

TOWARDS INCLUSION AND PARTICIPATION THROUGH ENGAGEMENT OF DISABILITY ORGANIZATIONS

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Introduction

Persons with disabilities in the Asia-Pacific Region have over the years, remained among the poorest of the poor. Cultures and societies treated disabled persons in one of just a few ways. We were frequently viewed as objects of misfortune or misdeed who were shunned, ignored and pitied.

Despite the emergence of international standards to promote the inclusion of persons with disabilities in development, proclamations and in-country legislations and policies, integrating people with disabilities in mainstream development remains a major challenge for most governments in the region. Disabled people are disproportionately undereducated, untrained, unemployed and underemployed, and generally poor.

Vast range of issues including physical and social barriers must be considered and addressed within the context of full participation of people with disabilities in community life, if we are to be included in the development process. Without access to the full range of community services and experiences as a vital step, people with disabilities will not be able to confront barriers to inclusion in general.

Fortunately, we see signs that a new paradigm is emerging – one that recognizes that people with disabilities have abilities and have the same rights to participate fully in their societies as do non-disabled people. This kind of thinking does not rely on charity nor on conformity to the so-called norm.

It is about leveling the playing field so that disabled people can access jobs and transportation services, ensuring universal design, accessible technology and coordinated public programs and services. It is about removing physical and societal barriers. It is about attitude

adjustment for employers, teachers, health care professionals and even family members.

Some key barriers to participation

1. *Accessibility barriers:* such as the lack of access to the built environment like access to transportation, buildings and structures; lack of mobility aids and appliances; lack of access to technology and assistive devices, sign language interpreters and brailled materials, among others.
2. *Institutional and attitudinal discrimination.* While all persons with disabilities suffer discrimination, women and girls face more discrimination in both the interpersonal and institutional levels because of negative perceptions regarding their abilities, potentials and even rights, as women and girls with disabilities.
3. *Low expectations and self-confidence.* Among the disabled, women and girls are generally least considered by their families for education, training and employment, even if they demonstrate stronger will to succeed compared with men and boys, simply because of their gender.
4. *The requirement to have higher skills.* While women with disabilities have fewer opportunities to develop skills to be productive, they need to demonstrate stronger qualifications compared to disabled men and to non-disabled women.

A woman with a disability may have to work twice as hard to earn half as much as a non-disabled woman earns.

5. *General lack of organizational support.* Projects by and for women with disabilities are hardly supported by organizations run by a majority of men with disabilities.

A. Engaging Disability Organizations in Development: an innovative step in bilateral development co-operation –

The Danish-Philippine disability NGO partnership

In the early 1990s, a new dimension has emerged within some donor countries' bilateral development co-operation with the increasing involvement of disability non-government organizations (NGOs). The new focus on equal rights for persons with disabilities recognizes their strengths and need for inclusion within the wider society. The

shift has highlighted disabled persons' right to inclusion in the development process.

One example is the Danish Council of Organizations of Disabled People (DSI), which is made up by a majority of the Danish disability NGOs representing an estimated 300,000 persons with disabilities. DSI has become a driving force in this process, with support from the Danish Ministry of Foreign Affairs (DANIDA).

Under this initiative, DANIDA has made use of Denmark-based NGOs as entities through which resources to support disability-related undertakings in countries of the South (including the Philippines), were channeled. This example demonstrates how the experience and expertise of disability NGOs in a developed country like Denmark, were positively utilized to provide funding and technical assistance and support to their counterpart-organizations in developing countries like the Philippines.

As of 2000, 14 of the 29 member-organizations under the Danish Council of Organizations of Disabled People (DSI), have been involved in providing financial support for persons with disabilities in developing countries. The Danish disability NGOs administer funds amounting to approximately DKK25 million annually to more than 20 countries to support disability initiatives.

Within a relatively short period of time, Danish organizations have established a substantial number of projects with significant variations in size, geography and development objective. They have also gained a lot of experience in a field that may have not been necessarily the same as the core activities of these Danish NGOs.

Danish disability organizations' involvement in major disability projects, 1990-1999

Organization	Country	Project type	Budget in DKK	Period
Danish Hemophilia Society	India	Combination	10,250,000	1998-2001
Mascular Distrophy Assn. of Denmark	South Africa	Service/Rehabilitation	2,910,081	1997-1998

The Danish National Association LEV	Bangladesh	Service/Rehabilitation	4,958,804	96-01
	Albania	Organizational Dev't.	713,801	95-97
Danish Association Of the Disabled	Nicaragua	Service/Rehabilitation	3,000,000	90-93
		Service/Rehabilitation	4,998,821	92-95
		Combination	3,084,849	95-97
		Combination	12,005,000	97-02
National Society of Polio and Accident Victims	Philippines	Combination	6,506,000	95-97
	Lesotho	Combination	2,772,713	97-00
Danish Association of the Blind	India	Combination	1,722,570	94-95
	Indonesia	Combination	960,340	94-97
	Ghana	Combination	4,448,191	94-99
	Bangladesh	Service/rehabilitation	4,154,236	94-02
	Nepal	Service/rehabilitation	2,450,692	95-99
Danish Association of the Deaf	Uganda	Combination	4,977,518	94-99
	East Africa	Service/Rehab	3,908,000	97-02
Federation of Hard of Hearing People	Nepal	Combination	14,300,000	94-97
The Danish Council of Organizations of Disabled People	Uganda	OD & Lobby	8,286,000	96-99
	South Africa	OD & Lobby	4,620,000	95-98
		OD & Lobby	4,700,000	97-98

OD = organizational development

Lessons learned

Majority of the Danish disability organizations which were involved in international development initiatives for developing countries in the South indicated that they had many positive experiences with their partner-organizations. They said that their interventions had produced good results, not least when combining a number of activities (i.e. organizational development, lobby, rehabilitation, direct service provision, income generation, etc) within a project.

The organizations, however, also indicated that they had, to some extent, underestimated the problems involved in providing funding and developing partnerships with poor developing countries. Their experience show that it was particularly difficult to work with small and often weak partner-organizations in a different cultural context without extensive experience and skills in the field of development co-operation. Many of the organizations had very high expectations and became quite frustrated when they found out that their partner-

organizations operated below par compared to how they ran their own organizations in Denmark. Many difficulties were encountered in day-to-day co-operation and these problems were usually related to issues of financial management, reporting and follow-up.

The Danish organizations learned that they must be more modest as far as goals and time frames are concerned. That in the future, they would undertake more detailed investigations before commencing a partnership with a counterpart in the South, develop and set more concrete and measurable objectives, and establish more specific requirements for reporting.

The disability organizations also acknowledge that their hands-on knowledge about relevant issues which people with no disability experience may easily overlook, is an advantage in doing international development work.

The potential of pursuing such initiative is promising, in view of the broad base of Danish disability movement that ensures a strong foundation in Denmark for support to activities in the South, which generally takes the form of exchange visits, advocacy work and meetings. For many of the Danish organizations, development co-operation is an activity which enables them to learn from the experiences of their counterparts in the developing countries. Such insights learned enables them to bring new perspectives into the lives of their own members in Denmark.

B. Engaging Filipinos with disabilities as catalysts for their own development

The **Breaking Barriers-Philippines** project (1995-1998), a partnership of KAMPI- the national federation of organizations of persons with disabilities in the Philippines and the Danish Society of Polio and Accident Victims (PTU), was the first project of it's kind to be implemented in the Philippines. It was a pioneering effort at

addressing the rehabilitation needs of children with disabilities – the most vulnerable yet the least served among disabled persons in the country.

The manner by which BBP was conceptualized and implemented is far from the conventional way of implementing foreign-funded projects. Disabled persons were involved in the planning, conceptualization, and day-to-day running of the project. They recruited, screened and selected non-disabled professionals (i.e. physical and occupational therapists, social workers, teachers and other staff) who provided the specific technical expertise to run the project. The funds was provided for by the Danish Foreign Ministry (DANIDA) through the Danish Society of Polio and Accident Victims (PTU).

Such “revolutionary” approach to project implementation has been largely doubted in the beginning but was proven feasible, effective and sustainable by project end in 1998. In fact, BBP was continued and further expanded through **Breaking Barriers for Children (BBC)** project (1998-2003) because of its many fine results and achievements.

Under BBP, 5 Stimulation and Therapeutic Activity Centers (STAC) were established in five pilot regions of the Philippines from 1995-1998. The project overshot its goal of providing services to 1,000 beneficiaries by at least 50%, having served a total of 1,500 poor children with disabilities when the project was terminated in April 30, 1998. As envisioned, the beneficiaries of BBP were provided free rehabilitation services (i.e. physical and occupational therapy, training on activities for daily living, pre-school training, supplemental feeding for those who are malnourished), school placement services and referrals to other facilities (government and NGOs) mostly for medical, dental, surgical and other interventions which were not available in the STACenters.

Other achievements of BBP include: launching of awareness campaigns on disability; policy research, formulation and advocacy in the areas of employment, accessibility, health care, legislation and

education for persons with disabilities; continued piloting and development of concepts and action plans on integrating disabled children and young adults in mainstream services; provision of assistive devices and technical aids to beneficiaries in need, generating support from local government units who were eventually convinced to assume and take-over the operation of the STACenters for sustainability when BBP ended in April 30, 1998; and provision of livelihood skills trainings and grants for small capital to augment the often limited income of parents of disabled children.

Unintended results

1. The STACenters established under BBP were accredited by the Philippines' Department of Social Welfare and Development, as government partners in the provision of rehabilitation and other services to persons with disabilities.

2. Some 25 colleges and universities in the Philippines have designated the STACenters as training facilities for graduating physical, occupational therapist-students, social works students and other students of allied medical courses. This partnership with colleges and universities has not only augmented the STACenters' manpower complement but also generated added revenues by way of the payment of minimal fees from the student-interns. These revenues were used to meet expenses of disabled children which were not covered by the BBP funds from Denmark.

Building on the success

The Breaking Barriers for Children (BBC), 1998-2003, was implemented to build on the fine achievements of the BBP. It has not only continued the efforts of its forerunner but also expanded its services and added more features and components to make the services for children with disabilities much more comprehensive and sustainable on the long term. It has succeeded in fostering and nurturing the goodwill and social-civic mindedness of communities and the citizens at large. BBC to some extent, has made Filipinos

become more conscious and caring about the well-being of persons with disabilities.

By end of 2001, the BBC serves more than 7,000 children with disabilities in the 5 project areas in five regions of the Philippines – with clear indicators that it will overshoot its projected targets. From the original 5 pilot centers established under BBP, BBC services is now being offered in the original 5 main training and resource centers and 60 community-based rehabilitation centers spread in 5 regions of the country.

Disabled persons evolved from being consumers to providers of services

The two projects – BBP and BBC- have demonstrated how disabled persons from a donor country like Denmark can be instrumental in supporting efforts of their counterpart in a developing country, like the Philippines, break barriers and stereotypes to become catalysts of change for their own development. With the Danish support, Filipinos with disabilities under KAMPI have become both consumers and providers of rehabilitation services.

Another fine “unintended” result achieved by BBC is the emerging appreciation and willingness of local government units in the Philippines to be partners in this initiative of providing low-cost but quality services for the rehabilitation of children with disabilities. Involvement of the local government units is critical and is of prime importance to ensure the sustainability and possible replication of the project in other parts of the country so that more beneficiaries can be served.

Suggested strategies to support the engagement of organizations of persons with disabilities in development

1. Support for disability initiatives in developing countries of the Asia-Pacific region must be implemented based on the framework of the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, and in support of the goals and targets

of the Asian and Pacific Decade of Disabled Persons, 1993-2002 and the follow-up Decade, 2003-2012.

2. Priority for funding and technical assistance, must be on projects and activities that promote the establishment of strong, democratic and rights-based disability organizations.
3. Emphasis must be placed on the formation of strong, decentralized disability organizations which recognize and promote gender equality among disabled persons in terms of leadership development, among other considerations.
4. "Positive discrimination" in resource allocation in favor of disabled persons in countries of transition as well as disability groups who have difficulty organizing themselves including women and girls with disabilities.
5. Support must be encouraged for pilot projects involved in service provision which takes the following into consideration: 1) the implementing organization has the capacity and the expertise to ensure successful project implementation; 2) the project shows high potential for replication or up-scaling in a broader/national scope; 3) the project has clear monitoring, evaluation and documentation component; and 4) the project includes a mechanism for sharing examples of good practices and lessons learned for the benefit of others involved in similar initiatives.#

Conclusion

The Asia-Pacific Region has a huge stake in furthering the participation of persons with disabilities in development. It is not only home to 60 percent or 360 million of the world's 600 million disabled people, it is likewise the region where most of the future members of the so-called human family will be born in the next several years.

Today, about a third of Asia's people live in dire poverty - average life expectancy is 65 and 70 percent of the region's population is said to be illiterate. Greater openness as a result of globalization still has to be translated into expected benefits for the region's poor – the majority of whom have disabilities as a result of malnutrition, inadequate health care and deplorable living conditions.

In the midst of all these are disabled persons and their organizations who face both risks and opportunities as a result of these changing world scenario. While organizations of disabled persons in many developed countries have taken spontaneous initiatives to change the social stigma attached to disability, the experience of grassroots organizations of disabled persons in the developing countries require a critical decade of concerted effort to develop the capacities of DPOs to participate in the development process for their own benefit and development. With the extension for another 10 years of the Asian and Pacific Decade of Disabled Persons (1993-2002), it is hoped that persons with disabilities will eventually be able to fully engage and participate in efforts for the improvement of their wellbeing.#

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*(Venus M. Ilagan's presentation at the Asian Development Bank's **Regional Workshop on Disability and Development**, 2-4 October in Manila, Philippines)*