

## International and national perspective of disability and policy disconnect in Pakistan: A narrative review

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### Abstract

In the developed societies, supportive environmental, physical and social conditions enable participation of persons with disabilities in the mainstream through actions, like provision of ramps and reserved parking. In contrast, in the developing countries like Pakistan, with focus on visual disability, years lost to disabilities compromise and restrict the productive life span of the disabled. The current narrative review was planned to highlight the perspective of disability in the context of Pakistan to bring to limelight the issues requiring immediate focus of the health authorities and the government through a holistic and sustainable approach. Of the 177 publications found on literature search, 33(%) English-language, full-text studies were reviewed. To address disability issues, long-term sustainable actions, like health reforms, including ensuring availability of rehabilitation professionals in hospitals, legislative reforms to initiate relevant legislations, capacity-building of persons with disabilities, including their mainstreaming, are deemed essential.

**Keywords:** Convention on the rights of persons with disabilities, CRPD, Disability, Millennium development goals, MDGs, Sustainable development goals, (SDGs), Persons with disabilities, PWDs, Quality of life, QoL, Years lost to disability, YLD.

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### Introduction

A developing country like Pakistan faces multiple challenges at diverse levels, including poor healthcare infrastructure and scarcity of healthcare professionals including rehabilitation professionals with barriers being faced as regards World Health Organisation's (WHO) Global Disability Action Plan (GDAP) implementation,<sup>1</sup> with setups responsible for provision of healthcare to the masses putting in a lot of effort trying to meet the demand.<sup>2</sup>

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With the definition of person with disability (PWD) given by United Nations Convention on Rights of Persons with Disabilities (UNCRPD) as one who has long-term mental, physical, sensory or intellectual inabilities or impairments, which, while interacting with a number of barriers can hinder effective and full involvement in society on the basis of equality.<sup>3</sup> Disability as umbrella term covers impairments, limitations of activity and participative restrictions with implications for the scope of legislation, disability prevalence and for fitness-related public programmes. Mitra S. described the capability approach to identify disability models<sup>4</sup>. The capability model includes capability level disability, potential disability and actual disability.<sup>4</sup>

World Health Survey puts the prevalence of disabled adults aged >18 years having significant difficulty in functioning to be 11.8% in high-income countries (HICs) and 18% in low- and middle-income countries (LMICs) with an average rate of 15%.<sup>5</sup> Keeping this in view, Pakistan may be having a population of 31 million disabled, but reliable statistics are lacking.<sup>6</sup> A study on the physically disabled in rural Pakistan reported poor access to healthcare.<sup>7</sup> The years lost to disability (YLD) compromise and restrict the productive life span of an individual suffering from a disability.<sup>8</sup> A World Health Organisation (WHO) report proposed that governments should make policies, systems and services compliant with UNCRPD and to develop, implement, enforce and monitor policies, regulatory mechanisms and uniform standards for adequate health coverage for PWDs.<sup>9</sup> A United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) report advocated 'accessibility' as a policy instrument so that PWDs may acquire indiscriminate access to information technology (IT) and other tools even if it entails capacity building of the policy-makers.<sup>10</sup>

With such soaring disability figures, the need for establishing preventive and curative health facilities is among the top challenges for the country's already struggling economy. Hence, the current review was planned to highlight the perspective of disability in the context of Pakistan to bring to limelight the issues requiring immediate focus of the health authorities and

the government through a holistic and sustainable approach to cater to the needs of the disabled. The involvement of all stakeholders, including the disabled population, healthcare professionals, academicians as well policy-makers, is essentially required with adequate financial resource allocation.

The narrative review comprised literature search using search engines, like Google and Google Scholar, as well as databases, like Medline and Web of Science, and bibliography associated with the published articles using key words, like 'disability', 'special education', 'healthcare', 'medical care', 'persons with disabilities', 'health policy', 'disability legislation', 'regulations' and the various combinations of these terms. Of 177 publications, reports

and articles shortlisted, 33(18.6%) were reviewed in detail (Figure).

**Comparison of healthcare for the disabled:** Among all the issues related to public health, WHO considers disability as a global issue related to public health, as well as an issue of human rights, since disabled people face barriers throughout their life, to get health as well as other related services, with about 80% of disabled living in developing nations.<sup>11</sup> WHO stresses that people with disabilities have the same health needs as non-disabled people, like immunisation and cancer screening, and may have a narrower margin of health due to poverty and health exclusion.<sup>12</sup> Health during travel is also an issue in this population.<sup>13</sup> Gender bias has also been reported to affect food and healthcare provision.<sup>14</sup> Zimba Y. noted that low income was a permanent national issue.<sup>12</sup> United Kingdom's Poor Law of 1601 equated PWDs with poverty.<sup>15</sup> In Pakistan, the gravity and extent of prevalence of disability is not perceived as a major concern by the policy-makers in view of the population explosion so much so that rehabilitation is being ignored in all categories, including demographics of disability, disease, learning and teaching, barriers, governance, research, financial resource, care, public awareness and beliefs.<sup>16</sup> Along with challenges faced in implanting WHO's GDAP, including lack of skilled manpower, a divided healthcare delivery system, lack of coordination among the healthcare areas of acute and subacute care, shortage of infrastructure as well as funds for health services, dearth of disability data and legislation, lack of accreditation and guidelines, shortage of awareness of disability and lack of national rehabilitation framework,<sup>17</sup> geographical and topographical as well as cultural issues.<sup>1</sup>

Hearing screening still remains unattended due to the fact that it caters to an invisible disability, hence most of the foreign sponsored funding is directed towards inclusive education and health.<sup>18</sup> A local study noted absence of advocacy for the rights of the disabled at grassroots level in Pakistan.<sup>7</sup> In Pakistan the elderly population's rehabilitation needs are not addressed adequately, where there is urgent need at the level of government policy-makers to develop and implement regulatory system as well as healthcare policy for the ageing, which should enable the large elderly community of Pakistan to ensure catering to their healthcare requirements.<sup>19</sup> This is being currently addressed through usually one son or daughter dedicating his/her time and resources acting as a primary caregiver, compromising the disabled individuals' mobility and independence and invariably contributing to chronic diseases which could otherwise have been delayed.

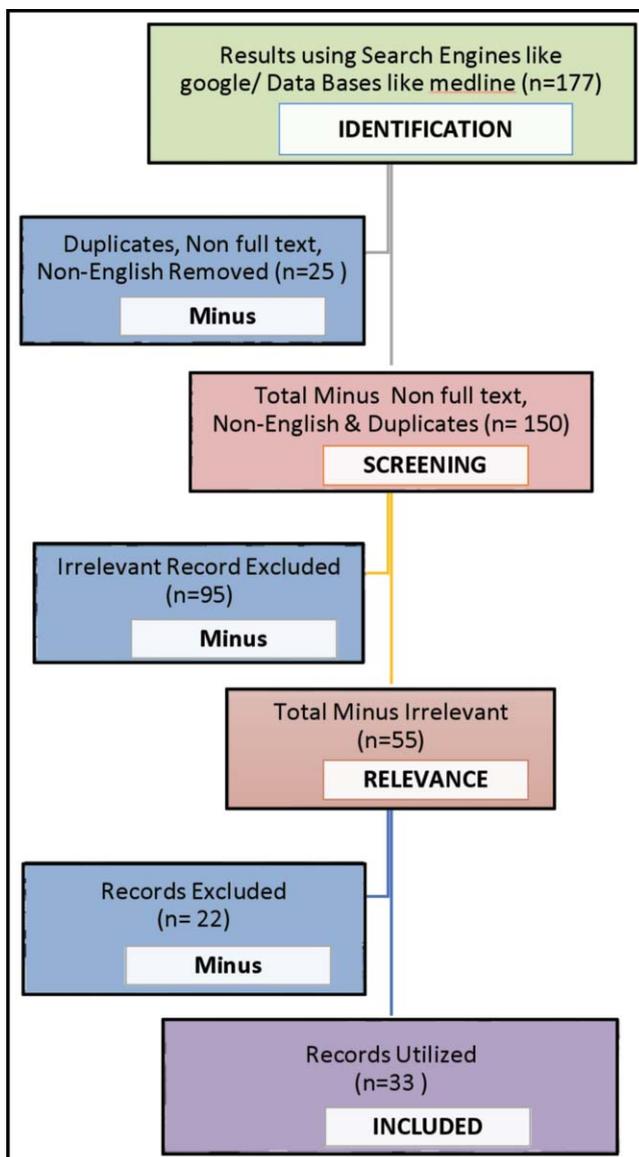


Figure: Schematic representation of data search.

**International framework:** The UNCRPD was adopted in 2006 with 82 signatories, marking a paradigm shift from adopting a charitable view of PWDs to enabling them to make independent and well-informed decisions and gelling as members of society empowered through shared decision-making. This concept is gaining reinforcement at medical and allied healthcare forums. CRPD recognises the right of all PWDs to be included in the general education systems and to receive the individual support they require.<sup>20</sup> Brolan CE. has cautioned that though the Sustainable Development Goals (SDGs) seem to be an advance to cater to PWDs and human rights in contrast to the Millennium Development Goals (MDGs), but disjunction is present between human rights treatment in the post-2015 SDG text.<sup>21</sup> In Japan, it is estimated that 6.5 million out of the total population of 127 million suffer from some form of disability. Officials in Japan intriguingly advocate the segregation of children with disability into a non-inclusive and special school system. PWDs are adjusted into state-managed centres where they are employed with lower wages. The Japanese Act on employment Promotion of Persons with Disabilities is centred on a quota system.<sup>22</sup> The former World Bank President, James D. Wolfensohn, said: "Unless disabled people are brought into the development mainstream, it will be impossible to give every girl and boy the chance to achieve primary education".<sup>23</sup> However, involvement of PWDs in policy processes and implementation of such policies is lacking, as was noted in an African study.<sup>24</sup> A participatory approach for disabled persons was noted in the European Union with implementation of internationally accepted model as embodied in the UNCRPD. The European Commission's European Disability Strategy 2010-20 was launched in 2010. Its positive connotations included access to the EU's financial resources, inculcation and acceptance of a sense of the rights of PWDs through ensuring of an enabling environment.<sup>25</sup>

The WHO estimates the number of disabled to be around 15% of the world population. Nations which recognise the plight of the disabled and their legitimate right to absorption in society as productive individuals, advocate mainstreaming, thereby improving quality of life (QoL) not only of the PWDs, but also of their caregivers and ultimately reducing the burden on society. A study reported participatory development by disabled population, indicating that disability is not inability.<sup>26</sup>

**Impact of disability on education:** A review article noted that provision of training and resources to teachers by leaders supporting equitable, inclusive education to all learners, both normal and disabled, can reshape

education.<sup>27</sup> However, children with disabilities are less likely to be enrolled in school, though education offsets the extreme disadvantages of cognitive disability<sup>28</sup> and educational level is also a source of increased income in spite of disability among the elderly.<sup>29</sup> With no accepted definition of disability, special needs education varies in terms of impairments, activity limitations and participation restriction, making the task of forging a global approach arduous. In spite of claims inequalities exist even in China.<sup>30</sup> Society is burdened by having to look after the PWDs, and a significant source of human capital remains untapped, but education and knowledge are sources of poverty reduction.<sup>24</sup> In Pakistan, shortcomings dominate. A local study comprising rural households revealed low literacy and school enrolment rates in disabled children compared to their normal peers, though parents seemed to be interested in their children to be in the schools, including the mainstream schools, hence requiring the attention of policy-makers.<sup>31</sup>

**Impact of disability upon employment:** In the United Kingdom, the matter of significance of human capital has been taken up and examined at the level of the Prime Minister's Strategy Unit.<sup>12</sup> Improving economic situation can reduce disability prevalence.<sup>32</sup> The policy-makers in Pakistan should initiate projects aimed at mainstreaming the PWDs by facilitating their entry into the labour market despite the disadvantage. In spite of the fact that as per government policy, a job quota of 2% should be allocated for the disabled in the provinces with a higher quota of 3% in the Punjab province, a study involving 16 government departments of Khyber Pakhtunkhwa (KP) revealed only 0.67% PWDs.<sup>33</sup> The Disability Act XXXV-2020 is a ray of hope,<sup>34</sup> but to improve the situation it is essentially required to enforce policy compliance for betterment of PWDs.

**Resource constraints and inconsistent policy initiatives:** Pakistan faces challenges, including poor healthcare infrastructure and dearth of healthcare professionals, including rehabilitation professionals. With a sizable population being unidentified, disability figures are swelling, with nearly half of total disabilities arising due to disease, and one-third being congenital, highlighting the need for establishing preventive and curative health facilities.<sup>35</sup> The Afghan war of 1980s, internally displaced persons (IDPs) and later the earthquake of 2005 saw a stream of PWDs presenting with physical, emotional and cognitive compromises, yet no sustainable steps were taken. The Disabled Persons (Employment and Rehabilitation) Ordinance was passed in 1981, which recognised the rights of PWDs in employment, rehab and for welfare of the special

population. However, it could not create an enabling environment free of discrimination. The National Disability Policy was formalised as recently as 2002 with the avid objective of providing an environment for PWDs to realise their potential. Ambiguity is prevailing as to how to translate these goals into reality. A National Plan of Action was launched in 2006 to translate the National Disability Policy into action, but lacked ownership. Pakistan became a signatory to UNCRPD in 2009, which was ratified in 2011. With the signing of the Disability Act, (Act No. XXXV of 2020), law now demands inclusivity for PWDs, and is a ray of hope for the disabled with the establishment of disability courts.<sup>34</sup>

Disability lacks sensationalism and has escaped the media glare accorded to infectious diseases, and health priorities remain misplaced. As depicted in the press and electronic media, an adult suffering from human immunodeficiency virus (HIV) is more vocal than a child with a disability. Within the four disabilities, as recognized by WHO, the disability which is most visible i.e., physical is highlighted, thereby reducing the significance of the other three disabilities. As such, disabled are faced with three times more chances of denial of healthcare, four times more chance of receiving bad treatment at health facilities and also more health expenditure.<sup>35</sup>

The legislative framework in Pakistan has missed out on factoring modern and contemporary communication trends, including digitalised hearing aids and implants, software and IT accessories and software applications, online job portals and its digital accessibility to facilitate rehabilitation of professionals and PWDs to ensure non-discriminatory and evolving online accountability and awareness mechanism. Such a legislative intervention can ensure that discrimination is immediately highlighted and addressed. Wherever the existing policy or statute contains provisions for mainstreaming, treatment or employment of PWDs, enforcement remains a tedious task. Employment and opportunity-related electronic or digital portals should be developed through statutory or legislative enactment and a database of PWDs be established, leading to accessible and low-cost national and international research, clinical and distance or remotely-based therapeutic networks and care systems to cut down the disparity for this group.<sup>36</sup> Presently, the policy and legislative environment of Pakistan lacks this harmonisation and synchronisation with the emerging international digital and contemporary trends.

## Conclusion

To address disability issues, long-term sustainable actions are required. The need of the hour is to redefine the

legislative and policy framework in Pakistan. Accordingly, the goal would be to narrow down and ultimately eliminate existing policy and legislative disconnects, thereby providing an enabling environment for mainstreaming of PWDs.

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