

SILENCED VOICES: HEALTHCARE NEEDS OF CHILDREN WITH DISABILITIES IN PAKISTAN

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Abstract

The number of children with disabilities is increasing and their healthcare needs are one of the most ignored areas of Pakistan's health care system. These children face multiple challenges to receiving needed healthcare services that include attitudinal, physical, policy, and programmatic level barriers. The commitment to leaving no one behind demands that children with disabilities (CWD) receive inclusive access to the healthcare system. Moreover, the specific healthcare needs of CWD are often overlooked due to lack of research, evidence, and policy measures. It is suggested that an inclusive healthcare system at primary level healthcare facilities should be implemented to improve health outcomes of CWD.

INTRODUCTION

Disability is a global public health and societal concern that affects over one billion people globally, constituting fifteen percent of the world population.¹ That includes almost 240 million children—that is 1 in 10 of all children worldwide.²

In recent years, there has been an increasing global focus on issues of disability. This is due to increased awareness of the need for inclusive development to address societal inequalities and meet the Sustainable Development Goals.^{3,4} Lower-middle income countries (LMICs) have a significantly higher burden of people with disabilities when compared to high income countries. However, there is lack of policies and planning to address the health and social issues in LMICs like Pakistan. It is estimated that 80 per cent of people with disabilities come from LMICs.¹ Moreover, research indicates that these people often live in impoverished, isolated, and underprivileged settings.⁵

A 2021 UNICEF report found that CWD are among the most marginalized and improvised groups across the world that face various health challenges and adverse health outcomes.² CWD face multiple and often compounding challenges due to their impairment for seeking health care facilities. For example, such children remain dependent on caregivers, lack of autonomy, face extreme poverty, and transportation problem while seeking healthcare. Moreover, CWD are entirely overlooked from health policy, planning, and their differential needs are not prioritized.

Pakistan has a mix of demographic and social factors that create a large burden of CWD. Children aged 0–17 constitute 41% of the country's population. Most of the CWD belong to poor, illiterate and consanguineous households that have multiple barriers to accessing health care. Data on CWD is scarce and under-reported in Pakistan due to various reasons.

National surveys do not include children, there is no unified definition of disability, and underreporting due to the stigma around disability is pervasive. The lack of data exacerbates the issues of CWD with disabilities and overlooks their healthcare priorities and needs.

People with disabilities in Pakistan are often seen differently than in most global north countries due religious and cultural beliefs, stigma, and discrimination.^{6,7} There are various folk interpretations of disabilities in Pakistani culture that create multifaceted challenges for CWD and their families seeking high quality health care. Persons with disabilities form Pakistan's largest neglected minority particularly in respect to addressing their healthcare needs. A study from Pakistan reported that cerebral palsy (21%), Epilepsy (20%), muscular dystrophies (13%), and developmental delay (9%) were major types of disabilities aged 2–5 years.⁸ Children with developmental disabilities experience stigma, and discrimination, from community members and healthcare providers in Pakistan and similar LMICs.³ Being victims of stigma and discrimination, in a healthcare setting, may discourage children and their caregivers from attending healthcare services or may cause mistrust of healthcare professionals. Negative attitudes of healthcare providers can also mean that children and adolescents may be excluded from universal healthcare programmes. In such situations, healthcare providers may assume that children and adolescents with disabilities do not need of sexual and reproductive health and education. Children with certain impairments have varied healthcare needs and both children and caregivers experience multifaceted barriers in accessing health care services.⁹ Available health interventions are not fully aligned with the needs of CWD particularly in primary health care facilities in Pakistan. These healthcare facilities are not equipped to address the specific needs of CWD. Additionally, primary healthcare facilities also

lack supportive infrastructure to meet the needs of people with disabilities.¹⁰ Moreover, children and adolescent also do not receive health information according to their disability. Healthcare providers also do not recognize the needs and priorities of CWD due to lack of training in Pakistan and similar LMICs.¹¹

Children with disabilities need specific rehabilitation services related to their impairment or functioning limitations. Research suggests that early detection of impairment and rehabilitation services for children improve the functional abilities of CWD, as well as improve their quality of life.¹²⁻¹⁴ A study from rural areas of Pakistan reported that only 56% of children were diagnosed having a disability from birth or soon after by a physician or family members.⁸ Identification of developmental delay at a later age undermines the optimal chances of intellectual development.¹⁵ Early detection of impairments can be increased by providing training to physicians and an effective referral system to reduce the potential for long-term disability.^{16,17}

Moreover, the available rehabilitation services are often costly, not physically inclusive, or accessible to all children particularly living under poverty and in rural areas of Pakistan. Additionally, In Pakistan, mothers or female caregivers usually take care the children and they have limited mobility, social, and financial independence to seek rehabilitation services that are scant, particularly in rural areas. Consequently, CWD and their caregivers are not able to fully benefit from such services. This increases the costs of caring for such children, creating further hardship particularly for mothers who are often the main caretakers of CWD.

There is limited research on children with disability in Pakistan and many gaps in our knowledge that undermine their inclusive healthcare rights. Furthermore, the lack of accurate epidemiological evidence on disabilities, inaccessible rehabilitation services in rural areas, lack of inclusive primary health care facilities and trained physicians undermine the health of CWD. Healthcare providers need to be trained to provide empathetic, effective, and inclusive care to all CWD. Such trainings programs must be designed and effectively implemented in collaboration with persons with disabilities to identifying their differential needs and priorities. Moreover, accessible health infrastructure particularly for children with disabilities within the health system can help to address the accessibility and disproportionately higher healthcare needs of CWD.

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