

## **Disaggregated Data: Making sure that excluded peoples are included**

(The experience of the Las Piñas Persons with Disability Federation, Inc. in participatory data profiling)

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*Addressing disability is a fundamental aspect of re-imagining social development and reclaiming people's development. An essential aspect of this is having disability-related data which can be used in measuring and tracking the progress of global development initiatives such as the Sustainable Development Goals as well as in deciding priorities, crafting policies, and developing and implementing development programs at the national and local levels. This article aims to describe the experiences of the Las Piñas Persons with Disability Federation, Inc. (LPPWDFI), an organization of persons with disabilities in developing, implementing, monitoring, and evaluating their own data-profiling project. This article utilized a combination of three methods: (a) Pakikiisa at Pakikipamuhay (Integration), (b) Kwentuhan at sama-aralan (Conversations, dialogue, reflection, and learning sessions) and (c) Pagbabasa at pagsusuri ng mga kwento at dokumento (Review and analysis of existing documents) with the underlying intent of listening to and valuing the perspectives and voices of persons with disabilities. Four critical factors that contributed to the success of the LPPWDFI's collective initiative are also discussed in the article: (a) Rights, identities, and aspirations of persons with disabilities, (b) Leadership development, capacity-building, and local initiatives, (c) The role of support organizations and the state, and (d) Facing the need to build on local gains. The article hopes that the story of LPPWDFI's data profiling initiative can open up spaces for introspection among organizations of persons with disabilities and eventually for their collective action aimed at creating inclusive communities in a more inclusive world.*

**Key Words:** disability-disaggregated data, participatory data profiling, social inclusion, persons with disability, LPPDFI

## Introduction

Addressing disability is a fundamental aspect of re-imagining social development and reclaiming people's development. Development, after all, is about making sure that excluded peoples, or what the 2030 Agenda for Sustainable Development refers to as people who are vulnerable—children, youth, persons with disabilities (of whom more than 80% live in poverty), people living with HIV/AIDS, older persons, indigenous peoples, refugees, and internally displaced persons and migrants—are in schools, in playgrounds, at work, in government offices, in avenues for decision-making, and everywhere else that those who are “included” often take for granted (Wolfenson, 2002; United Nations General Assembly [UNGA], 2015).

There has been a constant call for people living in poverty and vulnerable groups to be included not only in the targets, but in the planning and implementation of development policies and programs—in Agenda 21 in 1992, which reiterated the idea that poverty is a complex multidimensional problem; in the Copenhagen Declaration on Social Development in 1995, which stated that social development and human well-being are highest priorities; as well as in the 1st United Nations Decade for the Eradication of Poverty (1997-2006). In 2001, the Millennium Development Goals (MDG) further offered another promise for a global collaboration towards these ends, “to make the right to development a reality for everyone” (UNGA, 2015).

*Invisibility of persons with disabilities.* Up to the end of the implementation of the MDGs in 2015, there have already been admissions that the goals, targets, and indicators will not be fully achieved. While there would be various reasons for these bleak outcomes, one of the main reasons is that the MDG failed to include one of the most vulnerable sectors, persons with disabilities. The conspicuous absence of persons with disabilities in the MDG represents a lost opportunity to address the pressing social, educational, health, and economic concerns of the majority of the most marginalized citizens (Department of Economic and Social Affairs [DESA], 2012).

In 2011, the United Nations Secretariat's Department of Economic and Social Affairs came up with the report entitled *Disability and the Millennium Development Goals, A Review of the MDG Process and Strategies for Inclusion of Disability Issues in Millennium Development Goal Efforts*. The report associated the dismal achievements of the MDG with regard to persons

with disabilities with

[T]he lack of the systematic collection and monitoring of disability-related statistics and analysis of this data, which are the primary tools for tracking MDG efforts and allocating further funding and resources at the local, regional and global levels (DESA, 2012, p. x).

In 2015, the Philippine Statistics Authority (PSA) carried out POPCEN 2015 or the 2015 Census of Population. The primer for this document stated that this “is a complete enumeration of households in the country... designed primarily to take an inventory of the population of the entire Philippines” (PSA, 2015). Contrary to the claim of “complete enumeration,” however, questions related to persons with disabilities were left out of the census. This ultimately meant that data on Filipinos with disabilities remained inadequate to serve as bases for the inclusion of their strategic and practical needs in national-level socio-economic plans, policies, and programs. The policy and program implications of the lack of data on persons with disabilities at the national level are magnified when seen in the context that most of the 145 cities, 1,489 municipalities, and 42,036 barangays of the country do not have reliable disability-disaggregated data.

*Moves towards inclusion in data collection.* One of the main recommendations in the 2011 World Report on Disability “for action towards achieving a society that is inclusive and enabling, providing equal opportunities for each person with a disability to fulfill their potential... (is to) include disability in national data collection systems and provide disability-disaggregated data” (World Health Organization [WHO], 2011, p. 268). A few years later and promising to take on what the MDG failed to achieve, the Sustainable Development Goals (SDG) were more explicitly focused on empowerment and the needs of the most vulnerable. Persons with disabilities are referenced 11 times in the goals and targets of the SDG including but not limited to education (Goal 4), employment (Goal 8), inclusive cities (Goal 11), and in data disaggregation. While the 17 goals are integrated, a cursory examination of the targets under *Goal 10, Reduce inequality within and among countries*, drives home the point that inclusion, equal opportunities, reduction of inequalities, and elimination of discrimination are all important facets of re-imagining development considering the situation of persons with disabilities.

To support the abovementioned challenges, the SDG and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) emphasize on increasing 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” (UNGA, 2015). Apart from the importance of such data in measuring and tracking the progress of the SDG, these data are even more important in terms of deciding priorities, crafting policies, and developing and implementing development programs.

*Data inclusion, an uphill climb.* However, it has been observed that almost four years into the implementation of the SDG, “disability data overall are not being collected by National Statistical Offices (NSOs) for SDG monitoring” (Cuk, 2018). Pisani, Grech, and Mostafa’s (2014) assertion that the continuing absence of disaggregated data on persons with disabilities exacerbates the marginalization of disability as an area of practice migration and humanitarian affairs can be extended to development policies and practice in general. Grech and Soldatic (2016) note that the “call for disaggregated data to account for disability is a positive way forward but generating this data will not be a simple or precise endeavour, not least on account of different disability definitions, methods, costs and political inconvenience” (p. 15). The resulting lack of information on persons with disabilities poses a major barrier and challenge for inclusion of persons with disabilities in different communities (Pisani et al., 2014; Cuk, 2018).

*Generating disability data at the local level.* While the debates and finger-pointing continue on who gets the blame for the persistent situation described above, there are examples of local initiatives which can be sources of learning in coming up with a more reliable disability-disaggregated data at the local level. For example, in an unpublished article entitled *Community-Based Rehabilitation (CBR): Disability-Responsive Development*, Muego (2016) presented the case of the Local Government Unit (LGU) of Cervantes, Ilocos Sur when it partnered with the CBM Community-Based Rehabilitation Coordination Office in 2010.

The lack of reliable data on persons with disability at the LGU level was one of the main reasons why they were not included in mainstream programs and services of the LGU. One of the first steps taken by the LGU of Cervantes was to update its registry of persons with disabilities. After conducting a training on identifying persons with disabilities, the Barangay Health Workers (BHW) went to the different barangays and were able to register more than 700 persons with disabilities. The new data became the bases for the LGU of Cervantes’ policy issuance, Resolution No. 264 or the 2012 Community-Based Rehabilitation Action Plan of the Municipality “for the protection, rehabilitation, inclusion and participation of people with disabilities in the mainstream of society, honing and utilizing their God-

given gifts for the total development of the Municipality of Cervantes, Ilocos Sur.” The LGU of Cervantes “allocated a total budget of PHP4,987,000... and made sure that the Executive-Legislative Agenda of Cervantes would be disability-responsive by ensuring that persons with disabilities and their organizations were part of the process” (Muego, 2016).

## **Research Objectives and Significance**

The case briefly described above is an LGU-led data profiling initiative. While the data generated were utilized by the LGU in crafting a local policy and developing local plans, the process of generating the data did not significantly include persons with disabilities themselves. One factor that contributed to this is the fact that there was no organization of persons with disabilities to speak of during the time that the data updating project was conceptualized and implemented.

Thus, the present article aimed to describe the experiences of an organization of persons with disabilities (OPD), the Las Piñas Persons with Disability Federation, Inc. (LPPWDFI)<sup>1</sup>, in developing, implementing, monitoring, and evaluating their data-profiling project. The article also sought to identify and interrogate critical factors that contributed to the success of their collective initiative.

The data profiling project of the LPPWDFI covering all of the 20 barangays of Las Piñas City was their collective response to the dearth of disability-related data at the barangay- and city-levels which often resulted in local plans and programs that failed to include persons with disabilities. This was one of the organization’s ways of pushing the LGU of Las Piñas City to re-imagine local development that includes persons with disabilities. This was an example of organized collective action aimed at “creating inclusive communities in a more inclusive world” (Ledwith, 2012, p. 23).

The data-profiling project of the LPPWDFI and the lessons that were gleaned from their experiences can serve as an example as well as a source of insights for other organizations of persons with disabilities so that they can take the lead in producing reliable disability-disaggregated data at the local level to serve as important inputs in re-imagining and reclaiming development that includes everyone.

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<sup>1</sup> “LPPWDFI” and “Federation” will be used interchangeably in this article to refer to the Las Piñas Persons with Disability Federation, Inc.

## Methodology

The study is rooted in qualitative, critical, and emancipatory methodologies. Using qualitative methods ensured that the process of documenting the experiences of the LPPWDFI in data profiling captured the depth and richness of their contexts, experiences, and insights as well as privileged their voices and stories. Listening to and valuing the perspectives and voices of persons with disabilities leads to a deeper understanding of their lives, experiences, and aspirations (Hosking, 2008).

Data gathering employed a combination of three methods: (a) *Pakikiisa at Pakikipamuhay* (Integration), (b) *Kwentuhan at Sama-aralan* (Conversations, dialogue, reflection, and learning sessions), and (c) *Pagbabasa at pagsusuri ng mga kwento at dokumento* (Review and analysis of existing documents) (Muego, 2018). Relevant details from the author's engagement with the LLPWDFI since 2010, when he had begun working with them in different initiatives such as trainings, consultation workshops, and advocacy projects, also enriched the data gathered for this formal study, particularly as part of *Pakikiisa at Pakikipamuhay* and *Kwentuhan at Sama-aralan*.

*Pakikiisa at pakikipamuhay* emphasized the principle of “being there” and “being with them” which paved the way for the author to be included in the life of the organization and the people that form it. *Pakikiisa* included participating in their activities and programs such as their capacity-building activities for parents and caregivers, enrichment programs for children with disabilities, and sensitivity training programs for barangay officials. *Pakikipamuhay* included spending time with persons with disabilities and their families. This meant participating in their day-to-day activities including economic activities (e.g., rag-making or *paggawa ng basahan*, selling homemade trinkets made of beads), social activities (e.g., being at the wake of the sister of the LPPWDFI president), and political activities (e.g., joining them in their meetings with barangay officials). This also involved living for several days with five LPPWDFI leaders who were directly involved in the data profiling project. *Pakikiisa* and *pakikipamuhay* provided opportunities for the author to see firsthand the situation of persons with disabilities and relate these to their data-profiling project.

*Kwentuhan at sama-aralan* brought deeper meaning into this study, and in a very particular way in the analysis of the stories and insights that emerged. The leaders and members of the LPPWDFI that the author met with recalled how they developed the project at the beginning and

how they implemented it. They shared stories showing the difficulties they faced in the project such as having no previous experience in data profiling, not being allowed to enter some of the gated villages, inaccessible transportation, and even being ridiculed and threatened by a drunk man in one instance. More than these, however, they also shared stories such as the joy felt by a person with disability when she met the enumerators of the data profiling project who were also persons with disabilities themselves. The stories shared by the leaders and members of the LPPWDFI involved in the data profiling project were bound by the strong sense of pride, of individual and collective self-esteem brought about by being able to carry out a seemingly insurmountable task. Insights and learning were also drawn from their stories. A common lesson they expressed is the necessity of consistent participation of persons with disabilities throughout the design and implementation of the data profiling project if the aim is to really come up with disability-responsive data.

*Pagbabasa at pagsusuri ng mga kwento at dokumento* allowed the organization to collectively review and analyze existing documents regarding the data profiling project such as the project completion report prepared by the LPPWDFI and submitted to the City Social Welfare and Development Office, data validation presentations, and presentations made during disability-related fora and congresses (e.g., the 2nd Philippine CBR Congress). Other relevant documents, such as draft proposals, could no longer be accessed by the LPPWDFI since these were stored in an email and social media account that at the time of the study was no longer existent.

### **The Case Study: LPPWDFI Data Profiling Project**

The Las Piñas Persons with Disability Federation, Inc. (LPPWDFI) is a cross-disability and city-wide federation of 20 barangay-level associations of persons with disabilities in the City of Las Piñas, National Capital Region. Founding members of the LPPWDFI organized themselves in 2009 to assert their rights and to facilitate their access to government programs and services. Coming to a consciousness that they have often been relegated to being recipients of charity and beneficiaries of “special” services, they saw the necessity of organizing themselves—to be empowered, to be able to make decisions and influence decision-making processes, to be part of their communities.

*The need for data.* Even before the SDG came into force with its call for disaggregated data by income, gender, age, race, ethnicity, migratory status, disability, and geographic location, the LPPWDFI were already grappling with the problem of having no reliable data on persons with



disabilities and the implications of this with regard to local development planning, budgeting, service delivery, and more. The LPPWDFI officers shared that, after they had organized themselves, they had a lot of ideas to meet the different needs of persons with disabilities (e.g., sign language training for deaf people, parents, family and community members; therapy services for persons with disabilities and older persons) which they brought to the attention of the local government of Las Piñas City, particularly at the barangay level. In reply, they were often asked, “How many persons with disabilities are there? How many of them are needing therapy services? How many of them are blind? How many are deaf? What do the orthopedically impaired need?” At this point, the LPPWDFI realized that they were missing out on a lot of opportunities because they did not have the data.

*Taking on emerging opportunities.* Bottom-Up Budgeting (BUB) was implemented by the Human Development and Poverty Reduction Cluster (HDPRC), the Good Governance and Anti-Corruption Cluster (GGAC), and the Economic Development Cluster to “ensure the inclusion of the funding requirements for the development needs of poorest/focus cities and municipalities in the budget proposals of participating national government agencies” (DBM-DILG-DSWD-NAPC Joint Memorandum Circular No. 2, series of 2012). The initiative was also meant to involve grassroots organizations and communities in the planning and budgeting processes of local and national governments.

*Alyansa ng May Kapansanang Pinoy (AKAP-Pinoy)*, a national-level federation of organizations and individuals dedicated to advocating for the rights and promoting the interests of persons with disabilities, was among the organizations interested in the BUB process. AKAP-Pinoy was invited to participate in a National Basic Sector Consultative Workshop organized by the National Anti-Poverty Commission (NAPC) on April 8, 2011. AKAP-Pinoy saw that this could also be an opportunity for some of its member organizations like the LPPWDFI. Through the efforts of AKAP-Pinoy, an invitation to participate in the NAPC consultative workshop was extended to the LPPWDFI. The Federation designated two of its leaders, Dr. Jeana Manalaysay and Mr. Mars Jaymalin (both persons with disabilities, founding members of the LPPWDFI, and currently members of its board), to participate in that workshop.

After the NAPC-led consultation workshop, Dr. Manalaysay and Mr. Jaymalin met with the rest of the Federation officers and started brainstorming on the project that the LPPWDFI would submit to the BUB process. The organization did not take long to decide: They wanted to do a data profiling project aiming to



[R]ealign and justify appropriations for programs and services intended for persons with disabilities and at the same time help strengthen and consolidate the federation through active participation of its leaders and members in the data basing project. (LPPWDFI, 2014).

*Developing the data profiling project—working with partners.*

Dreaming of doing a data profiling project was one thing but translating that dream into reality was a totally different story. In preparing for the proposal, Dr. Manalaysay and Mr Jaymalin were joined by other LPPWDFI officers<sup>2</sup>, Ms. Maria Fe Maravillas, Mr. Napoleon Castillon II, Mrs. Epifania Maria 'Chona' de Guia, and Mr. Michael Manuel. Important questions were raised by the group to help them define how to proceed with the data profiling project: Who among us has experience in data profiling? What do we need to be able to do the project? How much does it cost? How will we manage it? What training does the Federation need to accomplish the project? They were able to answer some of the questions they raised, but there were certain questions which they believed could be answered better with the help of partners and like-minded organizations and institutions.

For the questions which they could not answer, the Federation turned to several of its partners. One of its partners was the Philippine Coalition on the UN Convention on the Rights of Persons with Disabilities (PCUNCRPD), a coalition involved in “policy review of domestic law in the context of international commitments, disability budget analysis, engagement with various national and local government agencies for participation in public finance, and legislative lobbying with Congress and Senate” (PCUNCRPD, 2013). Their contact in the Coalition, Dr. Lisa Martinez, linked them to another group in an academic institution that could help them in the data profiling project. The idea proposed by that research group was a pilot study covering only a sample of barangays in Las Piñas. While the LPPWDFI leaders could no longer recall all the details of the proposal, what they remember is the study was to be led by professional researchers and experts and would involve extensive training of enumerators. The Federation eventually turned down the proposal of that group saying,

The cost was way beyond what we could get from the BUB, the cost of paying their resource persons was already half of the BUB budget! And what they wanted was simply to do a small sample with the end in view of doing the same thing nationally. What we needed was data for all the barangays.

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<sup>2</sup> All of the officers of the LPPWDFI are persons with disabilities.

Not the kind to easily give up, the LPPWDFI leaders got in touch with another partner, Life Haven, Inc., an organization based in Valenzuela City and one of the leading organizations in the country in the advocacy for independent living through

*[A] philosophy and a movement of persons with disabilities who work for self-determination, equal opportunities and self-respect... (providing opportunities for persons with disabilities) to support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights.*

Two of the leaders of Life Haven, Mr. Abner Manlapaz and Dr. Benjamin “Jun” Bernardino, came up with suggestions—e.g., have enumeration done by persons with disabilities and by parents or relatives of persons with disabilities, utilize existing resources or tap resources such as transportation from the barangays—on how to go about the data profiling project in a more cost-efficient manner.

With these suggestions and after a series of discussions and consultations among the leaders of the LPPWDFI, they eventually came up with the Data Profiling Project, “a participatory project that will actively involve its members and help empower persons with disabilities” (LPPWDFI, 2014). This proposal was submitted to the LGU of Las Piñas for inclusion in its Local Poverty Reduction Action Plan (LPRAP). This was followed by a series of consultations from March to September 2012 that were actively participated in by two LPPWDFI leaders, Dr. Manalaysay and Ms. Maravillas. Within this period, the Federation also entered into a Budget Partnership Agreement with the Department of Social Welfare and Development in April 2012.

LPPWDFI documents show that the project was finally approved in September 2012. After the approval, the Federation was asked to submit an action plan for the implementation of the Data Profiling Project. Though already approved, there were still some changes in the proposal particularly in the calendar of activities. Implementation guidelines for the project were completed in April 2013, and actual implementation started in the first week of November 2013. Throughout the process, the LPPWDFI was also supported by one of its closest partners in the LGU, the City Social Welfare and Development Office (CSWDO).

Another crucial aspect in preparing for the data profiling project centered on the question: Who will do the actual gathering of data at the barangay level? At this point, the Federation was also coordinating with the Department of Social Welfare and Development-National Capital Region

Field Office (DSWD-NCR FO). The DSWDD-NCR FO suggested that the survey should be done by social workers. The Federation, however, asserted their idea that persons with disabilities and their relatives should be the ones doing the data gathering in the different barangays. As one of the Federation leaders said,

*We wanted to be the one to do the actual survey. It was our way of showing our ownership of the project. And besides, many of the persons with disabilities would rather talk or be interviewed by persons with disabilities.*

Furthermore, they also saw this as an opportunity for them to personally meet and get to know the life situation of persons with disabilities. The Federation's decision was respected by the DSWD-NCR FO; the Federation officers and the Disability Focal Person from the NCR FO worked together on the guidelines for doing the data gathering.

***Phases of the Data Profiling Project.*** The data profiling project had five phases namely: (a) Preparation, (b) Selection and Orientation of Enumerators and Encoders, (c) Actual Conduct of Profiling and Data Encoding, (d) Midterm and Final Evaluation of Data Gathering Activity, and (e) Data Processing/Data Analysis.

In the *first phase*, the LPPWDFI developed policies for the hiring of enumerators and for the profiling of persons with disabilities. They also reviewed and enhanced their data gathering instrument. The *second phase* saw the LPPWDFI selecting enumerators and data encoders—those selected were either persons with disabilities themselves or family members of persons with disabilities. They also did an initial mapping of the barangays for the purpose of identifying the targets per day in each of the barangays, as well as the number of enumerators that would be assigned in each of the areas. The total target was 5,000 persons with disabilities for the whole of Las Piñas. The last part of this phase involved training and simulation exercises on the use of the survey form. In the *third phase*, the LPPWDFI conducted the survey in the span of 25 days (from November 18 to December 17, 2013). The *fourth phase* focused on encoding the data as these came in from the enumerators. Monitoring the progress of the data gathering was also done midway and at the end of the data gathering. Monitoring was primarily done by the LPPWDFI.

The *last phase* centered on analyzing the data gathered from the 20 barangays. Statistical presentation of the data was done by Mrs. de Guia, one of the officers of the LPPWDFI, based on the 10 indicators they had identified at the outset: the total number of the different types of disability,

cause of disability, disability and age category, education, employment, assessment, mobility, voting population of persons with disabilities, and the number of persons with disabilities with or without disability card. The LPPWDFI also drew several recommendations based on the results of the profiling. The organization provided the local government of Las Piñas City (including the 20 barangays), the City Social Welfare Office, and the DSWD-NCR FO with the findings, analysis, and recommendations that arose from the data profiling. The table below provides details on key activities, dates, and accomplishments made during the different phases of the project.

Table 1: The Five Phases of the Project

Phase	Activity & Date	Accomplishments, Highlights
Preparation	Writeshop  November 4-6, 2013	<ol style="list-style-type: none"><li>1. Established guidelines in hiring enumerators, encoders, evaluators;</li><li>2. Established implementing procedures for enumeration process,</li><li>3. Identified strategies for enumeration phase</li><li>4. Developed goals &amp; indicators for evaluation of output</li><li>5. Started developing the survey forms</li></ol>
Selection and Orientation of Enumerators and Encoders	Screening of enumerators and encoders  November 7-8, 2013	<ol style="list-style-type: none"><li>1. 40 enumerators were selected; grouping of enumerators into 4 teams; 1 team of 10 enumerators per barangay</li><li>2. 4 Area Supervisors selected from the 40 enumerators</li><li>3. 5 encoders were hired</li></ol>
	Mapping of 20 barangays  November 11, 2013	<ol style="list-style-type: none"><li>1. Determined the schedule of the barangays to be surveyed per day and the number of enumerators assigned per barangay</li></ol>

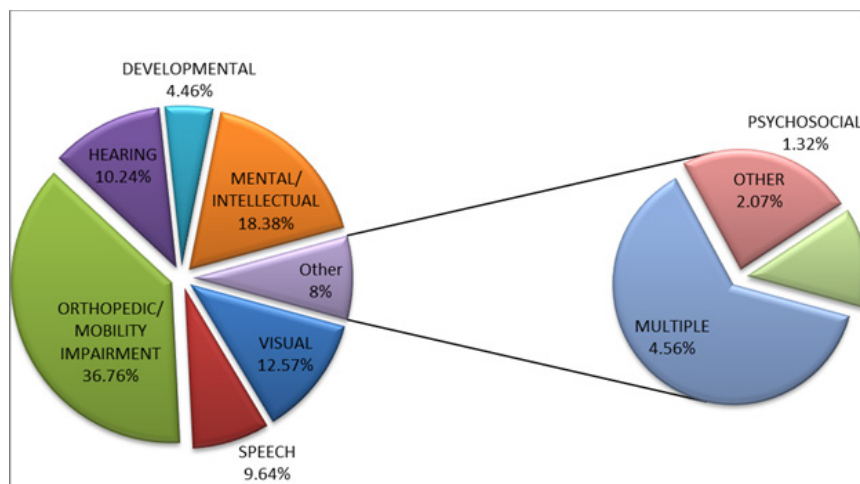
Phase	Activity & Date	Accomplishments, Highlights
	<p>Orientation of Enumerators and Encoders</p> <p>November 12, 2013</p>	<ol style="list-style-type: none"> <li>1. Conducted brief training on different types of disabilities</li> <li>2. Conducted interview simulations using the questionnaires</li> </ol>
Actual Conduct of Profiling and Data Encoding	<p>Actual conduct of profiling</p> <p>November 18 – December 6, 2013</p> <p>December 8 to 17, 2013</p>	<ol style="list-style-type: none"> <li>1. As of December 6, 2013, a total of 2,617 PWDs were surveyed covering 14 barangays</li> <li>2. Remaining barangays were covered after the mid-term evaluation</li> <li>3. Advised persons with disabilities to register with CSWDO</li> <li>4. Information on rights of persons with disabilities, privileges and benefits that can be accessed using the government-issued ID card, and LPPWDFI and the associations in their barangay</li> <li>5. Households were also informed on how to provide appropriate support to persons with disabilities</li> <li>6. New advocates and potential leaders were identified</li> </ol>

Phase	Activity & Date	Accomplishments, Highlights
Midterm & Final Evaluation of Data Gathering Activity	<p>Midterm Evaluation</p> <p>December 7, 2013</p> <p>Final Evaluation Workshop</p> <p>December 27-28, 2013</p>	<ol style="list-style-type: none"> <li>1. Team of enumerators identified learning and challenges faced during the enumeration</li> <li>2. Submitted the total number of PWDs they had interviewed per barangay</li> <li>3. 8 members of the LPPWDFI Core Group, 4 Area Supervisors and encoders together with the project facilitator from DSWD NCR, BUB Project Coordinator of Las Piñas City, and CSWDO Focal Person for PWDs evaluated the data profiling activities from Phases 1-5</li> </ol>
Data Processing/ Data Analysis	<p>Extraction of data</p> <p>Preparation of summary &amp; analysis</p> <p>Drafting of recommendations</p> <p>Presentation of final output</p> <p>January to March 2014</p>	<ol style="list-style-type: none"> <li>1. Prepared tables and graphs from the encoded data using the 10 indicators</li> <li>2. Prepared the final output</li> <li>3. Provided each barangay a copy of the findings, analysis, and recommendations</li> </ol>
<p><i>Source: LPPWDFI, 2014, Profiling of Persons with Disabilities in Las Piñas City</i></p>		

**Data profiling, an on-going endeavor.** Among the disability-disaggregated data that emerged from the 2013 data profiling project of the LPPWDFI is that there are 3,183 persons with disabilities, 36.76% of whom are persons with orthopedic/mobility impairments. The LPPWDFI (2014) report also showed that “the specific types of orthopedic/mobility impairment with most number are: poliomyelitis (22.31%), stroke (18.72%) and cerebral palsy

(15.41%)” (please refer to the figure below). The data generated further showed that there were slightly more men with disabilities, a total of 1,747, compared to 1,436 women with disabilities. The data profiling project showed that three of the highest causes of impairments are: (1) congenital or inborn, (2) illness, and (3) injury.

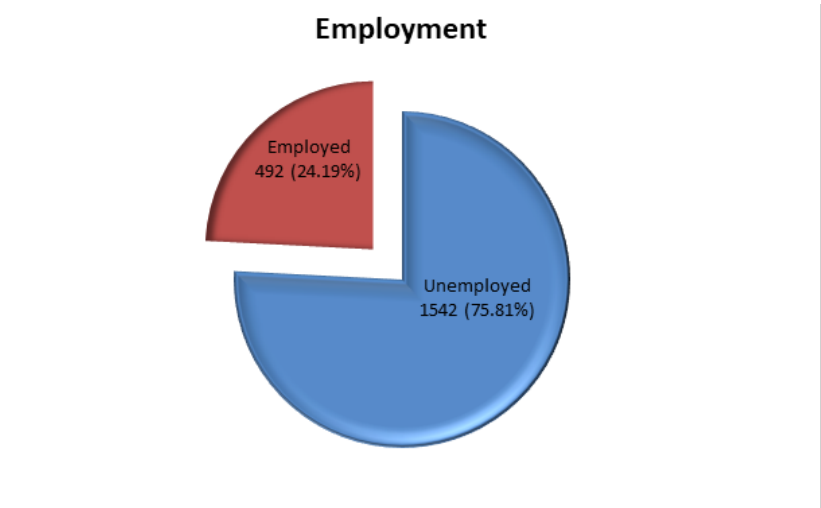
Figure 1: Types of Disability in Barangays from District I and II



For educational attainment, 75.56%, or 2,405 out of the 3,183 persons with disabilities identified, reported having gone to school. Close to half of these, however, reported attending school only until the primary level. Only 444 reported having attended college or enrolled in vocational training. The data also showed a total of 2,034 adults with disabilities. Of these, 492 were employed while 1,542 were unemployed. Men topped the list for both employed and unemployed. The data generated in the profiling project were further disaggregated by age, access to medical assessment services (the main reason cited for not accessing such services was financial difficulties), voting population of persons with disabilities, and the number of persons with disabilities with or without disability card (the main reason identified for not having a disability card is lack of knowledge or information).



Figure 2: Employment Among Adults with Disabilities in Barangays from District I and I



In 2013, the officers of the LPPWDFI who led the data profiling project stated/declared, “The output will serve as a basis in all future programs and activities for persons with disabilities towards their empowerment and in claiming the rights due them” (LPPWDFI, 2014). The LPPWDFI was able to use their disaggregated data to influence changes at the barangay level, such as through successful lobbying among many of the barangay officials to provide funding support for such projects and activities of the Federation as sensitivity and awareness-raising workshops for barangay officials. With the data, they were also able to convince barangay officials to give them access to use the barangay transport vehicles when they needed to attend meetings or trainings in the city hall or in other LGUs in the National Capital Region. Capacity-building activities for persons with disabilities also began receiving support as a result of the data on their educational situation. At the city level, LPPWDFI was able to leverage their data to influence the priorities of programs, projects, and activities of the City Social Welfare and Development Office thereby ensuring that these would address what persons with disabilities truly need. Whereas before, “services” for persons with disabilities consisted only of gifts given during the National Disability Prevention and Rehabilitation Week and during Christmas, the data that came out from the profiling project paved the way for more capacity-building activities (such as community organizing, leadership training of officers, local budget advocacy, and proposal making) for the LPPWDFI leaders and members.

Apart from these, the following are some of the other recommendations that the LPPWDFI came up with in 2013 and which are now being implemented. The LPPWDFI recommended that the LGU of Las Piñas pursue the establishment of the Persons with Disability Affairs Office (PDAO) in the city pursuant to Republic Act 10070. To date, the LPPWDFI have already drafted the implementing rules and regulations for the city PDAO, and these will likely be approved by the city council before the end of 2019. They also recommended the maximization of learning opportunities for persons with intellectual disabilities. To date, the Federation is already in its second year of implementing its Children with Disabilities and Parents Enrichment Program with funding support from the CSWDO.

*Data profiling, still an on-going endeavor.* The organization, however, did not stop at the 2013 Data Profiling Project. To date, they continue to regularly update their database. They are now in the process of validating their 2018 and first quarter 2019 data—with the raw figures showing that there are already over 12,000 persons with disabilities in their database. The LPPWDFI also sees further improvements in data gathering as it has partnered with the Center for Disaster Preparedness (CDP) which is currently implementing a project entitled Inclusive Data Management System for Persons with Disabilities. The data that will come out from this partnership will be used in influencing the disaster risk reduction and management (DRRM) plan of the City of Las Piñas towards being more disability responsive. It must be noted as well that the review of existing DRRM policies and programs in Las Piñas including rescue procedures, drill exercises, early warning systems, and information materials was also one of the recommendations made in the 2013 data profiling project.

Their experiences and their continuing initiative to build on their data profiling project has opened up opportunities for the LPPWDFI to partner with different organizations locally, nationally, and even at the international level in pursuit of their advocacy for inclusive development. Speaking from their context in Las Piñas, this means, “Truly inclusive—not just for persons with disabilities. This includes older persons, children and youth, women, the urban poor, and fisher folk.” This, for them, is their re-imagination of development.

## **Discussions of Critical Factors**

The discussions of the author will focus on four critical factors that he sees contributed to the success of LPPWDFI’s collective initiative:

(a) Rights, identities, and aspirations of persons with disabilities, (b) Leadership development, capacity-building, and local initiatives, (c) The role of support organizations and the state, and (d) Facing the need to build on gains.

*Rights, identities and aspirations of persons with disabilities.* In a conversation with Dr. Manalaysay, one of the founding leaders of the LPPWDFI, she stressed that they organized themselves around human rights and their shared aspiration to have a voice, to be empowered. Further conversations with officers and members at barangay-level associations showed a growing appreciation of their being claimholders and of their organizations as avenues for holding the local government accountable in fulfilling its obligations.

Being a cross-disability organization, the LPPWDFI was also very much aware that they needed to have disaggregated data that they can use in holding the local government accountable in enhancing existing programs and services or developing new ones that will include the different needs of its members. While the majority of those identified in the 2013 data profiling were persons with orthopedic/mobility impairments, the recommendations they drafted covered the needs of all their constituencies. Apart from impairments, there was also a good effort to identify women and girls with disabilities so that they can be rendered more visible and thus included in mainstream development programs and services (LPPWDFI, 2014). The data profiling project also provided the LPPWDFI the opportunity to have a deeper appreciation of who among them needed the most support due to their socio-economic status.

The Articles of Incorporation of the LPPWDFI speaks of aiming for the improvement of the lives of persons with disabilities. Conversations with leaders and members of the LPPWDFI and its barangay-level associations provided a glimpse into how they see this aspiration hopefully playing out in their communities: communities that are more respectful, communities that are more sensitive to the needs of vulnerable people, communities that provide opportunities for them to participate in all aspects of community life, communities that are becoming more aware of the different barriers that exclude people and the need to reduce, if not remove, such barriers.

The rights, identities, and shared aspirations of persons with disabilities belonging to the LPPWDFI, or what might also be referred to as collective identity and organizational unity, provided the firm foundation for the data profiling project of the LPPWDFI. All these taken together

have led to the Data Profiling of Persons with Disabilities, a participatory project that involved persons with disabilities themselves from planning, to implementation, to monitoring and final evaluation (LPPWDFI, 2014).

*Leadership development, capacity-building, local initiatives.* The lack of reliable data particularly on disability had become an easy go-to excuse for local government units and different agencies. This attitude provided fertile ground for business-as-usual development, i.e., development that sees persons with disabilities as beneficiaries and not as agents. The continuous development of the LPPWDFI leaders—through participation in different capacity-building programs—enabled them to gain more confidence to develop more complex local initiatives such as the data profiling project. At another level, investing in capability-building has contributed in levelling the playing field to allow more room for participation. For example, pushing for persons with disabilities to serve as enumerators for the project and ensuring that they are sufficiently trained so that they can carry out their tasks allowed for greater participation. There was also a strong sense of ownership of the data profiling project since this idea emerged from the organization's analysis of its situation and it was perceived to be a relevant response to their need to influence how local government programs and services are developed and implemented.

*Role of support organizations and the state.* While the LPPWDFI were at the front and center of the data profiling project, it was evident from their story that different individuals, organizations, and institutions also played important roles at different phases of the project. Partnering with other organizations has been one of the main strategies of the LPPWDFI that enabled it to develop and implement many of their ideas, including the data profiling project. In partnering with other organizations, it was essential for LPPWDFI to have a firm belief in their capacity and the centrality of their role with regard to their local initiatives. For their partners, on the other hand, like the DSWD-NCR and the Las Piñas CSWDO, it was essential for these organizations to take a step back and recognize their facilitative role in the process. It must be said however that such a situation did not simply come about. In the words of the leaders of LPPWDFI, “We fought for our views, our rights.” The respect that support organizations have come to accord to them is a result of their collective struggle and their local initiatives to change their situation.

Facing the need to build on gains. The Federation recognizes that, while there have been positive outcomes across the barangays and even within the city government, these changes have been uneven and have not really levelled the playing field, so to speak. There is a recognition that most

of the outcomes respond to practical needs of persons with disabilities and their families, but outcomes in terms of strategic concerns around social barriers (prejudicial attitudes, environmental and institutional barriers) are still wanting. In this regard, the LPPWDFI sees the need to continue to deepen their analysis of the data they have produced and are producing, and utilize the results of this in further enhancing and developing their strategies, programs, and projects towards broader and deeper societal changes. They also see the need to use the data (and the continuing generation of disaggregated data on persons with disabilities) to inform their initiatives in (a) consolidating their organizations at the barangay and city levels, (b) partnering with support institutions, and (c) pursuing their advocacy for a more inclusive society.

## **Conclusions**

While having disability-disaggregated data, be it at the national level or at the level of the barangay, is not enough to ensure that excluded peoples are included, it cannot be denied that having such is critical in ensuring that the rights of persons with disabilities are included in all development efforts. The value of disaggregated data in shaping development policies and programs is further increased if excluded peoples themselves play a central role in producing such data. In the case of the LPPWDFI, however, it seems that it was not merely the resulting disaggregated data which convinced policy makers and program implementers at the barangay and city-levels. Rather, it was the collective action of persons with disabilities and their commitment to their cause to be included in their communities, which persuaded the government to start to change and be more disability-responsive.

Furthermore, the value of the data profiling project of the LPPWDFI goes beyond the fact that relevant data was produced. Being at the front and center of the data profiling project gave LPPWDFI the opportunity to deepen their (a) understanding of the different but intersecting realities of persons with disabilities in Las Piñas City; (b) appreciation of their individual and collective capabilities; and (c) relationships with each other within their organizations—which they believe is essential if they are to continue to genuinely participate in re-defining and re-imagining development in their communities.

The lack or absence of disability-disaggregated data in the majority of Philippine communities continues to be a major barrier that results in the exclusion of persons with disabilities in social development. While local government units can take the lead in doing this, such as in

the case of the LGU of Cervantes mentioned in the earlier section of this article, the Data Profiling Project of the LPPWDFI shows the significance of persons with disabilities themselves being at the forefront of such an endeavor. Not only does it ensure that the data generated are relevant to their lives, experiences, and aspirations, but the process itself contributes a lot to their empowerment as individuals and as an organization. While many organizations of persons with disabilities in the country are looking and waiting for their respective LGUs to take the lead in data profiling, perhaps the story of the LPPWDFI can open up spaces for introspection and eventually for their collective action.

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