

## Disability in Pakistan: Past experiences, current situation and future directions

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The world disability day is celebrated all around the globe on 3rd December every year. It is a day marked by disability awareness walks, official statements by the governments, functions held by the persons with disability (PWD) and the social organizations working in the field of disability management. However, for many developing countries like Pakistan this is the only day that PWD and their problems get attention.<sup>1</sup> From 4th December onwards, it is life as usual. Disability is a global issue and a significant public health problem. It is present in some form in every country and affects every individual directly or indirectly at some stage of life. According to the World Health Organization (WHO) report of 2011, one billion people in the world are living with some form of disability.<sup>2</sup> This number is expected to rise to 2 billion by 2050.<sup>3</sup> Majority of the PWD are living in the developing countries. Many PWD require assistive technologies (AT) in the form of low-vision devices, wheelchairs, prosthetics, or hearing aids. However, it has been estimated that only few PWD in the low and middle Income countries (LMICs) have access to the assistive technology they need for better mobility and functioning.<sup>4</sup> The lack of rehabilitation services negatively impacts the PWD and can lead to activity limitations, participation restrictions, and can result in poorer health and quality of life.<sup>2</sup>

The situation in Pakistan is not much different from other LMICs.<sup>1,5</sup> Pakistan still lacks a uniform national definition of disability.<sup>6</sup> There is no national disability registry to accurately determine the total burden of PWD in the society. The present data on the epidemiology and patterns of disability in Pakistan is limited and mostly unreliable.<sup>5</sup> Detailed statistical data collection has never been a part of any of the national population census in the past. According to a 2014 estimate there might be up to 27 million people in Pakistan living with some form of disability.<sup>7</sup> The PWD face mobility barriers and socio-cultural discrimination in the community. They are still not part of the mainstream society and have difficulty

accessing healthcare services. It is difficult for them to get even an official certificate of disability<sup>8</sup> or vote for their candidate in elections.<sup>9</sup> According to one report "PWDs continue to be victims of charitable model, sympathy model, medical model, the social model, the economic model, and the minority group model in a number of policies and laws designed and implemented so far."

Government of Pakistan addresses the needs of PWD via a Directorate General of Special Education and Social Welfare (under the Capital Administration and Development Division) and several institutes and centres established in the Islamabad Capital Territory. After the 18th amendment provincial governments also have a mandate of facilitating PWD in their provinces. Many legislations regarding PWD have been passed in Pakistan since 1980. The first was the Disabled Persons (Employment and Rehabilitation) Ordinance, 1981. This was followed by National Policy for Persons with Disabilities (2002) and a National Plan of Action for Persons with Disabilities (2006). Other efforts include, the Accessibility Code of Pakistan, 2006, the Special Citizens Act, 2008, and Special Citizens (Right to Concessions in Movement) Act, 2009.<sup>6</sup> However, true implementation of these legislations and laws in real life remains a challenge. In addition, Pakistan is also signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) held in the United Nations general assembly in 2008. The Government of Pakistan ratified the UNCRPD on 5th July 2011.<sup>10</sup> Implementation of these legislations on ground is not complete yet.

Despite all these shortcomings and neglect of the PWD there are some indications that PWD are reclaiming their place in the society. They are organizing themselves and raising their voices against the discrimination they have faced in the past. Although the mandate may vary but generally most of the Non-Governmental organizations lead by PWD are actively working for creating disability awareness in the society, networking among the PWD in Pakistan, providing training opportunities and pushing forward for a grass root level change in the society. The family network is stronger in Pakistan than many developed countries. This social support network can provide the psychological and moral support to PWD for their reintegration into the society.

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Now there is a need for the medical community in Pakistan to realize their responsibilities regarding the advocacy, optimum management, and adequate rehabilitation of the PWD in the country. Disability studies are not part of the curriculum either at the undergraduate level or post graduate residency training in Pakistan. As a result, most of the health care professionals are only familiar with the curative model of disease management. They do not realize that disability is a complex phenomenon with social implications and not only a medical issue. It is not only the PWD who suffers from lack of adequate assessment and treatment. The immediate family members and the society also suffers and pays the price for the exclusion of PWD from the mainstream. According to a 2014 British Council, Pakistan report, a lack of engagement and inclusion of these people could be costing the Pakistan's economy between 4.9% and 6.3% of gross domestic product each year.<sup>7</sup> This is an alarming statistic considering the current economic situation in the country. But it also gives us hope that if these talented and passionate PWDs are facilitated for community reintegration and job opportunities, they can make an important contribution to the society and the country. The medical community in Pakistan should embrace the multidisciplinary and multifaceted concept of disability management instead of myopically focusing on the medical aspect of the disability and impairment. It is important to sensitize the future physicians about PWD and disability management. This can be done by integrating Physical Medicine and Rehabilitation in the undergraduate medical curriculum prescribed by the Pakistan Medical and Dental Council. In medical colleges where Rehabilitation modules are already being taught. Steps should be taken to ensure that only rehabilitation physicians teach and assess the subject instead of allied health care professionals like physiotherapists. In addition, physicians should focus not only on management but also the prevention and accurate assessment of disabilities and their impact on the lives of PWD.

The government also needs to ensure that the legislation is implemented and the mobility barriers for PWD are removed. Along with the PWD themselves and social

workers, medical professionals involved with disability management must be consulted before drafting any healthcare policy or legislation for the PWD in the country in future. Community based data on PWD is the essential to guide these policies. Specific job opportunities for PWD should be created and they should be provided adequate training. We need to understand that the challenges of Pakistan are different from other countries. All stake holders involved with disability in Pakistan need to collaborate and coordinate to best serve the interest of PWD. Only then we can ensure a future for PWD in Pakistan which is better than their present and past.

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