELEVANT POLICIES
Updating of the Magna Carta for Disabled Persons, and other disability laws, in accordance with the rights-based and social model of disabilities	• Republic Act No. 7277 ("Magna Carta for Disabled Persons") • Batas Pambansa Blg. 344 ("Accessibility Act")
Greater enforcement of the Magna Carta, as amended by Republic Act No.10070, which mandates the creation of Persons with Disabilities Offices or a focal person for disability affairs in all local government offices	• Republic Act No. 7277 ("Magna Carta for Disabled Persons") • Republic Act No. 10070 ("An Act Establishing An Institutional Mechanism To Ensure The Implementation Of Programs And Services For Persons With Disabilities In Every Province, City And Municipality")
Establish and cascade more appropriate, comparable and representative data profiling for persons with disabilities, with specific consideration of various sub-groups such as the d/Deaf.	• Republic Act. 10625 ("Philippine Statistical Systems Act") • Executive Order No. 867 ("Providing for the Adoption of the National Household Targeting System for Poverty Reduction…"). • Republic Act No. 11315 ("Community-Based Monitoring System (CBMS) Act of 2018")
Institutionalize the importance of integrating disability data in all phases of CC and DRRM strategies, from risk and vulnerability assessments, climate and disaster planning, disaster response, post-disaster needs assessments, to recovery and rehabilitation.	• DILG Memorandum Circular 2015-77. Guidelines on Mainstreaming Climate Change Adaptation and Disaster Risk in Local Development Plans • National and Local Climate Change Action Plan • National Strategic Framework on Climate Change • National Adaptation Plan (currently being developed) • National and Local Disaster Risk Reduction and Management Plan

CONCLUSION

In the pursuit of more inclusive action and compliance with our commitment to "leave no one behind", it is critical to give a face and voice to those that are most vulnerable. Persons with disabilities experience differentiated and more severe impacts of CC compared to people without disabilities, and this can be further exacerbated for communities that have even more intersections (e.g. women and children with disabilities). There is an indisputable consensus among stakeholders that data is critical as the first step in better understanding the impacts of CC on marginalized sectors and providing the necessary evidence to guide the identification of appropriate, accessible, and inclusive strategies to address their specific vulnerabilities (Smith, 2022; Kett, 2018). Though this will inevitably require more effort and resources, it is critical to exert the extra effort to pay attention to those most often left behind and unaccounted for in official databases and ensure that their needs are integrated in plans and policies (OHCHR, 2015).

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