



# Rehabilitation through a gender lens



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**Cover image**: The mobile rehabilitation team visits a rehabilitation user in a village, in Pakistan. The visits aims to assess her ability to use a wheelchair, support her exercises to increase her arm strength, and to provide a speficic toilet chair to improve her independence.

### Key facts and observations

- 2.4 billion people<sup>1</sup> are in need of rehabilitation services worldwide.
- Changing demographics, the increase in non-communicable diseases, injuries and traumas, as well as COVID-19
  risk an escalation in numbers of people affected.
- Gender shapes access, use, adherence and outcomes of rehabilitation services.
- Globally, women are less likely to access rehabilitation, and when they do are more likely to experience poorer outcomes.
- In low- and middle-income countries, women and girls are less likely to have access to assistive technology, such as wheelchairs and glasses.
- Data and research documenting and analyzing gender minorities' exclusion in access to and utilization of rehabilitation are very scarce.
- Rehabilitation is not sufficiently integrated in health systems, and it is extremely rare to find specific efforts to ensure gender-responsive planning and service delivery.

This factsheet builds on the scoping review conducted by the Gender & Social Inclusion (GESI) Working Group of ReLAB-HS on access to rehabilitation for women, girls, men, boys, and gender minorities<sup>2</sup>, to deepen understanding, explore solutions, and reveal gaps in knowledge. The scoping review yielded 65 research articles and editorials.

Learning, Acting and Building for Rehabilitation in Health Systems Consortium (<u>ReLAB-HS</u>) is a USAIDfunded global project that seeks to co-design and implement innovative, comprehensive and costeffective interventions that strengthen health systems for provision of rehabilitation and assistive technology that are responsive to growing needs, focusing initially on Pakistan, Uganda, Ukraine, and Burma. Led by the Johns Hopkins International Injury Research Unit at the Johns Hopkins Bloomberg School of Public Health, and co-led by the Nossal Institute for Global Health, the consortium comprises of four other international partners: Humanity & Inclusion, MiracleFeet, Physiopedia, and Momentum Wheels for Humanity.

### The big unmet needs of rehabilitation are marked by significant gender inequities

While 2.4 billion people globally need rehabilitation<sup>3</sup>, in low-and-middle income countries more than 50% of people do not receive the rehabilitation services they require<sup>4</sup>. Further, only one in ten people globally have access to the assistive technology that they need<sup>5</sup>. Rehabilitation has traditionally been underdeveloped and resourced, and has not been well integrated within health systems. This is in spite of the fact that nearly everyone will need some kind of rehabilitation in their lifetime.

**For women and girls, the unmet need of rehabilitation is even greater**. According to data from the Global Burden of Disease Study (2019), women accounted for just over half of an estimated 2.4 billion individuals with conditions that would benefit from rehabilitation services, but they spent about 10% more years living with disability than men<sup>6</sup>. Available evidence describes lower participation rates, and worse rehabilitation outcomes among women and girls compared to men and boys. For example, women have lower cardiac rehabilitation access, use, and adherence than men, in addition to higher mortality rates<sup>7</sup>. Despite longstanding evidence<sup>8</sup>, it has not been adequately addressed. In addition, women bear a disproportionate burden of caregiving. "As mothers of children with disabilities, women are particularly affected by disability-associated stigma, which can sometimes make it very difficult to access rehabilitation care for their children", says Anna Cuthel, Technical Advisor at MiracleFeet.

From what very limited data is available, gender minorities' experience of accessing health care shows frequent exposure to stigma and discrimination, and for some a reluctance to participate in certain



### Experience in conflictaffected areas

In a study of 14 countries affected by conflict, researchers expected higher rates of participation in rehabilitation among men due to increased exposure to conflict-related conditions, but they found that more men than women also attended the rehabilitation centers for other reasons not related to conflict, such as stroke, cerebral palsy, and polio<sup>9</sup>.

health services mainly due to the discrimination they are facing<sup>10</sup>. For example, transgender persons with disabilities have disproportionately negative experiences with health care providers and are more likely to experience financial barriers to accessing rehabilitation<sup>11</sup>.

Gender-responsive rehabilitation is rehabilitation that meets the needs of people of all sexes and genders to overcomes inequities in access, use, adherence, and outcomes, caused by gender norms, roles and structures in the health system and wider society.

Quality of care and the dignity of the person are essential. Genderresponsive rehabilitation requires planning and delivery of services which take action on physical, communication, attitudinal and financial barriers – shaped by gender and sex – across and beyond the health system.

### Rehabilitation is crucial to health, development, and gender equality

Rehabilitation is an essential health service, alongside prevention, promotion, treatment and palliation. It encompasses diverse interventions, including the provision of assistive technology, to optimize the physical, social, and mental functioning of individuals. As such, it is a critical component for achieving Sustainable Development Goal (SDG) 3 on health and wellbeing, as well as goals on poverty (SDG 1), decent employment and economic growth (SDG 8), and education (SGD 4).

 Rehabilitation is an impactful health investment: it shortens hospital stays, reduces readmissions and secondary health problems<sup>12</sup>, thus generating economic benefits for the health system and for the households. Furthermore, the return on investment is significant: for every dollar invested in assistive devices, there is a return of nine dollars<sup>13</sup>.

- Improving the health-outcomes and functioning of a person can foster their autonomy, alleviating a need for caregiving. Because women bear a disproportionate burden of caregiving responsibilities, women especially benefit from an alleviation of caregiving needs.
- By improving functioning of women, girls, and people of all genders it increases access to education, social engagement, and work activities, greatly contributing to women's ability to participate in multiple spheres of life<sup>14</sup>.

### Gender-related barriers affect rehabilitation access, use and adherence

Limited decision-making power with regard to access and use of household's resources, social norms, as well as expectations around how much time is spent on personal activities have a significant impact on rehabilitation access, use, and adherence<sup>15</sup>. As testimony collected by Momentum Wheels for Humanity from the CoRSU Rehabilitation Hospital, in Uganda, reports: "You have to do a lot of community sensitization because social norms challenge women's access to wheelchairs". Furthermore, Graziella Lippolis, Technical Unit Manager at Humanity & Inclusion, observes: "In some contexts, girls' and women's access to services may be subject to the authorization of the father, the husband or even in some cases the eldest son. As some women are not allowed to be away from their children, or their family obligations, they often shorten the duration of care". Although there is limited evidence on differences in access for children and young people, data available indicates that boys are prioritized over girls on the

whole, and girls are less likely to participate in and complete rehabilitation. **"Delays and lack of care can have alarming consequences including causing comorbidities"**, explains Graziella.

Women are also less likely to receive informal, unpaid care provided by a person within the family or social network, when they have rehabilitation needs. This can be partially due to to care not being a socio-culturally accepted role for men, as well as to women living longer than their spouses and experiencing ill-health as they age.

Gendered barriers exist across the key dimensions of health (and rehabilitation) services: availability, accessibility, affordability and acceptability. Disability, ethnicity, race, socioeconomic status, and lower educational levels can further affect participation or compound bias in referrals and assessment, and throughout the pathway.

### Looking through a gender lens into...

Availability of rehabilitation and assistive technology Rehabilitation has not been prioritized within health, and the shortage of services is a major problem in lowand-middle income countries. There is a massive deficit in the trained rehabilitation workforce (in the African and Eastern Mediterranean Regions, there is only 10% of the rehabilitation workforce required)<sup>16</sup>, and limited facilities at all levels. There is also a lack of availability of quality assistive devices, such as hearing aids and prosthetics, for people in low-and-middle income countries.

Persisting gender bias can affect decision making over what services are offered and funded, thus limiting the availability of rehabilitation services required by women and girls, due to sex or gender-specific needs. This is compounded by the limited gender diversity in leadership positions in health and rehabilitation.

### Accessibility of rehabilitation and assistive technology

There is a tendency for services to be concentrated in urban areas. For people living in remote and rural areas, distance to services has a profound effect on access and cost, and this particularly affects women's access and pursuit of rehabilitation care. Indeed, limited access to households' financial resources, safety concerns, social norms, and family obligations can significantly hinder the possibility for women to travel away from home to attend rehabilitation care. For women with disabilities, for example with mobility limitations or neurological conditions, access can be problematic without appropriate transport, assistance, accommodations at the rehabilitation site, and equipment.

Discrimination in attitudes held by staff and wider society can affect assessment and referrals. An Iranbased study showed that physicians were less likely to refer women on the basis that they would face barriers, including attitudinal barriers, to attending services<sup>17</sup>. Regarding information accessibility, evidence shows that women often received less comprehensive inpatient education than men, and report poorer communication with providers<sup>18</sup>.

#### Affordability of rehabilitation and assistive technology

Rehabilitation and assistive technology can represent an extremely high out-of-pocket expense. Women have a higher likelihood of having a lower socioeconomic standing or of not having insurance, which can be a significant barrier in women's decision to participate in rehabilitation<sup>19</sup>. Women with disabilities are even more likely to face financial barriers, as there is evidence that poverty and disability are strongly interlinked<sup>20</sup>. The cost of services is increasingly acknowledged as a barrier, including for assistive technology's access and use<sup>21</sup>. According to the literature, the unavailability of insurance serves as a barrier to women's participation in rehabilitation in Indonesia<sup>22</sup>, in Europe and North America<sup>23</sup>, and particularly among marginalized women in high-income countries<sup>24</sup>. Conversely where rehabilitation is included in health insurance, access and use is increased<sup>25</sup>.

### Acceptability of rehabilitation and assistive technology

Services are often delivered without accounting for diverse genders' needs or requirements. For example, in some cases providers do not believe the level of pain or consider women's pain as requiring specialized pain rehabilitation<sup>26</sup>. Men may be less likely in certain contexts to seek pain rehabilitation due to gendered social expectations that men should appear strong and limit their expression of pain<sup>27</sup>. While women can have concerns around safety related to personnel or a rehabilitation site, "they may not be comfortable to request rehabilitation treatment from a woman, or have the luxury of waiting for one to be available and in some settings, none may be available", says Dr. Linda Thumba, Physical Therapist on her work in South Africa. The shortage of women personnel and the fact that many women report services or equipment that are not adapted to their needs<sup>28</sup> may feel intimidating to women and discourage attendance. Regarding assistive technology, a study reported worse functional gains among women in Sierra Leone who received lower limb prosthetic or orthotic devices<sup>29</sup>. It could be that like many other medical devices<sup>30</sup>, orthotic and prosthetic devices were developed based on male anatomy and men's gendered tasks.

## Gendered dimensions of policy frameworks on rehabilitation and assistive technology

Governments are primarily responsible for ensuring that quality rehabilitation services are available, accessible, affordable and acceptable, for everyone, without discrimination, to meet the obligations set in international human rights instruments<sup>31</sup> and to progress towards Universal Health Coverage (UHC)<sup>32</sup>. The best way to ensure that rehabilitation services reach all those who need them is by integrating rehabilitation across all levels of the health system, in particular at the primary health care level, in order to bring services closer to the community<sup>33</sup>.

The World Health Organization (WHO) is undertaking steps to support Member States in integrating rehabilitation within health systems. Since the launch, in 2017, of "Rehabilitation 2030: A Call for Action"<sup>34</sup>, the WHO has deployed resources and developed tools through which some efforts have been made to incorporate a gender dimension: for example, the Rehabilitation Menu of Indicators can be disaggregated by sex/gender; and the new Rehabilitation Competency Framework outlines that rehabilitation professionals' values include sensitivity to diversity including by sex, gender minority, and sexual orientation<sup>35</sup>. Globally, attention to assistive technology is gaining ground, with the adoption by the World Health Assembly of the Resolution on 'Improving access to assistive technology" in 2018<sup>36</sup>, and the launch of the Global Partnership for Assistive Technology (ATscale) in the same year. The Rapid Assistive Technology Assessment<sup>37</sup>, which is one of the sources informing the Global Report on Assistive Technology to be released in 2022, is designed to collect disaggregated data about population use, need, and met need (with the options male/female/ non-binary, intersex, other not specified).

Understanding gender inequities is a prerequisite to develop and implement relevant rehabilitation policies and programming that effectively respond to the needs of diverse populations. However, the conflation or 'merging of meaning' of sex and gender<sup>38</sup> across research and programming exacerbates the lack of understanding about access, use and adherence across sexes and genders. Evidence collected will need to pay more attention to the manner in which biological and sociocultural factors affect rehabilitation, in order to adequately inform policies and programming.

**Below**: Mary Josefine, a 15 year old girl living in Uganda, has paralysis because of contracting polio at the age of five. Identified by the community-based rehabilitation volunteers, Mary Josefine was provided elbow crutches that greatly improved her quality of life. The psychosocial worker played an important role in counselling the girl to cope with her disability. Identification and referral to rehabilitation care is often delayed for girls living in rural areas.



### Good practice - Increasing polio rehabilitation for girls in Pakistan

In Pakistan, the Global Polio Eradication Initiative<sup>39</sup> integrates rehabilitation as part of the response. Since 2007, the Polio Rehabilitation Initiative has supported one thousand children with polio paralysis<sup>40</sup>, in particular girls, via proper assessment and provision of medical and social rehabilitation care.

Thousands of women work in the Pakistan polio eradication program, including as rehabilitation professionals<sup>41</sup>, whose presence has helped reach out to women and girls in communities.

Through its new Strategy 2022-2026<sup>42</sup> and its Gender Equality Strategy 2019-2023<sup>43</sup>, the Global Polio Eradication Initiative commits to integrate a gender perspective into programming, increase women's meaningful participation and decision-making across all levels of the program, and utilize gender-sensitive indicators in order to ensure that girls and boys are reached equally.

## Good practice - Important steps for rehabilitation for women and girls in Ukraine

In Ukraine, there are challenges and inequities in gender relations, with women with disabilities experiencing intersectional discrimination<sup>44</sup> that further restrict their access to services. As Diana Shcherbinina, Project Support and Inclusion Officer at Momentum Wheels for Humanity, says: **"women face more financial barriers to treatment than men do, and women are more likely than men to suffer from chronic diseases, especially elderly women. Social packages for people with disabilities are inequitable as women get fewer social benefits"**.

Some important policy developments are underway to integrate a gender perspective on health and rehabilitation. The National Action Plan on Implementation of the Convention on the Rights of Persons with Disabilities (2021- 2025) states the need to provide rehabilitation services for women and girls with disabilities, in particular those victims of genderbased and sexual violence in the context of conflict. The Decree "On approval of the State Strategy for Ensuring Equal Rights and Opportunities for Women and Men until 2030"<sup>45</sup>, which is undergoing public discussion, plans to conduct a gender audit of the healthcare system; to strengthen the training of nurses, including rehabilitation nurses; and to conduct research on barriers to access to health care for vulnerable groups of girls and boys, women and men living in urban, rural, and mountainous areas.

### Recommendations for health decision-makers:

## 1. Invest in a gender-inclusive and gender-responsive rehabilitation workforce

- Significantly increase numbers of rehabilitation workforce trained and posts created, ensuring gender diversity in the workforce, including in key positions within health governance bodies and in particular for women.
- ii) Develop curricula and training incorporating genderresponsive approaches to policy-making and service delivery, ensuring that rehabilitation takes into account the specific expectations and needs of each individual and avoid stereotypical gender-biased needs and expectations.

## 2. Incorporate rehabilitation and assistive technology in UHC, with attention to gender-related barriers

- i) Incorporate rehabilitation and provision of assistive technology into insurance and other financing mechanisms to overcome impoverishing out-ofpocket payments, with specific action to reach women, girls, and people of all genders, including persons with disabilities.
- ii) Monitor coverage of women, girls, and people of all genders, including persons with disabilities.

## 3. Strengthen rehabilitation services and assistive technology within health systems

- i) Integrate rehabilitation across the health system, improving multidisciplinary coordination and patientcentered care across different levels, strengthening primary and community service delivery.
- ii) Provide alternative solutions to reduce longdistance travel to attend rehabilitation care (for example via community-based rehabilitation, mobile clinics, home-based care, or tele-rehabilitation), as women stand to particularly benefit.
- iii) Review and implement rehabilitation and assistive technology services, to ensure that they are acceptable and meet the needs of people of all genders.

### 4. Ensure meaningful participation in health and rehabilitation governance and planning

Consult people of all genders and persons with disabilities throughout all rehabilitation planning processes, accounting for diversity of barriers, intersectional factors, and spectrum of rehabilitation needs and severity.

## 5. Build demand for rehabilitation services and assistive technology

Conduct outreach campaigns and awareness-raising (in partnership with local and patients' organizations, non-governmental organizations) among family members and community leaders about the importance of rehabilitation for all persons in need, providing opportunities for people of all genders to be seen and included.

## 6. Increase collection and availability of evidence on sex and gender in rehabilitation

- i) Collect data using the WHO Rehabilitation Indicator Menu disaggregating relevant indicators by sex and gender.
- (ii) Invest in and expand research and data collection on access, experiences and outcomes in rehabilitation and assistive technology for people of all genders.

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- 32. According to the World Health Organization, universal health coverage means that all people have access to the health services they need, when and where they need them, without financial hardship.
- 33. See: Integrating rehabilitation into health systems (who.int)
- 34. World Health Organization (2017), Rehabilitation 2030: A Call for Action.
- 35. See Rehabilitation Competency Framework (who.int)
- 36. See Seventy-first World Health Assembly adopts resolution on assistive technology (who.int)
- 37. World Health Organization (2021), rapid Assistive Technology Assessment tool (rATA).
- 38. The World Health Organization regional office for Europe describes sex as characteristics that are biologically defined, whereas gender is based on socially constructed features (WHO Europe, <u>Gender Definitions</u>)
- 39. The Global Polio Eradication Initiative is a publicprivate partnership led by national governments with six partners – the World Health Organization (WHO), Rotary International, the US Centers for Disease Control and Prevention (CDC), the United Nations Children's Fund (UNICEF), Bill & Melinda Gates Foundation and Gavi, the vaccine alliance. Its goal is to eradicate polio worldwide.
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