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***The Role of Women with Disabilities in Community Based Inclusive Development***

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**Preface:** I am thankful to God who has given me strength and wisdom and blessed me with loving parents who have extended unconditional love and support in understanding my disability and live a wonderful life.

I would like to express my heartfelt gratitude to my mentors Shoji Nakanishi San, Akiie Ninomiya San and to my brother, Atif Sheikh, who has been a guiding spirit for me since the day I started my work in the disability movement. I would like to take the opportunity to acknowledge the support of the Center for Women Policy Studies for awarding me this opportunity to write for the 2011 online series of new BARBARA WAXMAN FIDUCCIA PAPERS on women and girls with disabilities.

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I owe a lot to the women with disabilities of Asia Pacific; with whom I have worked for almost one decade and earned experience and love.

**Introduction and Summary:** Women with disabilities are disadvantaged in several key areas when compared with other women, men with disabilities, and the society as a whole. Women with disabilities face a triple handicap and discrimination due to their disability, gender and developing world status.

It is estimated that approximately 300 million women and girls around the world have a mental and/or physical disability. Globally, women make up three-fourths of disabled persons in low and middle income countries; between 65 percent and 70 percent of these women live in rural areas. <sup>i</sup>Despite this alarming situation, the resolution of the High Level Plenary Meeting of the General Assembly United Nations Headquarters, 22 September 2010 states that persons with disabilities, especially women with disabilities, have remained largely invisible in the implementation, monitoring and evaluation of the Millennium Development Goals (MDGs). In 2000, persons with disabilities were absent, invisible and ignored by the Millennium Development Goals. Discrimination against so called non-disabled girls and women as a whole in the developing countries is an overwhelming reality<sup>ii</sup>. It results in millions of

individual barriers and discrimination, which add up to eliminate the potential for the development of the entire community.

Initiatives for community based rehabilitation programs have often been top-down, initiated by policy makers at locations far removed from the community level and designed without the involvement of persons with disabilities specially voices of women with disabilities completely unheard.

This Paper provides deeper insights into the thinking of women with disabilities about leadership and community based development, the barriers they perceive as women with disabilities, their leadership styles, and strategies that should be undertaken to facilitate and promote their status and roles in community based development. The challenge for women leaders with disabilities is to unite and lead their peers in promoting Community Based Inclusive Development not only for the rights of women with disabilities but also to create an environment where they can have equal opportunities with men with disabilities as well as so called non-disabled persons to participate fully in all activities of the society. The Paper also examines the role of women with disabilities in the empowering and encouraging, motivating, inspiring, directing and supporting stakeholders to achieve community based development goals and outcomes. The Paper begins with a brief review on women with disabilities' leadership styles and community development in the light of supporting policies and legislation. It is followed by the challenges and discussion and finally the conclusion and recommendations.

**Magnitude of Disability Issues in Development – Addressing the Concerns of Women with Disabilities:**

Most writings on disability tend to focus predominantly on health or social welfare and there is little coordination or integration between research on disability and research on associated issues in gender, social development, and human sciences. Specific attention needs to be given to both quantitative and participatory components to ensure that the different dimensions of disability are appreciated. Persons with disabilities face a multitude of social, economic, physical and political barriers that hamper their mainstreaming in the society. These barriers include stigmatization and a misunderstanding of the abilities and aspirations of women with disabilities.

This Paper underscore the endeavors of Disabled Peoples' Organizations (DPOs), international and national non-governmental organizations (NGOs), Government, UN Agencies and other disability stakeholders for community based inclusive development, in the milieu of the International Disability Movement, encompassing a review of Community Based Rehabilitation (CBR) Guidelines and international policy frameworks. The underpinning concept for analysis is women with disabilities' participatory development and social model of disability.

In the 1980s, 250 million persons with disabilities lived in the Asia Pacific region, which embraced the Middle East, South Asia, Southeast Asia and Far East. Ninety percent of persons with disabilities were unable to read or write and 80 percent lived in rural areas with little access to services because 90 percent of services and rehabilitation facilities were in cities. For millions of families in absolute poverty, the birth of a disabled child (or an illness or accident producing serious impairment) places them in a slightly worse position than their neighbors. It may affect adversely the marriage opportunities of the rest of the family.

In the developed countries, where the women's movement and the disability movement have been active for more than 50 years, women with disabilities tend to be underrepresented in decision making positions. Because of the barriers faced, women with disabilities in the developed countries decided to organize themselves to raise their voices to highlight their concerns, by starting groups specifically for

themselves. In the 1990s, women with disabilities were more strongly represented at different levels in the disability movement.<sup>iii</sup>

In the South Asian context, gender equity is an issue for a large majority of women, given the sociocultural practices and traditional attitudes of society. If we just take the *example of Pakistan*, the systematic care of persons with disabilities was brought into focus in Pakistan in the 1980s with the observance of 1981 as UN International Year of Persons with Disabilities. The need was then felt for the education, rehabilitation and mainstreaming of persons with disabilities both by government and by the private sector. A law on the employment and rehabilitation of persons with disabilities<sup>iv</sup> was passed in 1981. This comprehensive legislation spells out the responsibility of the state towards the prevention of disabilities; protection of the rights of persons with disabilities; and provision of medical care, education<sup>v</sup>, training, employment and rehabilitation for persons with disabilities

But the law does not include the commitment to create barrier free environments for women with disabilities to remove any discrimination against them in sharing the benefits of development and to counteract any situation resulting in abuse and exploitation. There was a need to establish a framework for comprehensive development of strategies, programs and services for the equalization of opportunities for women with disabilities and special provisions for their integration into the social mainstream. And a National Policy was formalized in 2002. The vision of the policy was to provide, by 2025, an environment that would allow full realization of the potential of persons with disabilities through their inclusive mainstreaming and by providing them full support from the Government, the private sector and civil society without any age, sex, and cultural discrimination. However, even after having comprehensive legislation, women with disabilities are mostly unseen, unheard and uncounted persons in Pakistan<sup>vi</sup>.

The mainstreaming of disability in government policy and practice has been the key demand of the international disability movement for decades. Women with disabilities are also the central theme of the Biwako Millennium Framework Mainstreaming disability into development cooperation is the process of assessing the implications for persons with disabilities of any planned action including legislation, policies and programs in all areas and at all levels. It is understandable that the culture and practices of community initiatives cannot be changed at a stroke especially in areas with the very strong influence of culture and religion; but the challenge for government and development agencies in Pakistan is to begin the journey by bringing women with disabilities into development action and policy dialogue as equal partners<sup>vii</sup>.

Addressing the concerns of women with disabilities requires specific indicators in traditional disciplines. People speak about disability and development using different vocabularies, and the way they view the subject reflects varied geographic backgrounds. The new perspective is an inclusive approach, which puts the vision of women with disabilities and other marginalized persons at the center and includes all the dimensions of development in a holistic and synergetic manner, which encourages emphasis on building the capacities of women with disabilities, equally to men with This leads to the implementation of women with disabilities' leadership, and in community based development there is a new and growing appreciation that women with disabilities who understand and take their disabilities as different life styles use his understanding to keep families together and to organize volunteers to unite and make change in the shared life of their communities.

**Invisible Leadership:** The response to rising inequality and discrimination faced by women with disabilities at the local, regional, national and international levels is continuing in developing countries.

For many women with disabilities, however, the biggest challenge in taking leadership roles is that their families tend to be overprotective about them, and prevent them from going out of the house. Families of women with disabilities spend huge budgets on their physical rehabilitation instead of on their social and economic rehabilitation; for fear that they may be exploited in some way because of their disability. Although well-intentioned, these anxieties can be stifling to women with disabilities, especially to their own personal confidence. In addition, there are superstitions in village communities about the presence of women with disabilities being inauspicious in community gatherings. It is also believed that the presence of a woman with a disability in a family can block the chances of marriages of their female siblings. As a result, many women with disabilities remain confined to their parental homes, without being able to play the roles traditionally expected of women in society. This can lead to feelings of isolation, loneliness and low self esteem in women with disabilities. Families in traditional societies are generally supportive in terms of physical assistance to their disabled women family members, but often fail to provide emotional support, which is a more complex issue as many families prefer to ignore the existence of feelings, emotions and the need for emotional support in women with disabilities. <sup>viii</sup>

The first disability-specific initiative must be to sustain Disabled Peoples' Organizations (DPOs). An early and strong focus on assisting DPOs to strengthen their capacity is critical in establishing the foundation for disability-inclusive development. Development of sound leadership, management and organizational capabilities, in addition to effective advocacy skills, are critical areas for support of DPOs. These organizations then can support basic literacy, numeracy and computer literacy skills for adults with disabilities who have had limited or no access to education. Effective DPOs will become catalysts for other positive changes in ensuring inclusive development through establishing Independent Living Programs with focus on peer-counseling services to empower and motivate women with disabilities and encouraging them to use their leadership capabilities. Further, there is a need to provide accessible information to women with disabilities and their families in the most accessible forms and IL Programs and DPOs must support women with disabilities. This will promote progress towards a social structure in which women's leadership is commonplace even in contexts currently defined as male. Organizations can strive to avoid isolating women with disabilities in community work which should specifically benefit them and established women leaders will be the most effective role models<sup>ix</sup>.

In fact, the involvement of women with disabilities in the planning process can itself help women overcome the barriers to their leadership and participation and it will become normal to see women with disabilities playing leadership roles in gently re-shaping the social structure. The significant changes in access to leadership roles by women with disabilities over the past few decades are a necessary, but still insufficient. There is a need to empower more women with disabilities. In this era of development and mainstreaming disability approach community based inclusive development program designed and implemented through a twin track approach to identify the most pressing needs. It is a unique planning process that is extremely useful in both the initial planning stage and the future evaluation of human services programs. The process of coherent program development and planning begins by situation analysis of service recipients or potential service beneficiaries in order to gather information. An extensive needs assessment produces important information beyond the immediate direct services needs that can influence future program design<sup>x</sup>. This includes information about women with disabilities and their family members, such as their social and economic status, ability to access other community activities and services, and personal relationships.

**Women with Disabilities in Community Development:** One of the key indicators for the success of any community based development project is participation. In most situations, technical management authorities for making the final decisions; however, it is important that all key stakeholders, particularly

women with disabilities and their family members, are actively involved at all stages of the management cycle, within the context of their culture and religious constraints. Women with disabilities can provide valuable inputs by sharing their experiences, observations and recommendations. Their participation throughout the management cycle will help to ensure that the program responds to the needs of the community and that the community helps to sustain the program in the long term. It emphasizes the process by which individuals in the community have joined forces to plan and take actions regarding community problems; they identify community problems and needs and plan and conduct activities together using available community resources.

It is important to focus on the major shifts enlightened in international and national policies about the role of women with disabilities in community based development to ensure that the benefits of the program can reach people with disabilities at the local level, especially women with disabilities and their families through actively promoting the UN convention on the Rights of Persons with Disabilities and helping people to understand its meaning with practical examples from their daily lives. For women with disabilities, it is a big challenge to work at the local level with nongovernmental organizations (including disabled people's organizations, human rights organizations and other development organizations) and with local governments, on an equal level. Women with disabilities need to be involved in advocacy activities which aim to develop or strengthen inclusive national and local policies relating to sectors such as health, education and employment. Role of Women with Disabilities reveals around the trend in current Community Based Inclusive Development philosophy, and in more recent "social model" programs that aim to include women with disabilities in community-wide development initiatives. It needs to look carefully at their effectiveness in terms of relevance and responsiveness to the current challenges. Which focused on specific requirements and concerns of women with disabilities according to the cultural context and from local initiatives?

Finally, providing hands-on skills training and leadership opportunities to women with disabilities in the field of livelihoods and disability rights provides employment. On the other hand, CBR programmes should sensitize members of the community on issues of disability, i.e., causes, nature, implications and services available, to help improve the various conditions. Members of the community should also be made to understand about the potential capabilities of PWDs by allowing them equal opportunities to participate in community activities, or through apprenticeship training among other things. This helps the community to understand the nature of PWDs, accept them and allow them equal opportunities to participate in the socio-economic activities of the community.

**Challenging Scenario:** Examination of existing community based rehabilitation practice shows that major difficulties arise from a number of issues. These include the inclination of community based rehabilitation program to focus their activities on individuals with impairments, the limited involvement of the community in planning and development, underestimating the effect of culture and what is required to change this and, finally, the limited engagement, participation and commitment of Governments. Using the community based development model in designing and implementing community based rehabilitation programs would be beneficial to women with disabilities because the community development model is more collaborative and comprehensive in nature. Its three components include: leading change through dialogue, collective empowerment and connective leadership, ensuring that community leaders involve community members in the early stages of program planning and also in the conduct of the programs. In the developing world, some women's organizations at the grassroots level have taken spontaneous initiative to change the social stigma, offering hope for change. As social awareness increases, so do the confidence and negotiation skills of women with disabilities. For example, as recently as the 1960s and 1970s, disabled people in Uganda

were subject only to pity and charity. However, in the mid-1980s, Disabled Peoples' Organizations (DPOs) in the Global North started arguing that international development agencies should provide direct financial support to their counterparts in the Global South. So, with support from abroad, disability groups in Uganda were transformed into strong representative associations. In 1987, local DPOs came together to form an umbrella organization the National Union of Disabled Persons of Uganda (NUDIPU) which used the foreign assistance it received to enable persons with disabilities to gain a foothold in politics; as a result, persons with disabilities are now guaranteed five representatives in the Parliament, at least one of whom must be a woman<sup>xi</sup>.

The major reason for the continuing poverty, lack of rights, and disempowerment of women with disabilities, and for the ignorance and prejudice towards them, is women's voicelessness, which means lack of representation. This is where an alliance between Community Based Development programs and DPOs is so important; and they must be mutually reinforcing. In Nepal, for example, self help groups enabled women with disabilities in their community to become self-motivated and self-reliant. In many developing countries, the needs of women with disabilities have been recognized and addressed through existing DPOs but there is still a clear need for more disability-specific initiatives, to decrease the barriers that women with disabilities experience. Supporting people with disability so they can make their own decisions and assume an active leadership role in the policy and planning processes affecting them is fundamental to improving their quality of life.

In developing countries many types of initiatives were identified as priorities by people with disabilities during strategy consultations including capacity development for DPOs, support for women with disabilities, support and self-help groups for parents and carers of people with disabilities, community-based rehabilitation, independent living, teacher assistants to ensure effective inclusion and instruction of students with disabilities, sign language and Braille instruction, construction and provision of assistive devices, mobility aids and assistive technologies to facilitate access to education, employment and community services by people with disability, and specific vocational training. But the lack of capacity of DPOs was raised everywhere in international conferences and discussion forums by disability stakeholders as a major obstacle to empowering people with disabilities and building their capacity to raise awareness and advocate effectively<sup>xii</sup>.

Most development specialists agree that sustainable development is not possible without the full participation of both halves, female and male; of the world's population development is about the process of change to achieve sustainable outcomes its essential to start in a modest but focused way, build strong foundations and scale-up activities of women with disabilities as experience and capacity in disability-inclusive development.<sup>xiii</sup>

Organizations composed entirely of disabled persons with various disabilities physical, mental and sensory have sprung up in 100 countries since the mid 1970s. Disabled people have come to the realization that their societies were built without their input and participation. The disability movement for the rights-based society was initiated in 1980 with the formation of Disabled Peoples International (DPI). Disabled citizens of Pakistan joined the movement in the same year.

Development policies that incorporate gender as a factor reflect a growing understanding of the necessity for women's and men's full and equal participation in civil, cultural, economic, political, and social life. Gender-focused development means that female and male infants are given equal opportunities to survive, boys and girls are equally nourished and educated, and women and men have

equal opportunities to contribute to and benefit from social, economic, and political processes. And for women with disabilities it is obvious that with equity, women with disabilities will enjoy full and equal legal rights and access to and control over resources<sup>xiv</sup>.

**Making it Work:** Today promises to be the dawn of a new era – an era in which persons with disabilities will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long. “This Convention is a remarkable and forward-looking document,” said Kofi Annan, former Secretary General of United Nations about the Convention on the Rights of Persons with Disabilities (UNCRPD). The Convention is historic and path-breaking on several levels, both in protection terms for the world's 650 million persons with disabilities who may now draw upon its provisions in defense of their internationally protected rights and in relation to the unprecedented level of civil society input and engagement in the negotiation process (Melish, 2007).<sup>xv</sup>

The UN General Assembly adopted the Convention on the Rights of Persons with Disabilities in December 2006 marking a leap forward to mainstream the social model of disability, which is a cornerstone of the rights-based society for all. Persons with disabilities have a distinctive history of struggle through which they have organized themselves to speak out for their own rights (Driedger, 1989<sup>xvi</sup>), and ‘at the social level, there has also been an extremely positive development as increasing importance is attached to the integration of persons with disabilities in the community.<sup>xvii</sup> For too long, persons with disabilities were excluded from decisions concerning themselves until they established their own organizations. At the founding meeting of Disabled Peoples International (DPI) in Singapore in 1981, the 400 delegates from 53 countries adopted its philosophy of "nothing about us without us." The DPI newsletter was entitled "Vox Nostra" "a voice of our own" reflecting the demand for change, since disabled people were neither listened to nor talked to and people often literally "talk over" disabled people and talk to their personal assistants, their friends and family members as if disabled people do not exist

The strength of Disabled Peoples International lies in the equal regional representation in its decision making body, the World Council. The world is divided into five regions of Africa, Asia-Pacific, Europe, Latin America and North America and the Caribbean. Each region nominates five members to the World Council, thus ensuring that the regional balance is well-maintained. Among the six world officers, the majority are from developing countries (Nagase et al, 1989). The bond between the United Nations and DPI is ever growing and the observance of the International Day of Disabled Persons in 2003 was focused on giving a voice to the human experiences of disabled persons, as the voice of persons with disabilities is seldom heard in the mainstream media. As the press release noted: “When persons with disabilities are portrayed, they are either stereotyped or presented as an inspiration for “overcoming” a disability, observance of the Day should therefore be used to offer an opportunity for persons with disabilities to speak for themselves” (<sup>xviii</sup>UN, 2003).

The disability movement sees inclusion as an ideal goal while exclusion from society, especially in the form of institutionalization or segregation, is seen as detrimental. This goal has gained popularity through the Independent Living movement. It is especially important to ensure that women with disabilities participate as fully as possible in the assessment of their own needs and in the design, innovation, and evaluation of all components as persons with disabilities are the best advocates of their rights. It will improve the role of women with disabilities as they can better share and raise their own concerns in a perfect way, its time for them to learn from the experience of disability movement and can join hands together for success.<sup>xix</sup>

Perhaps most important of all, as peer counselors, women with disabilities can support other women with disabilities by sharing their own experiences and giving them confidence that every person has the capacity to live independently. Since peer counselors are persons with disabilities who have similar experiences and are facing similar challenges, they can be role models and serve as a link between the person seeking help and the service provider by drawing on a wide range of unique experiences which cannot be observed by anyone else.

It enlightens and encourages women with disabilities about their own possibilities when they see villagers in wheelchairs and on crutches running the program, providing medical and nursing care, performing a wide range of skilled services, earning their living, raising families, enjoying life and doing more to assist other people than most non-disabled persons do. This also gives parents of children with disabilities a whole new sense of what is possible. And that is the first big step of rehabilitation - or enablement – and ultimately of empowerment. In this discourse people agreed on the need to adopt strategies which can provide support to women with disabilities, but held different views on the involvement of lay people and (semi) professionals, the roles of governments and (inter)national NGOs, the need for institutions and referral centers and the feasibility of an adequate support service at community level according to cultural norms and available resources<sup>xx</sup>.

Developing and implementing Community Based Inclusive Development enables to join with others to exert influence and demonstrate leadership in disability and development. It is important that during implementation, to look for supporting leadership development and efforts of women with disability to be advocates and leaders in their own right, they can be set an example for others by modelling good practice in disability-inclusive development further they can identify opportunities to build strategic partnerships through which can support and strengthen efforts of international and other potentially influential partners including disabled persons organizations.<sup>xxi</sup>

Further, providing hands-on skills training and leadership opportunities to women with disabilities in the field of livelihoods and disability rights provides employment. And community based rehabilitation program also should sensitize members of the community on issues of disability, including causes, nature, implications and services available to help improve the lives of persons with various disabilities. Members of the community should also be made to understand the potential capabilities of persons with disabilities and the importance of ensuring that people with disabilities have equal opportunities to participate in community activities, to promote acceptance and provision of equal opportunities for persons with disabilities to participate in the socio-economic activities of the community.

It is important to influence those who are in power and having authority to take decision they should realize seriously the empowerment of women with disabilities is key to making progress, this is the role of women with disabilities to realize them by their contribution and work in disability movement. As per our experiences sharing information between women with disabilities and disabled persons organization's leaders which will assist the promotion of effective working relations of these leaders is an important landmark towards inclusive development

**Conclusion:** To seriously address the challenges that women with disabilities face over an extended period of time, a commitment to the community must be developed. The main challenge of a holistic approach to community based development is that it requires a long-term commitment as well as flexible support mechanisms so that women with disabilities can make their own decisions, which can provide assistance for an active leadership role in the policy and planning processes to improve quality



of life both on the local and national levels. Strategies might include, for example, cooperative agreements among DPOs, NGOs, service providers and community groups.

This is the time that law must guarantee the enjoyment of the rights enumerated in the UN Convention.

As women with disabilities are the best advocates for their issues and have been agents of change, they can be the best partners for implementation of policies on the ground. Implementation of the Convention and realization of well written laws is not possible until States recognize the rights of women with disabilities to represent themselves at national, regional and local levels, recognize the advisory role of organizations of persons with disabilities in decision making on disability matters, and ensure that international donors include capacity building of organizations of persons with disabilities among their priorities

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