REVIEW ARTICLE

Closing the Gap on Access to Assistive Technology

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Abstract

Assistive technology (AT) helps people not only with a disability but also aged population and people with non-communicable diseases to participate in various activities- thus alleviating a feeling of neglect and promoting self-reliance and well-being. By 2030, it's estimated that over two billion people will need AT worldwide. To assist individuals with assistive devices, low- and middle-income countries (LMIC) must overcome a number of obstacles, the most significant of which is a lack of awareness that leads to an imbalance between supply and demand. Additionally, there are financial barriers, scarcity of trained human resources, inadequate knowledge about the products, illiteracy, and social stigma–all of which limit the use acceptance and use of these devices among the masses. There is insufficient data about the number of people requiring assistive devices and the burden of disability, as there are very few surveys have been conducted in LMICs. Consequently, research and development of suitable, sustainable, and premium quality AT devices suffers. To increase awareness among people, Assistive Technology must be included in the National Policy framework - with greater emphasis on indigenous, high-quality production of devices, at a sustainable cost. Caregivers and healthcare workers must assume a much more important role in propagating the information and promoting acceptance or AT. Their participation in surveys is paramount as it will result in the formulation of consumer-friendly production models. Bridging the gap between AT's demand and availability is a significant challenge.

Keywords: Assistive technology, Disability, Awareness, Sustainable Development Goals, Barriers

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Introduction

The United Nations' Sustainable Development Goal (SDG) 3 is "Health for All," with a focus on "People with Disability" (PwD). Although the United Nations published this report in 2018, data on actual implementation have shown that there are issues of people being disregarded and left out of the mainstream, including lack of access to jobs, health care, education, and participation in policy and decision-making.

Thus, it is important to change the mindset of people at the grassroots level. The following parameters warrant due consideration:

1) To address fundamental barriers causing exclusion of PwD, for example, lack of access to assistive technology and rehabilitation.
2) Prioritizing disability in the implementation of different SDGs, for example, accessible infrastructural development in urban as well as in rural areas.
3) Since the data and research on disability are limited by several constraints, it is important to develop a sustainable monitoring and evaluation process to assess the progress of SDGs.
4) Indicators for assessing the situation of PwD, especially disability-specific indicators must be developed. For example, to evaluate and increase the access of education to children with disability, the indicators proposed could include –
   - Primary school attendance ratio of children with disability.
   - Percentage of teachers in service who have received in-service training in the last twelve months to teach students with special educational needs.

Numerous factors are restricting the use of assistive devices in LMICs such as lack of access and awareness, high cost, scarcity of trained personnel, lack of governance, compromised quality of the products and affordability of the people.

Assistive Technology

The World Health Organization describes Assistive Technology (AT) as an umbrella term that describes any product or service that will help an individual to perform all possible activities independently to enjoy a healthy and productive life. It will strengthen the position of PwD in society allowing them to participate in education opportunities, become active workforce and enjoy sound mental health, at par with the rest of the World and with the dignity they deserve.[1] AT is not only useful for people with disability but also for those affected by noncommunicable diseases (NCD), and age-

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related dependency, as well as for rehabilitation. Currently, more than one billion adults and children are living with some form of disability as per the World Report on Disability and this number will exceed two billion by 2030. Out of these, 200 million people experience functional disabilities.[2] The major challenges posed to global health now are diseases like diabetes, cardiovascular diseases, cancer, Stroke, and chronic respiratory and mental health problems which are primarily non-communicable. NCDs have a large impact on impairing productivity and contribute to increased healthcare expenditure.[3] NCDs and disability are increasing in magnitude due to more aging population, and the shift of disease burden towards chronic conditions. This is a double-edged sword because NCDs cause limited activity and restricted participation in society and the absence of supportive personal and environmental factors for PwD – they may become more prone to NCDs due to exclusion from health care services.[4] Marked advancement in clinical care and public health policies has resulted in the survival of millions, who may have been lost to infections, malnutrition as well as to diseases having potentially disabling sequelae increasing DALY (disability-associated life years).[3]

Challenges Faced by Low And Middle-Income Countries

Challenges in Acceptance of Assistive Devices

Demand and Supply

There is a gross mismatch between the need, demand and supply of AT. This can be attributed to many reasons such as - ignorance and unawareness among users, caregivers and health workers, etc. It has been observed that more than 200 million people do not have access to spectacles or low-vision aids.[1] According to the WHO, in many LMIC, only 5–15% of people who require AT have access to them.[5] Another area of concern is the associated multi-systemic disabilities. It has been observed that only 10% of the total potential beneficiaries reached the end of the chain to access assistive devices. So once the projected demand is low, the availability of AT takes a hit. Further, high costs and lack of financial incentives for manufacturing are hindering factors contributing to the lack of availability.

Affordability

The study done in Bangladesh by Johan-Borg *et al*. states that affordability was the major reason for not possessing the assistive technologies.[6] The study done in Brazil, India, Egypt, Cambodia and Turkey by Marasinghe *et al*.[5] also highlighted cost as an important factor for the use of assistive technology in LMICs. The cost of services and production is a significant factor preventing PwD from availing the required health care and rehabilitative services in developing nations such as India. World Health Organization reported that about 53% of people with disabilities were unable to afford healthcare costs compared to 32% of those without disabilities in their report on disability and health reviewed in 2018.

Awareness and Capacity Building

Insufficient data regarding awareness among AT users as well as among the health care provider caregivers, especially in rural areas – leads to fewer people seeking them- so even if they are available at subsidized rates, the utilization is limited.[5] Training of healthcare workers to provide these technologies is a limiting factor not only in low and middle-income countries but also in countries like the USA.[1] The other commonly found barrier especially in rural areas is the perception of "no need" stigma in the older rural population. Illiteracy and lack of adjustment to technology limit the use of computer and mobile-related software. Issues often cited with computer usage are screen design, Input device design, complex commands and operating procedures. Therefore, senior citizens and those with disabilities must be consulted while designing computer-based AT, to not only make these devices user-friendly but to make them more accepted among the beneficiaries as well.

Gaps in Research, Technology Transfer and Product Design

For the best suitability to physical and social environments, feedback from the users and health workers is essential. Since there is no such response because of the limited use of the products in LMICs, research and development of user-friendly devices with indigenous materials take a backseat.

Lack of Evidence

There is a wide variation in the data available on disability, especially in LMICs like India. This can be attributed to lack of uniformity in definition, insufficient sample size and collecting information on a scientific basis resulting in underestimation.[7]

Barriers between Disability and Healthcare Usage in India

People with disabilities face many difficulties in accessing either general or specialized healthcare services in India and the majority of them have no access to rehabilitation services.

Rehabilitation services are reportedly used by 15% of disabled persons who live in urban areas and 3% of disabled people who live in rural regions, for a total coverage of 5.7%.[8] Nonetheless, the Telangana study conducted in southern India found that while vocational and medical rehabilitation programs were well covered (76–78%), assistive device coverage was very low (44–46%).

In terms of devices, the lowest were hearing aid (6%), wheelchair (26%) though good coverage in walking stick, and guide cane >85%).[9] The difference could be due to methodologies used in the measurement of rehabilitation services or the domain of rehabilitation covered.

Studies reported that health-seeking behavior is higher with people with disabilities than without disabilities.

The South Indian Disability study reported that the most significant barriers encountered by people with disabilities when compared to those without are lack of awareness of the availability of services (13.3% vs. 2%), cost of transportation (13.3% vs. 2.2%), inaccessible due to physical building like narrow doorways, internal steps, inadequate bathroom, inaccessible parking areas (12.7% vs. 2.3%), not fitting of hospital equipment (13.2% vs. 2.1%). People with disabilities also face discrimination or stigma from hospital staff as well as society and are frequently denied or neglected their right to be included in the general pool which leads to barriers. The WHO's review also reported that the lack of appropriate disability-oriented services is a significant barrier to health care access. For instance, in Uttar Pradesh and Tamil Nadu, it was the second most important barrier next to the cost of services. Inadequate skills and knowledge of health providers or workers and their skewed distributions were also important barriers in low and middle-income countries as per WHO disability survey made in 2018. Disability, poverty, and health are interrelated concerns. Poverty also poses a significant barrier to healthcare access in the country.

How To Overcome?

The cornerstone of the UN's principles is healthy lifestyles and well-being for everyone, and SDG 3 puts this goal forward with the aim of "No one left behind". To "ensure healthy lives and promote well-being at all ages," SDG 3 is set forth. It encourages everyone to have access to primary healthcare that is comprehensive, equitable, and of high quality.

Poor health outcomes have been noted in PwD as a result of delayed presentation, slow economic growth, poverty, and restricted access to medical facilities. The obstacles in LMICs are employment, transportation, cost, health awareness, and education.

Some nations have taken various measures to address these problems. The Brazilian Government finances technological development and innovation program and plans to establish National Centre for Excellence in Adaptive Technology. In Egypt, NGOs are assisting in the procurement of AT.[5]

Addressing The Issues in India and Recommendation

The World Health Organization has been pushing hard to enhance the lives of individuals with disabilities worldwide in the recent past. Assuring everyone with disabilities has the best possible health, functioning, well-being, and human rights is the aim of the WHO Global Action Plan for Disabilities (WHO Global Disability Action Plan 2014-21). According to the UN Convention on the Rights of Persons with Disabilities (UNCRPD), individuals with disabilities are entitled to the highest possible standard of health without facing any kind of discrimination due to their handicap. India is a signatory to this international organization, which works to enhance the health and quality of life of individuals with disabilities. In India, the Ministry of Social Justice and Empowerment (MoSJE) and the Ministry of Health & Family Welfare (MoHFW) are the two main ministries that deal with matters of those with disabilities. The National Policy for Persons with Disabilities, the ADIP scheme, the Deendayal Disabled Rehabilitation Scheme, the District Disability Rehabilitation Centers, and other programs and schemes about the health and rehabilitation of people with disabilities are just a few of the initiatives that fall under the purview of the Ministry of Social Justice and Empowerment, which is tasked with ensuring the welfare of the marginalized Indian population, minorities, and people with disabilities.

Among the numerous statutory organizations under MoSJE are the National Institutes for Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities. The Persons with Disabilities (PWD) Act of 1995 was revised and passed by both chambers of Parliament in 2016 to bring it into compliance with the UNCRPD (United Nations Convention on the rights of person with disabilities. The Act placed a strong emphasis on the social model of disability, which includes things like equal rights for men and women, full and effective participation, respect for differences, acceptance of disabilities, and non-discrimination.

A plethora of welfare programs exist in India, but still there is a vast lacuna in terms of accessibility to health care and rehabilitative services between people with disabilities and those without. It is of paramount importance that inter-ministerial collaboration is achieved. For example, the anecdotal evidence shows that MoHFW perhaps has no involvement in rehabilitation for people with disabilities.

All persons with impairments initially come into touch with the health sector. As a result, the MoHFW should prioritize inclusive service delivery in their National Health Policy; additionally, all healthcare facilities should be made aware of the necessity for medical staff to be informed and trained. Under MoHFW, problems include inaccessible hospital facilities and equipment, unfavourable attitudes among hospital employees or their negligence, and a lack of training in effective communication with patients having speech and hearing impairments must be addressed.

According to its specific program rules, any National Health Program under MoHFW that has the potential to benefit from offering services connected to disabilities should strive to do so in an affordable, accessible, accountable, and quality-controlled manner, i.e., the Mental Health Program, and the Deafness Control Program. To strengthen inclusive service delivery in the states and hospitals, the MoSJE should assist MoHFW.

Given the rising costs of medical care, everyone with a disability should be covered by health insurance, especially those living in low- and middle-income countries like India. Including integration into the curriculum of medical education programs at the undergraduate and graduate levels will also help to improve care for those with disabilities.

To reach as many disabled persons as possible nationwide, the MoSJE should increase the current support it provides to the NGOs. Planning inclusive services will be aided by creating high-quality databases on disability, needs, impediments, and research on quality of life.

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