Engaging persons with disabilities in organizing and development work

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*Working with persons with disabilities has emerged as a "new" arena for development work. A critical reflection on community organizing work of persons with disabilities is necessary at this point since there is a growing interest on disability and disability-inclusive development. The study seeks to examine how disability is understood by support institutions, mainly by Local Government Units (LGUs), and how such understanding shaped why and how they engage in community organizing work with persons with disabilities. The study puts forward the concept of **ka-pasan** to examine the experiences in organizing persons with disabilities from the perspective of strengthening people's capacities to live together.*

Three data gathering methods were used: 1.) Being there and being part of (integration and observation), 2.) Conversations and dialogue (interviews, focus group discussions), and 3.) Leafing through, reflecting on (review of existing documents). The study focused on the experiences of the Las Piñas Persons with Disabilities Federation, Inc. The study shows that developing deeper disability awareness comes hand in hand with enhancing skills and capacities for collective action. In the process, everyone can become part of building better communities— 'kasama sa pagpasan sa paglalakbay tungo sa ganap na kaunlaran'.

Key words: persons with disabilities (PWDs) , community organizing, working with LGU

Context of the Study

In the Philippines and globally, people are marginalized and excluded based on class, gender, ethnicity, age and sexual orientation. A closer look reveals many more people marginalized and excluded because of being labelled as "with impairment" or "with disability."

The World Report on Disability says that at least 15% of a given population live with some form of disability (WHO, 2011). While the Philippine Statistics Authority's Census of Population and Housing 2010 shows 1.57% of Filipinos with disabilities (PSA, 2014), a far cry from the 15% WHO estimate, this still means 1.443 million Filipinos are largely excluded from development initiatives.

The adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by the UN General Assembly on December 13, 2006 and the subsequent ratification by member countries like the Philippines[1] underscored a new way of understanding disability and a new way of engaging persons with disabilities. The UNCRPD Preamble recognizes that "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others." It moves away from the often default approach to persons with disabilities as "objects of pity" or "problems to be fixed" towards an approach that regards persons with disabilities as "subjects" with rights, capable of making decisions and of being active members of society (UNOHCHR, 2014). Article 4 of the UNCRPD also emphasizes the active involvement of persons with disabilities through their representative organizations "in the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes."

Working with persons with disabilities has emerged as a "new" arena for development work. In the Philippines, one of the organizations that took the lead in engaging in this area of work is the

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1 The Philippines signed the convention on September 25, 2007 and ratified the same on April 15, 2008.

Philippine Coordinating Center for Inclusive Development (PCCID[2]). PCCID's conversations with persons with disabilities and support institutions working with and for persons with disabilities all over the country point out one crucial aspect of their struggle for inclusion— the setting up and strengthening of organizations of persons with disabilities or DPOs[3].

These conversations provided a good insight into the organizing work involving persons with disabilities. There are organizations from the national to the local levels "participating" in various avenues set up by the government for participation, such as the municipal, provincial or regional councils on disability affairs. However, the stories of how these organizations have been set up and are being managed are more reminiscent of what Manalili (2012) describes as the practice of support institutions, e.g. non-government organizations (NGOs) and local government units (LGUs), to be "commanding officers" rather than community organizers -- a marked departure from the idea of people-centered community organizing.

Research Objectives

The study seeks to examine how disability is understood by support institutions, mainly by local government units (LGUs), and how such understanding shaped why and how they engage in community organizing work with persons with disabilities. Parallel to these concerns, the study also aims to surface the DPOs' assessment of the LGUs' understanding of disability and community organizing practices.

A critical reflection on community organizing work of persons with disabilities is necessary at this point since there is a growing interest in disability and disability-inclusive development

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2 Before being formally organized and registered with the Philippines Securities and Exchange Commission, PCCID was set up in 2004 as the CBM Community-Based Rehabilitation Coordination Office by the CBM Southeast Asia and Pacific Regional Office to coordinate CBR work of its local partners in the Philippines. PCCID carries out different activities in pursuit of its vision of Philippine communities inclusive of everyone and mission of building capacities for inclusion.

3 Organizations of persons with disabilities are referred to in many official documents as "disabled peoples' organizations" or DPOs.

internationally, e.g., the inclusion of disability as a key marker in the Sustainable Development Goals (Lockwood, 2016), and locally, e.g. the push by the National Council on Disability Affairs (NCDA) and persons with disabilities themselves for the implementation of Republic Act No. 10070 or the setting-up of Persons with Disability Affairs Offices (PDAOs) in local government units. The role of DPOs is of great significance to ensure that such changes and processes are cognizant of disability as a development issue, and that DPOs are capable as agents of change and transformation.

Disability and Community Organizing: Perceptions, interpretations and understanding

Disability. It is all too common to hear people say, "Disability should not be an obstacle." The confusion lies in what is really meant by "disability." Is disability referring to what other people term as "impairment"? The term "impairment" itself is being challenged as well, as it is seen to be too focused on deficits and the idea of "normalizing" rather than starting from a perspective of differences, diversity, capacities and abilities that are innate in each person (Shier, Sinclair, & Gault, 2011; Macartney, 2011). Or are they referring to something else? In the Philippines only one term is used for both— *kapansanan*.

There are different definitions, opinions and understandings of disability and about persons with disabilities. All of these exert influence on the kind and quality of relationships they have with individuals and society in general and vice versa. There are four dominant approaches to disability: (1) charity, (2) medical, (3) social and (4) human rights. Table 1 provides a summary of these approaches.

Table 1: Four dominant approaches to disability: How is disability understood?

Charity	Medical	Social Human	Rights
Persons with disabilities are in a tragic situation, they cannot take care of themselves, they inspire compassion, they are objects of benevolence	Persons with disabilities need to be cured and fixed; passive patients; considered abnormal; are unable to live independently	• Disability is the result of a wrong way of organizing society: thus, persons with disabilities face bias and barriers that prevent their equal participation • It is not an individual problem, and mainly lies in the social environment • Persons with disabilities can and should participate in society	• Ensures full and equal enjoyment of all human rights to persons with disabilities, and promotes respect for their inherent dignity • Focuses on equal opportunities, non-discrimination, and participation in society • Requires authorities to ensure rights and not restrict them • Views persons with disabilities as rights-holders

Based on The Convention on the Rights of Persons with Disabilities: Training guide. Professional Training Series No. 19, UNOHCHR.

The concept of disability continues to evolve. This evolution, however, does not necessarily mean that the human rights model has already supplanted the three other models of disability. Dalit (2016) points out that these models continue to operate and are often intertwined particularly in the context of the Philippines. While the models described above dominate most of the literature, Pfieffer (2002) identified nine versions of the disability paradigm. Yee (2013, pp.20-21) provides a summary of Pfieffer's nine models of disability studies as shown in Table 2 below.

Table 2: Pfieffer's nine models of disability studies

Version of the Disability Paradigm	Key Premise(s)
1. Social Construction (United States)	• Disability is a social construct • Environmental factors can play a role in the social construction of disability identity
2. Social Model (United Kingdom)	• Informed by a class perspective, this model holds that society bears the onus to provide adequate services for the disabled and to include the needs of persons with disabilities in social structures
3. Impairment	• This version argues for the inclusion of impairment and personal experience into the social model
4. Oppressed Minority (Political)	• Persons with disabilities face ongoing discrimination in their daily lives; they are thus denied many rights and access to social, cultural, and economic capital
5. Independent Living	• As a philosophy and a movement, this version regards persons with disabilities as responsible agents for themselves; endowed with agency and self-determination, they must be granted the right to choose
6. Post-Modernist, Post-Structuralist, Existential	• Genesis of this version lies in cultural studies; the lens of culture, as both a social and political construct, may be applied to examine the experience of disability
7. Continuum	• As an emergent, proto-version, it holds that different representations of disability exist and that these are both inter and intra-related to each other
8. Human Variation	• Disability is multidimensional in nature and impairment is heterogeneously complex; the capacity of social systems currently is limited in adequately addressing the entire range of human variation
9. Disability as Discrimination	• Discrimination is the unifier of all the above versions; disability is a policy concern, rather than a health or medical concern

Pfieffer (2002: p.7) drives home the point: "All of the previous eight versions of the disability paradigm have some basis in logic and experience, but a person with a disability only feels she is disabled when confronted with discrimination. It is this discrimination which brings together the other versions."

Community Organizing. The right of persons to organize is enshrined in the Universal Declaration of Human Rights. This same right is reiterated in the UNCRPD. This is also reflected in the 1987 Constitution of the Republic of the Philippines, as well as in various acts, policies and programs of different government agencies. People's participation via their organizations is recognized as an essential part of our government and of national and local governance and development.

Development, however, remains to be an exclusive domain of a few. This is precisely the context of Manalili's (1990) call for community development to be concerned with the welfare of the whole community, particularly those who are discriminated, exploited, marginalized, oppressed and subordinated. In our experience, one of the sectors that is often excluded from development initiatives, as partakers of the fruits of development and much more as agents of change, are persons with disabilities. As the description of disability in the UNCRPD shows, the exclusion of persons with disabilities is the result of their interaction with the discrimination and prejudices that are extant in communities.

It is imperative to work for social change, to transform unjust social conditions. This imperative also serves as the reason for community organizing. The DPO is the embodiment of the hopes of people with disabilities and as such must be rooted in their lives, experiences and aspirations. The Philippine CBR Manual points out that community organizing aims to empower people, build institutions, and improve quality of life for all (Manalili, 1990; McGlade & Mendoza, 2009).

The process of community organizing should enable people to be able to "define their deprivations and increase their entitlements… enlarge their choices and capacities… leading to equality, freedom, empowerment" (Torres, 2010, p.25). Putting it in a different way, Manalili (1990, p.65) speaks of community organizing as "a process

that is people-centered and geared towards their continuing capability-building, self-reliance, and empowerment." The Philippine CBR Manual also emphasizes that it is a process that people undertake consciously and not something that is done to them. Furthermore, it also emphasizes that "core values, goals and basic principles should be collectively agreed upon prior to setting up the organization (of persons with disabilities)" (McGlade & Mendoza, 2009, p.91). The development of strong people's organizations, like the DPOs, is crucial in the context of policy reforms and in responding to strategic needs of vulnerable groups.

Analytical Framework

Conventional studies focusing on disability are often focused on the individual; this focus is largely informed by the medical, individual, deficit model of disability (Oliver, 1992; Barnes & Mercer, 1997). This perspective limits the potential of studies on disability to contribute in confronting power structures and social relations that exclude many people, including people with disabilities, from participating in and benefitting from decision-making and development processes. Addressing this gap is necessary if any study on disability is to be consistent with emerging realities.

This study is guided by the critical disability theory which posits that there are new ways and other possibilities of conceptualizing and understanding disability, "a new understanding of citizenship that encompasses the disabled, new policies to respond to the needs of the disabled, and a new legal vision of the entitlements of the disabled… (a new understanding and conceptualization of) disability that focuses on genuine inclusiveness, not just abstract rights" (Pothier & Devlin, 2006, p. 2).

The study also draws from four 'models' that expound the critical disability theory. **First**, the Community Development Framework espoused by Manalili (1990) is anchored to the fundamental belief on people's capabilities, particularly the poor and excluded, as agents of change and transformation. **Second**, the reiteration of the CD framework as grounded practice that emphasizes people's potentials and capabilities, their active participation and collective action in pursuing people's wellbeing and social

transformation (Luna, 2009). **Third**, the TIDES[4] Model (developed by Colin Craig) highlights the significance of "Transformation, Interdependence, Diversity, Equity and Sustainability" principles to guide decision making, actions and the use of resources (Nilsson, 2011). And **fourth**, the inclusive education framework developed by Naas Demyttenaere of the Institute for Inclusive Education in Baguio City. Demyttenaere emphasizes the "building of a better Philippines by developing potentials" of every Filipino. Foremost is the potential to "live together" (*mamuhay ng magkakasama*) which is simple but profound and revolutionary in a deep sense, as it runs contrary to the neo-liberalist emphasis on individualism and competition. Booth and Ainscow (2011) also said that inclusion means putting inclusive values (e.g., equality, participation and respect for diversity) into action.

These concepts are synthesized into a conceptual framework that serves as a basis for this study. The Filipino word used for disability is kapansanan, which is usually associated with words like *walang kwenta* (worthless), *pabigat* (burden to the family and to society), *walang kakayahan* (not able; no capacities), *walang lakas* (weak; no strength; no power), *kawawa* (pitiful), impairment of functions, someone being in a tragic situation, broken, poor, feeble, crazy and the list goes on. To move away from such definitions and understanding of kapansanan, and in the process, emphasize people's dignity and rights, the study puts forward a coined term: ***KA-PASAN***. The prefix *KA-* denotes "partnership, being included as a part of" while the word *PASAN* emphasizes the act or process of carrying. Merged together the word *ka-pasan* means *kasama sa pagpasan*. This underscores the belief that building better communities is a collective effort of everyone—*lahat kasama sa pagpasan*. It is a movement away from the deficit-oriented label that is usually attached to the words "with disability" or "*may kapansanan*" towards recognizing the person as an empowered agent of change and transformation.

The concept of *ka-pasan* is inspired by the idea to come to new ways of looking at and understanding disability from the perspective of genuine inclusiveness. *Ka-pasan* is another way of looking at the experiences of LGUs, disability-focused NGOs, and organizations of

4 TIDES stands for Transformation, Interdependence, Diversity, Equity and Sustainability. The model was adopted as one of the core models of conflict management and mediation by the Dialogue for Peaceful Change project which was started in 2004 in Utrecht, The Netherlands. The author was part of the group coming from 16 countries that started the project.

persons with disabilities focusing attention on inclusive values and how such can be nurtured and brought to fruition at various levels of the community. It also deals with aspects of diversity or differences and interdependence. *Ka-pasan* calls on 'empowered' individuals and communities, to enhance their skills and capacities needed to genuinely participate in the life of the community. The concept of *ka-pasan* also opens another possibility of looking at the experiences in organizing of persons with disabilities from the perspective of strengthening people's capacities to live together. This 'frames' the analytical lens used in examining the interplay of how disability is understood with how community organizing is done (see Figure 1).
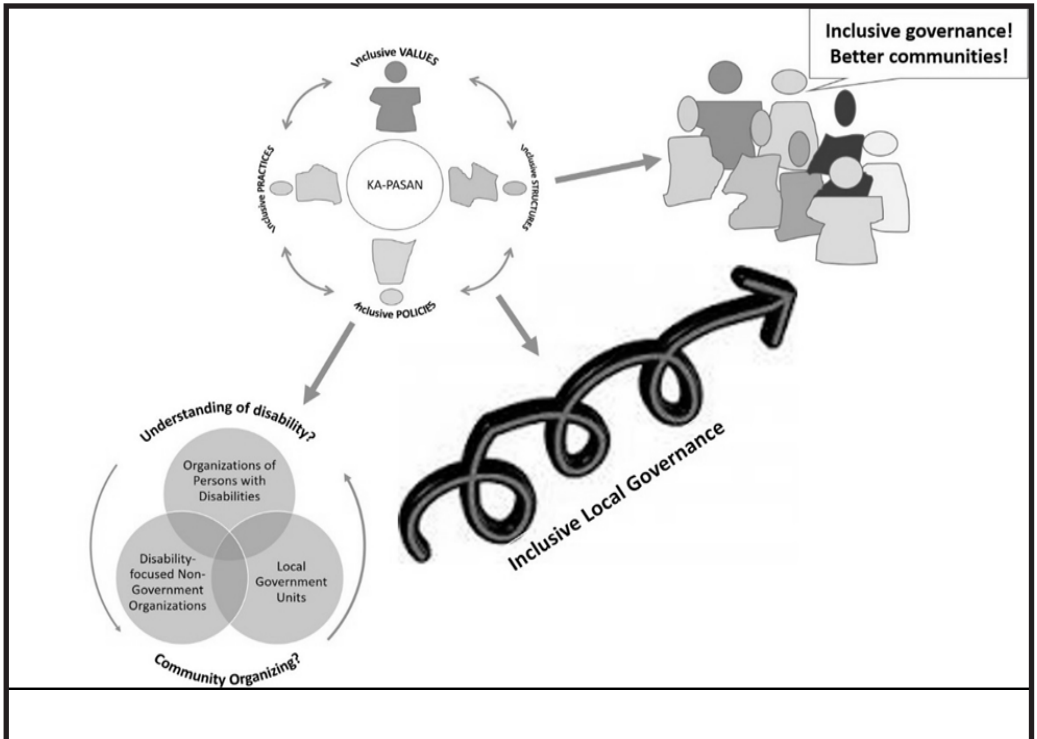

Figure 1 : Analytical Framework

Methodology

The selected locale of the study is Las Piñas City since the LGU has existing policies, programs and services for persons with disabilities. The city is also home to 20 barangay-level associations of persons with disabilities as well as a city-level federation, the Las Piñas Persons with Disability Federation, Inc. (LPPWDFI). Additional data were also generated from the results of the PCCID-organized workshop in Bacolod City wherein five cities and municipalities from Negros Occidental were represented by their respective Disability Focal Persons and/or PDAO officers and representatives from the local DPOs.

A combination of three data gathering methods were used: (1) being there, being with them, and being part of (integration and first-hand observation); (2) conversations and dialogues (interviews, focus group discussions); and (3) leafing through, reflecting on (review of existing documents).

True to the spirit of conversations and dialogues, the participants expressed that they preferred the usual *kwentuhan at bahaginan* (sharing of stories) over the more formal key informant interviews and focus group discussions. The LPPWDFI leaders also suggested an important change in the sharing guidelines—to look at both previous and current perspectives of the LGU with regards to disability and the involvement of persons with disabilities in local governance.

A total of six formal conversations were held with the DPO representatives during the data gathering period. While an initial conversation with the current Disability Focal Persons of the City Social Welfare and Development Office (LSWDO) was conducted. Other data used in the study came from documents provided by LPPWDFI as well as materials culled from PCCID-organized workshops. The narratives and stories shared in the conversations as well as those presented in the documents were used as bases for analysis, insights and recommendations.

Summary of Findings

Conversations on Disability

Common definitions, perceptions and understanding. The group of leaders from LPPWDFI pointed out that the organizing effort of the LSWDO started after the issuance of DSWD Administrative Order No. 13 series of 2008 or DSWD AO No. 13 s2008 entitled "Guidelines in organizing persons with disabilities into self-help groups (SHGs)". This AO provided the rationale, legal basis, goals and objectives, core components as well as procedures in the organizing of persons with disabilities.

AO No. 13 s2008 defines disability as "any restriction or lack of ability resulting from impairment, to perform an activity in a manner considered normal given the age and sex of the individual." This is similar to what is stated in Republic Act 7277 or the Magna Carta for Persons with Disability: "a physical or mental impairment that substantially limits one or more psychological, physiological or anatomical function of an individual or activities of such individual." Both documents see persons with disabilities as "those suffering from restriction of different abilities, as a result of mental, physical and sensory impairment (to perform an activity in the manner or within the range considered normal for a human being)."

The leaders who joined the conversations reflected that prior to the issuance of AO No. 13 s2008, the LSWDOs' perspectives of disability, and addressing disability for that matter, could be categorized into three. The first is the Charity perspective. This perspective sees persons with disabilities as having very limited or no capacity and thus should simply act as recipients of the goodness of others. Several of the leaders said, "*Ang inaasahan lang ng community noon sa amin ay maghintay kung ano ang ibibigay sa amin; dole out kumbaga.*" Second is the *Pa-picture* (photo-op) perspective. Closely related to the first, addressing disability is limited to simply taking photos of persons with disabilities receiving goods/gifts during special occasions, e.g., National Disability Prevention and Rehabilitation Week. The main goal is to simply be able to show that something was accomplished. Last is the Medical perspective. This perspective sees people with disabilities as being "not physically fit." Based on the group's experience, this perspective resulted in persons with disabilities being discouraged from attending

meetings and other activities because it was very difficult for them to participate.

DPO feedback on how actions are shaped by how disability is understood. When asked how perceptions and understanding of disability affect how policies, programs, projects and activities were developed and carried out, the Disability Focal Persons from the different LGUs that were represented in the conversations unanimously said, "How we understand disability shapes the way we develop our programs and services and how we deliver these. If our perspective of disability is *kawawa* (pitiful), *walang kaya* (incapable), then our resulting approach is basically dole out."

The participants representing the DPOs agreed with the observations mentioned above made by the Focal Persons. They recalled: "*Ang tingin nila sa taong may kapansanan noon ay taga-ganap lang. Sila (LSWDOs) pa rin ang magpaplano, magsasabi ng mga gagawin… artista lang ang tingin nila sa amin pero sila ang producer, sila ang direktor*" (before, persons with disabilities were merely seen as stage/movie actors, but it was still the LSWDO that acted as producers, directors; LSWDO planned and told us what to do).

Others remarked that before in the past, the LSWDOs did not believe that persons with disabilities had the capacities to organize, or to plan. The role given to persons with disabilities was merely to listen and to follow instructions. One of the leaders said, "P*arang mga puppet lang ang tingin nila sa amin. Sila ang mga puppeteer, sila ang nagpapagalaw.*" (They just saw us as puppets. They were the puppeteers.) The other leaders shared, "Before, local leaders in the barangay often thought and believed that persons with disabilities no longer need to learn. Thus, they did not support us to participate in trainings and meetings. They simply wanted persons with disabilities to receive, to be dependent on the goodness of other people."

Conversations on Community Organizing

Purpose, Strategies, Steps by the government and NGOs. The organizing of DPOs done by LSWDOs of the cities and municipalities all over the country is guided by the DSWD AO No. 13 s2008. The document outlines the goals, objectives, core components, and implementing procedures of the organizing of DPOs. The stated

goal is to "Develop skills, positive attitude and confidence as well as maximize the residual capacities of persons with disabilities to become self-reliant, productive and contributing members of society through organized SHGs (Self-Help Groups)." (DSWD AO No. 13 s2008). The stated objectives are: (a) Organize persons with disabilities of different nature into SHGs by cluster barangays, municipalities, provinces/cities, regions and a national federation, (b) Nurture the psychosocial well-being of the persons with disabilities through SHGs' mutual help and peer support and counselling, and (c) Develop productive skills and confidence of employable members of the SHGs organized, thereby improving their economic status and autonomy. Apart from these, the LGU Disability Focal Persons also shared that organizing was also pursued to provide opportunities for persons with disabilities to participate in the achievement of the LGUs' goals.

The guidelines identified five core components for the organizing of SHGs: 1) Social Preparation, 2) Organization of persons with disabilities into SHGs, 3) Capability Building, 4) Networking and Resource Generation, and 5) Monitoring and Evaluation.

The guidelines explicitly mentioned that the groups and organizations to be formed will be cross-impairment. LSWDOs play the primary role in the different phases of the organizing process. The role of persons with disabilities, however, becomes more prominent once the organizations are already organized, i.e. when membership is being expanded.

The organizing of DPOs done by Non-Government Organizations (NGOs) was also explored. In one of the conversations, it was mentioned that NGOs that have been working with the DPOs engaged in community organizing work "to contribute in changing how people with disabilities are being treated." This was coupled with other objectives such as the formation of local chapters and establishing links with LGUs. Some of the strategies that were used by the NGOs were strengthening barangay-level organizations, identifying and developing leaders, and putting emphasis on training, capability building, and mentoring.

DPO feedback on the LSWDO's community organizing purpose, strategies and steps. In one of the conversations with the group of LPPWDFI leaders, they shared that prior to the efforts of the LSWDO

to organize persons with disabilities, there were already efforts by persons with disabilities to organize themselves. One of them recalled his previous involvement in the setting up of an organization of persons with disabilities in another city; that organization, however, was short-lived due to funds mismanagement. The dream to organize, however, stayed with that leader. Another LPPWDFI leader got the inspiration to organize from attending workshops and training organized by Akap-Pinoy. The other leaders in the conversation group also shared that before setting up their organization most of them were already involved in different initiatives involving persons with disabilities.

The group of leaders from LPPWDFI shared that prior to 2008 there were only token efforts from the LSWDO with regard to setting up an organization. Persons with disabilities were often remembered only during occasions such as the National Disability Prevention and Rehabilitation Week. After the issuance of DSWD AO No. 13 s2008, the leaders still felt that the efforts were merely attempts by the LSWDO to comply with the guidelines. The organization serving as a mechanism for participation in local governance was not part of the agenda in the initial stages of the initiatives of the LSWDO.

For the leaders, however, they wanted to organize themselves as they see this as their right. They believed that having an organization would help them in accessing much needed support from the government and from other support institutions. LPPWDFI shared that they wanted to organize themselves because "people with disabilities want to be empowered; that people with disabilities will be the one to implement plans and make decisions, to have a sense of ownership over programs."

Some of the founding leaders of the organization looked for possible support from the government in getting themselves organized. One of them went to the National Council for the Welfare of Disabled Persons (now called NCDA). He was handed a book on community organizing and was told, "Your sector is very difficult to organize!" No further assistance or support was given.

Another leader went to the LSWDO to talk about setting up barangay-level organizations of persons with disabilities. The LSWDO Disability Focal Person shared with her a list of persons with

disabilities. She got in touch with the people in the list, through phone calls and home visits. During the visits, she talked about their rights and the need for them (persons with disabilities) to come together and regain their voice. She challenged them, "Would you not like to change the situation wherein you are only remembered by the government during December or during election time?"

An initial group of 16 people met, got to know each other, talked about setting up an organization, and even went to visit and learn from an organization of persons with disabilities in the province of Nueva Ecija. They eventually agreed to organize themselves as a rights-based organization of persons with disabilities. This decision, however, was not accepted by the LSWDO since an ad hoc committee had already been organized composed of five individuals—only one was a person with disability. They were advised by Akap Pinoy to "go with the flow" and so they collectively decided to join the ad hoc group and worked with the LSWDO in conducting barangay visits, identifying persons with disabilities, electing officers for the barangay associations, and the like—following the process outlined in the DSWD guidelines.

By August 2009, the group had been able to help organize 15 barangay associations. They decided to federate themselves. For the second time, a decision made by persons with disabilities was not recognized by the LSWDO since they (LSWDO) were not present when the decision was made. The LSWDO insisted on repeating the process of formally setting up the Federation—the barangay associations acceded, but they also re-affirmed the decision they had previously made. One of the original members of the ad hoc committee, related that his attention was called by the LSWDO for allowing the first assembly to take place. He recalled telling the LSWDO then, "Is it not you who told us that we should be the one to act? That we should be the one to organize ourselves? That we should be the ones to plan?"

According to the group, the relationship between the LPPWDFI and the LSWDO has improved considerably over the years. Now the LSWDO, with the Disability Focal Person playing an important role, continues to provide a lot of support to the Federation, e.g. conducting capacity-building activities, as well as facilitating the Federation's participation in local governance. However, they still have an ongoing struggle with the LSWDO on how the LPPWDFI should be structured. The LSWDO is pushing for the idea that all association presidents

should automatically be the board members of the Federation (a set up akin to the federation of older persons). LPPWDFI, however, is holding on to the idea of having different sets of officers. They see this as necessary since it provides an opportunity to develop new leaders.

Conversations with the Disabled People's Organization: LPPWDFI

Influencing changes in the LGU. Las Piñas Persons with Disabilities Federation, Inc. (LPPWDFI) is a city-level federation of 20 barangay-level associations of persons with disabilities. According to their Securities and Exchange Commission registration papers, the LPPWDFI was set up to "unite all persons with disabilities in Las Piñas City, generate avenues, opportunities, and establish a network for their empowerment thus improving their lives to become productive, self-reliant and active members of the society."

The organization has gone a long way since 2009 in influencing changes in the way the LGU, particularly the LSWDO and the barangay officials, regard persons with disabilities. Some barangay associations are already part of their respective Barangay Development Councils. The LPPWDFI is also recognized as a member of the city's Local Development Council and a member of the Local Poverty Reduction Action Team (LPRAT).

One of LPPWDFI's major accomplishments was the conduct of a Data Profiling Project in 2013 covering the 20 barangays of the city. The project was developed and implemented fully by the organization. They were able to secure funds from the DSWD's Bottom-Up Budgeting. As a result, they were able to identify 3,183 persons with disabilities in the 20 barangays 2013. LPPWDFI says that this number has more than doubled since the profiling, as more and more persons with disabilities are coming forward to be registered. In recognition of this project the Federation was given the Apolinario Mabini Award.

Another accomplishment that came out of this project is the conduct of Sensitivity Training for Barangay Officials in all 20 barangays of the city. This was followed up by sensitivity trainings with the different agencies of the LGU. These resulted in further gains, such as influencing the barangays and the city to include disability concerns in the annual investment plans, purchase of an accessible van, the setting up of the DPO and the installation of an elevator going

to 2nd floor offices of the city hall. To date, the LPPWDFI continues to access funds from the LGU through the LSWDO for projects and activities.

Strengthening the organization. The LPPWDFI's annual investment plan (AIP) is submitted to the LGU. The plan is drawn up after a process of consultations with the different barangay associations as well as looking at external opportunities being offered by national and regional government agencies and other support institutions. The local associations also have their respective AIPs.

Key leadership positions are allocated for persons with disabilities. The LPPWDFI has a nine-member board of directors and, from this body, a smaller six-member core group leads in the day to day operations of the organization. Decisions such as planning of activities are made through a process of consultations with the different associations. A LPPWDFI leader explained, "Even if it proves to be very difficult for us, even if we fail because we do not know how to do it yet, it is still ok. What is important is, this is ours!"

Presence of women and men leaders. The 2013 data gathering that was done by the Federation listed down 3,183 persons with disability. Of the total number, 1,445 were women and 1,738 were men. Of the 20 barangay associations, in the Federation, nine are led by women and 10 are led by men (Brgy. Ilaya was not accounted for at the time of the conversation). Out of the nine LPPWDFI officers, five are women. In the six-member core group, three are women and three are men. The group clarified that, while there is a seeming balance in the number of men and women leaders, this was not something that was intentionally done by their organization.

On intersecting identities, roles and positions. Before women with disabilities are seen as women, they are first seen as being "with impairments" or "with disability." The group observed that these two identities, of being a woman and being "with impairments," make it doubly difficult for women with disabilities. One of the leaders, however, pushed this even further when she said, "It is even more difficult for an older person with disability, who is also a woman, who is not 'retired'—because she was not able to work as a professional, and who is blind."

While LPPWDFI has a good number of women leaders, there are still many women with disabilities who continue to be deprived of the opportunity to explore and expand their horizons because they are held back by responsibilities and duties at home. A story was shared about a woman with disability being 'asked' by her family not to accept any leadership position in the organization or else her allowance would be cut off. She should not take on a leadership role as this will take time away from fulfilling her obligations in the family, such as taking care of her three nieces and nephews. And while there are women leaders in the organization, women's capacity to face off with local officials is often belittled. "*Naku, baka di kayanin niyan ang humarap sa kapitan* (She might not be able to stand her ground in front of the barangay captain)," is but one of the remarks often made.

Are these realities equally true for men with disabilities? The group agreed that it is very rare, if at all, that you would hear a man saying that he cannot be a leader in the organization because he must take care of his children. According to them, men have very few responsibilities in the home in comparison to women.

Discussion and Analysis

Disability as a lens and perspective. Disability as defined in AO No. 13 s2008 and RA 7277 is different from how it is described in the UNCRPD where it is stated that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others." The latter description reflects the evolution of how disability is understood—from a charity-based orientation to one that is socially and rights-based oriented. It shifts the focus of analysis and the locus of action from the individual to the society. It is saying that the poor living conditions and lower status of persons with disability relative to those "without disabilities" is not due to their "impairments" but is due to the attitudinal and environmental barriers of the society in general.

If disability is viewed as the problem of an individual, as is the case in AO No. 13 s2008 and RA 7277, the solutions and strategies are also geared at fixing the individual person with disability. It assumes that there is nothing wrong with how society is structured or organized. It does not question social relationships nor the current dominant development paradigm that puts emphasis on an individual's capacity

to effectively compete. If disability is understood from the social and rights-based perspectives, then this also influences the direction and methods of work of different institutions. Attention and resources are directed at transforming society, enabling it to effectively work with differences and diversity. It brings societal transformation into the center or heart of development and disability-responsiveness. It puts emphasis on ensuring that practical and strategic needs are met, while also ensuring that appropriate supports are in place.

The charity (welfarism, dole-out) and medical (fixing the individual and presuming that there is nothing wrong with how society is structured and organized) perspectives that guided the early organizing work of LSWDOs have contributed greatly to developing, reinforcing and maintaining the attitude of dependency among persons with disabilities and even in their organizations. Charity and paternalism still play a dominant role in shaping how disability and persons with disabilities are viewed and understood. Such an understanding continues to promote the idea that persons with disabilities are simply objects of services and support and cannot really be meaningful subjects in development processes (Keogh, 2014). This is in stark contrast with the call and challenge for empowerment and genuine participation in the life of the community.

Whatever gains have been achieved, for example in the case of Las Piñas, with regard to how things are done to include persons with disabilities not only as beneficiaries but as agents of change, can be sustained and further broadened and deepened if there is a conscious effort to modify how disability is understood and how persons with disabilities are seen by society.

A good starting point would be to critically examine the inconsistencies in definitions. AO No. 13 s2008 describes persons with disabilities as "those suffering from restriction of different abilities, as a result of mental, physical and sensory impairment." Yet the same document also states that the target beneficiaries (of organizing work) are persons with disability who are "physically fit as certified by a medical practitioner"—by definition, this excludes most if not all people with disabilities.

The role of NGOs and LGUs in community organizing. The stories shared by LPPWDFI and other DPO leaders show how the mind-set of support institutions such as the LSWDOs with regards to disability

and persons with disability shapes how these institutions regard the capacity of persons with disabilities to set up and manage their own organization. The comment made by an official of a national agency that is supposed to champion the rights of persons with disabilities in the Philippines shows the prevailing assumption, or rather the prevailing prejudice, that persons with disabilities do not have the capacity to set up their own organization and much less manage it.

Even when organizations have already been formally set up, their capacity to sustain their initiatives is still put into question. The assumption is still biased against them—with the expectation being that they will eventually fail. This recalls a story shared by a disability advocate in Mindanao. He asked the LGU Disability Focal Person about the repayment scheme for loans given to persons with disabilities for their livelihood projects. The Focal Person answered, "Ah, don't worry about it. Yes, it is a loan, but we do not really expect them to be able to pay it back."

If organizations of persons with disabilities are vehicles for their empowerment and their participation in local governance, it is crucial for support institutions to hurdle this first obstacle. This means that support institutions should move away from seeing the setting up of organizations as merely a means to receive benefits and privileges and move towards seeing community organizing as a matter of right. DPOs are not organized to serve as mechanisms for service delivery of support institutions. DPOs are organized—by persons with disabilities themselves or with the assistance of support institutions—in recognition of their capacity as agents of change and transformation in their communities. Support institutions must shift their views towards people with disabilities and see them as partners in transforming prejudicial attitudes and in ensuring that the government includes persons with disabilities in its programs and services. In essence, a major task of DPOs is ensuring that local governance is guided by inclusivity.

AO No. 13 s2008 places the primary role of organizing in the hands of the LSWD officer. This leaves persons with disabilities at the periphery, their role only to come at a later stage in the process. Persons with disabilities have been and continue to be at the receiving end of prejudices, resulting not only in their marginalization and disempowerment as a sector but also in the erosion of their belief in their own capacities. Being born and growing up in a society that tells

them that they are not capable, that they are weak, that they should simply be passive recipients has resulted in the creation of attitudes of dependency and submissiveness. Recognizing and respecting the right of persons with disabilities to be at the front and center of setting up and strengthening their organizations is imperative. The process itself should be empowering and liberating; it should be a process of capacity building.

AO No. 13 s2008 provides a template for organizing. The community organizing process is placed in neat phases which are, as mentioned previously, led by the LSWDO, e.g. the tool for assessing the needs and problems of persons with disability shall be made and administered by the LSWDO in coordination with the persons with disabilities; the consolidation and validation of findings shall ensue with the LSWDO as the lead person, in coordination with persons with disabilities. In the end, it is expected that the process that is clearly initiated and led by the LSWDO will generate interest, participation, commitment and involvement among persons with disabilities in the organization that will be formed. This template of community organizing fails to capture the dynamism of the process. The centrality of the role of the LSWDO in the community organizing process goes against the challenge for support institutions to play an enabling and facilitative role.

"Enabling" is not merely tokenism or lip-service; this means coming up with concrete actions such as making information accessible, removal of physical barriers in public places, providing appropriate support when needed, etc. The government's enabling role extends to ensuring that persons with disabilities, and other marginalized people for that matter, are involved through their organizations in all phases of development initiatives including policy and decision-making processes (Groce, 2011).

Looking at the experiences of several DPOs, Dalit (2016) identified several points that describe how support institutions should work with persons with disabilities. Such an institution:

- Works with people with disabilities so that they recognize and believe in their innate capabilities;
- (Serves as a) Facilitator of opportunities and avenues for persons with disabilities to enhance and build their capacities as community organizers;

- Does not set up and hand over the organization to people with disabilities; (but) works with them as they set up their organization;
- Supports and facilitates avenues that build persons with disabilities' self-reliance and capacities to decide for themselves;
- Affirms the organizations' strengths and encourages them to improve their weaknesses; recognizes that both factors contribute to organizational strengthening;
- Serves as resource/support for specific needs that are beyond the current capacities of DPOs;
- Works with persons with disabilities to enrich/support various efforts in reducing/eradicating societal barriers; and
- Encourages the organizing efforts of persons with disabilities towards the building of inclusive communities.

LPPWDFI, starting from where they are and building on what they have. The barangay associations have been organized prior to the setting up of the city-wide federation. Based on the information that emerged from the conversations, the associations are still largely dependent on the federation leadership for whatever projects and activities they will work on. There is a need to strengthen the barangay associations so that these can also develop their own programs of action that respond directly to more parochial concerns, without of course compromising the need for a broader front (via the Federation) to effect lasting changes in their community.

LPPWDFI 's experience is significant in examining the societal barriers that have prevented the active participation of DPOs in efforts to respond to their own needs and aspirations—as opposed to simply being spoken for and being spoken about (Khasnabis & Heinicke-Motsch, 2010). Awareness building and capacity building are prerequisites to the formal setting up of the organizations. These could be developed through different learning activities and community engagement aimed at enhancing their awareness as well as their organizing skills.

Conclusions and Recommendations: LPPWDFI as KA-PASAN, everyone as KA-PASAN

"Ngayon may respeto na sila sa amin." (Now they respect us.) Numerous gains have resulted from the persistent struggle of the LPPWDFI to effect changes in their community, to be a ka-pasan. If the Federation's members had previously been regarded by the LGU of Las Piñas, particularly the LSWDO, from a charity/welfare and medical perspective, they are now regarded more as partners in development. The consistency of the messages from LPPWDFI with regard to their rights as individuals and as an organization coupled with the openness of their counterparts in the LGU, particularly the LSWDO, have resulted in a significant shift in values, practices, policies and structures towards being more inclusive.

The LPPWDFI is now being sought out and consulted on concerns pertaining to persons with disabilities, and are now being involved in the crafting of local policies. Physical accessibility of key infrastructures is being addressed. They are now being involved in the crafting of local policies. The Federation's plans and activities, e.g., trainings and sensitivity workshops, are being supported by the LGU. There is greater appreciation and respect for the capacities of the individual members as well as the capabilities of the organization. The role of the LGU Disability Focal Person has also been delineated —as an ally, a facilitator, helping the LPPWDFI navigate the intricacies of the bureaucracy, but never taking the centerstage.

While many positive changes and gains have been achieved, there are also 'preconceptions' that must be surfaced and unmasked. Persons with disabilities must constantly 'prove themselves' because the dominant mind set among both people and institutions is that such persons do not have the capacity. Thus, people are often 'awed and amazed' when persons with disabilities accomplish something— the expectation being that they are incapable because they have disabilities/impairments.

Furthermore, while there have been changes within the LSWDO, can the same be said with regard to other agencies or departments within the LGU? Apart from being largely invisible, it is also common to see the pervasiveness of developing programs and services solely for persons with disabilities (often euphemistically called 'special

programs') without first ensuring that existing programs and services that are meant for all truly include persons with disabilities and other marginalized sectors. Persons with disabilities have the same needs that everyone else does, e.g. food, shelter, education, etc. Likewise, they also have unique needs like everyone else, e.g., assistive devices, medicines, rehabilitation, etc. And above all, there are the strategic interests—reduction of prejudices, discrimination, etc.—that must be pursued to improve their position in society.

LPPWDFI and the other DPOs that joined the conversations for this study provided insights and recommendations for their counterparts in the LGUs, NGOs as well as other DPOs. These are summarized in Table 3.

Table 3: Insights and Recommendations from LPPWDFI and other DPOs to improve CO

Principles & Values	Purpose & Direction	Steps & Strategies
• Believe in the person, in the capacity of people as agents of change • Move away from being puppeteers; from regarding people as beneficiaries of help to regarding them as partners in development • Change methods of work—from dole out to empowerment • Support institutions as facilitators in the development process • Learn the art of diplomacy • Recognize and work through differences • Become more selfless rather than selfish. Leaders should be concerned with the needs of all impairment groups • Develop more love and concern and other values such as tolerance/respect for differences in the organization, forgiveness, volunteerism, caring • Develop values of cooperation and collaboration (as opposed to individualism) • Do good to the poor	• Emphasize on changing mind-sets; disability consciousness is a continuing struggle • Inclusion—go beyond the issues of the sector; work with other sectors to pursue a broader development agenda • Recognize and respect the person • Avoid the tendency to fall back to the charity/welfare and medical approaches • Focus on empowerment	• Start with children. Right attitudes with regard to differences, diversity start at a very young age. At a very young age, the children become advocates to their parents! • Ensure that needs are met and appropriate support services are provided • Focus on strengthening barangay-level organizations • Education work at the barangay level
For Support Institutions	**For DPOs**	
• Develop a deeper understanding of the situation and aspiration of the sectors they are working with—immersion, integration is necessary • Increase investments and support on conscientization, advocacy and awareness activities for the whole community • Increase investments on capacity building of DPOs	• Build up links with other local support institutions • Continually identify new leaders and develop second liners • Develop assertiveness; to use the laws and policies to hold the government accountable, e.g., emphasize Article 4.3 of the CRPD—participation in all written communications to government offices	

The following additional recommendations are put forward based on the findings and analysis presented in this study:

1. Definitions of disability in key documents, such as those in AO No. 13 s2008 and RA 7277, must be aligned with the UNCRPD.

2. The current tools being used for data gathering, such as those used by LPPWDFI in their data profiling project, are impairment-focused. To have a better analysis of the situation of disability, an appropriate tool or combination of tools is needed.

3. More conversations and dialogues with DPOs are needed to surface their experiences and learning with regard to community organizing for the purposes of influencing the way support institutions carry out their work. DPOs can be supported to document their own experiences, to relate their stories through their own voices and images.

4. The role of development professionals in supporting the disability movement is crucial: How disability is understood, how it is considered in development, how it is an important perspective or lens in analyzing social relationships—all these must be integrated into academic and institutional programs.

5. Lastly, critical reflection on disability work must be pursued to assess whether it is indeed dealing with the systemic nature of socially constructed relations between people 'with and without impairments', with special attention on prejudices that result in the lower position of persons with impairments. The concept of the 'able-bodied' remains prevalent and supports the subordination of people that are 'dis-abled', people with impairments. If prejudices based on sex must be rooted out, this is also true for prejudices based on abilities and impairments.

Community organizing work with persons with disabilities must take off from a social and rights-based perspective of disability. Previous attempts and initiatives in organizing persons with disabilities often tended to view them as a homogenous group— when in fact, there are differences that are inherent among persons

with disabilities. This calls for more creative ways of dealing with differences while at the same time building on interdependence.

Conscious efforts must be made on the part of support institutions and even among DPOs to focus not only on providing programs and direct services, but on reducing prejudices, transforming unequal power relations between people labelled as 'with and without impairments', and promoting the empowerment of persons with impairments. Equal, if not more, energy and resources must be geared towards developing our potentials and capacities to live together. This is what inclusive local governance is—collectively transforming our relationships as a people, collectively transforming our communities to become better than what they are now.

It is important to highlight the need for conscientization for disability awareness— for everyone. Developing deeper disability awareness comes hand in hand with enhancing skills and capacities for collective action. In the process, everyone can all then become part of building better communities—*kasama sa pagpasan sa paglalakbay tungo sa ganap na kaunlaran, katarungan at kalayaan* (partners in the journey towards genuine development, justice and freedom)—*tayong lahat ay ka-pasan!*

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