

## CASE STUDY

# Disability and rehabilitation in Tajikistan: development of a multisectoral national programme to leave no one behind

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## ABSTRACT

**Background:** In the 21st century, the world faces a new challenge: rapid population ageing accompanied by a rise in chronic conditions and multimorbidities. People live longer and with disabling chronic conditions that impact their functioning and well-being. Rehabilitation and assistive technology are critical for preventing and minimizing functional limitations, including the health, social and economic impacts of health conditions, and for improving well-being. In the aftermath of the 2010 polio outbreak in Tajikistan, improved rehabilitative services for people affected by polio were needed. Subsequently, new approaches to rehabilitation and a reformed system for providing services and assistive devices were established for patient groups such as those with injuries, impairments or disabilities due to noncommunicable diseases. This article describes the involvement of WHO in this process and the work undertaken in Tajikistan during 2013–2017 to support the establishment of a multisectoral national programme on rehabilitation.

**Methods:** Using the 2010 polio outbreak as an entry point, WHO provided technical support to the Government of Tajikistan to identify existing challenges

in the health care system and to develop approaches to improve access to rehabilitation services for all. Activities included (i) setting up an initial system for polio rehabilitation and (ii) developing a comprehensive national rehabilitation policy, along with a multisectoral system and accompanying services. The methodology used for this case study was a desk-based review.

**Research:** In the eight years since the 2010 polio outbreak, improvements have been made in four key areas: strengthening rehabilitation services; human resource development; introducing community-based rehabilitation; and policy development.

**Conclusion:** Aided by external funding and by guidance from WHO, along with determination, and high-level political engagement and leadership, Tajikistan has established a modern rehabilitation system, including the supply of a basic package of assistive devices, within a relatively short period of time. Rehabilitation is indispensable to optimize functioning and improve well-being for people affected by a range of potentially disabling health conditions and plays a fundamental role in achieving universal health coverage.

**Keywords:** ASSISTIVE TECHNOLOGY, DISABILITY, HEALTH, REHABILITATION, UNIVERSAL HEALTH COVERAGE

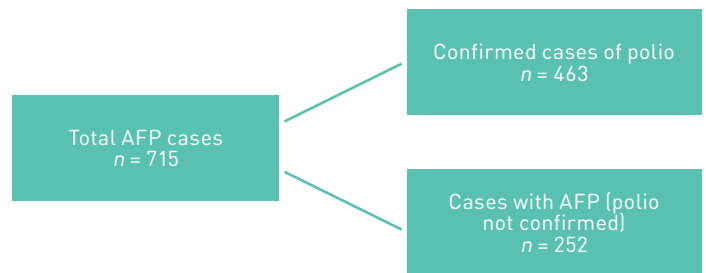
## BACKGROUND

The increasing prevalence of noncommunicable diseases (NCDs) and an ageing population are major challenges for health systems in the 21st century. It is therefore imperative that people with health conditions are supported to remain as independent as possible, participating in education, being economically productive and fulfilling meaningful life roles to lessen the

health, social and economic burdens of these epidemiological and demographic trends. Rehabilitation comprises a set of interventions designed to optimize functioning and to reduce disability in individuals with health conditions in interaction with their environments (1). Health conditions are generally disease (acute or chronic), disorder, injury or trauma, but may also include other conditions such as ageing, congenital anomaly, genetic predisposition, pregnancy or stress (1).

Tajikistan is a landlocked country in central Asia with a population of 8.5 million (see Box 1 for more information) (2). In 2010, Tajikistan experienced an outbreak of poliomyelitis (polio). Irreversible impairments due to polio require the lifelong provision of appropriate rehabilitation and assistive products. In the past, the most common contributory factors for polio outbreaks have been war, poverty, natural disasters (such as floods and earthquakes) and/or gaps in vaccination (3). The cause of the 2010 Tajik outbreak was probably transmission from migrant workers to a population that did not have adequate vaccination coverage (4). More information about polio and acute flaccid paralysis (AFP) is provided in Box 2. Most of the affected population in 2010 were children and young people: 70% were under 14 years of age and 86% were under 20 years. Approximately 28% of the children under 14 years of age had upper limb involvement. This is unusual because all polio epidemics since 1951 have reported upper limb involvement in only 6–10% of children. A detailed breakdown of the total number of AFP cases in Tajikistan in 2010 is provided in Fig. 1.

FIG. 1. BREAKDOWN OF THE TOTAL NUMBER OF AFP CASES IN TAJIKISTAN IN 2010



Source: Yakovenko et al., 2014 (4).

In 2015, a situational assessment of rehabilitation was undertaken in Tajikistan in collaboration with WHO (5). This assessment revealed that, in addition to polio patients, a significant number of children had other impairments (such as cerebral palsy or congenital anomalies) requiring rehabilitation. There were also underserved people affected by NCDs (especially stroke and diabetes) and road traffic accidents, as well as older people with reduced functioning or mobility. The leading cause of disability and death in Tajikistan is NCDs, which places significant demands on the social welfare and health systems. According to WHO, NCDs accounted for 59% of all deaths in the country in 2014 (7). Based on this data, the Ministry of Health and Social Protection (MOHSP) of Tajikistan approached WHO for technical assistance to provide an evidence-based solution (i) to address the needs of people with polio and (ii) to strengthen rehabilitation policies, systems and services for all people in need of rehabilitation.

This paper discusses the challenges that existed in the Tajik health care system, the contribution of WHO, and the subsequent development and implementation of a multisectoral national strategy for disability and rehabilitation in Tajikistan.

## CHALLENGES

In 2013, Tajikistan had no formal rehabilitation policies and only limited rehabilitation services. There was an urgent need to develop rehabilitation policies, systems and services to meet the needs of people affected by polio following the 2010 outbreak. The challenges for the rehabilitation services jointly identified by WHO and the MOHSP (in collaboration with various stakeholders) through a situational analysis (5) are discussed below. The situational analysis focused on rehabilitation policy and governance and the impact of service provision on people with health conditions, impairments and disabilities. Formation of an interministerial working group, a desk review, national

### BOX 1. TAJIKISTAN

The Republic of Tajikistan is a landlocked country in central Asia with a population of 8.5 million: 49% are women and 35% are youths (2). Tajikistan is located in the south-western part of the central Asia region, covering a territory of 142 600 km, of which more than 93% is covered by mountains. Tajikistan is divided into four administrative divisions: two provinces (viloyatho – Khatlon Region in the south and Sughd Region in the north), one autonomous province (viloyat) in the east, Gorno-Badakhshan Autonomous Region (Viloyati Mukhtori Kuhistoni Badakhshon) and the central Districts of Republican Subordination, governed directly from the capital city, Dushanbe. Each of these regions consists of smaller administrative zones, called districts (nohiyaho). Tajikistan has 58 districts, 17 cities and 57 townships (5).

### BOX 2. POLIO AND AFP

A polio outbreak includes both confirmed and unconfirmed cases of polio. In unconfirmed cases, children develop muscle paralysis that cannot specifically be labelled as polio; these children are said to have acute flaccid paralysis (AFP), defined as a “sudden onset of weakness and floppiness in any part of the body in a child under 15 years of age or paralysis in a person of any age in whom polio is suspected”(6). Several viruses other than poliovirus can cause AFP: such cases are classified as non-polio AFP. However, all cases require rehabilitation and the provision of assistive products to minimize the impact of the impairment and to maximize functioning, independence and participation in society.

workshops, field visits, interviews, a focus group discussion and a review of situational analysis findings contributed to the final report (5).

## HUMAN RESOURCES

The situational analysis found a scarcity of trained rehabilitation professionals in the country. There were no formally trained physiotherapists, occupational therapists, speech language therapists or specialists in physical medicine and rehabilitation; only two prosthetics and orthotics professionals were working in Tajikistan at that time. Tajikistan also lacked educational facilities and training programmes in these fields. In addition, other health professionals (such as doctors and nurses) had limited competencies relating to disability and rehabilitation. Within the health care system, there was limited knowledge and understanding of rehabilitation and a lack of information about the potential benefits of rehabilitation in reducing impairment and disability, improving functioning, and promoting inclusion and participation for people with disabilities. Supposed rehabilitation treatments, such as massage and electrical muscle stimulation, were provided by health professionals who had received on-the-job training in the use of these techniques.

In general, physicians and surgeons had very limited knowledge of the medical and rehabilitation needs of people affected by polio. There were only 15 orthopaedic surgeons in Tajikistan, 13 of whom worked in the capital city of Dushanbe. All of these surgeons had been trained according to outdated guidance that recommended surgery for children affected by polio should not be performed before the age of 14 years. Most surgeons had seen fewer than three children affected by polio in their professional careers prior to the 2010 polio outbreak.

## REHABILITATION SERVICE PROVISION

Most of the available rehabilitation services were located in urban areas and were particularly lacking in rural areas, where most of the population (73.6%) resides. Quality standards varied throughout the country, with inadequate monitoring of rehabilitation services. Coordination between service providers and a referral mechanism between service providers and stakeholders were limited. Funding for disability and rehabilitation activities was inadequate. Finally, the availability of assistive products (such as wheelchairs, orthoses or prostheses) for people with disabilities was limited across the country.

## OTHER CHALLENGES

In Tajikistan, 39% of the population lives below the poverty line (8). Disability and poverty reinforce and perpetuate one another: poverty increases the likelihood of impairment through malnutrition, poor health care and hazardous living conditions,

and disability can lead to lower living standards and poverty through lack of access to education, employment and earnings, and increased health care expenditures. People with disabilities also face environmental and information barriers due to stigma and prejudice. Thus, poor socioeconomic conditions of people with disabilities creates barriers to their effective and meaningful involvement in decision-making related to health and rehabilitation services.

## WHO INVOLVEMENT IN TAJIKISTAN

The polio outbreak of 2010 prompted the MOHSP to review the existing challenges faced by the Tajik health care system. The MOHSP recognized that conventional approaches to rehabilitation (inherited from the Soviet era) did not adequately address the needs of those affected by polio. In addition, families of people with polio demanded a response from the MOHSP that would better meet their needs.

Based on the recommendations of the World report on disability (9), and in line with the principles and ethos of Health 2020 (10), WHO initiated a disability and rehabilitation programme in Tajikistan to support the implementation of the WHO global disability action plan 2014–2021 (11). By initiating a programme on disability and rehabilitation, WHO and the MOHSP aimed to meet the needs of people affected by polio and their families and of people throughout Tajikistan with impairments and health conditions requiring rehabilitation services.

The disability and rehabilitation programme was implemented in two phases. In phase I (2013–2016), WHO provided technical support to the MOHSP to develop national policy, systems and services for rehabilitation. In phase II (2016–2019), currently under way, WHO provides technical support to the MOHSP to strengthen and expand rehabilitation services. The key strategic pillars of the disability and rehabilitation programme are:

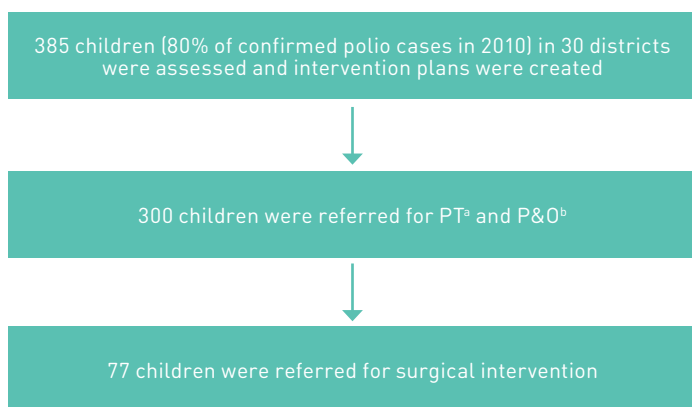
- strengthening rehabilitation services;
- human resource development;
- developing community-based rehabilitation (CBR) services; and
- policy development.

Each of these strategic pillars will be discussed in the following sections.

## STRENGTHENING REHABILITATION SERVICES

Rehabilitation camps took place in March 2014 to assess the medical and rehabilitation needs of children with polio. Details of the number of children receiving services from the camps are provided in Fig. 2. Many surgical treatments and their associated health system burdens could have been avoided if children had received timely and appropriate rehabilitation. WHO developed plans in partnership with the MOHSP to ensure that all children referred from the camps received appropriate rehabilitation (12).

**FIG. 2. NUMBER OF REFERRALS TO REHABILITATION CAMPS IN TAJIKISTAN IN 2014**



<sup>a</sup> - PT: physiotherapy;

<sup>b</sup> - P&O: prosthetics and orthotics

Source: Yakovenko et al., 2014 (4).

A second phase of rehabilitation follow-up included providing postoperative rehabilitation therapy along with advanced training for orthopaedic surgeons and training for public health professionals (primary and secondary levels) from the 30 polio-affected districts to ensure regular patient referral and follow up. In total, 138 health and rehabilitation professionals were trained (13, 14). The targeted interventions provided through the two camps addressed the rehabilitation needs of 422 children (approximately 90% of the confirmed polio cases in the 2010 outbreak).

A booklet on managing poliomyelitis (15), published in English and Tajik, was developed jointly by WHO and the MOHSP. This publication, based on the results of the rehabilitation camps, targeted rehabilitation personnel. It was used to train public health and rehabilitation professionals. WHO, in collaboration with the International Society of Prosthetics and Orthotics, provided further technical support to train medical and rehabilitation personnel, including a course on managing people with polio (16).

A situational analysis of assistive products was completed with the participation of assistive technology stakeholders: the MOHSP, international and national nongovernmental organizations, disabled people's organizations and United Nations agencies (17). Following the situational analysis, WHO worked with the MOHSP to improve the quality of assistive product procurement in the country. A key achievement of the MOHSP was the procurement of a variety of assistive products (such as wheelchairs for children and adults, white canes for blind people and hearing aids for hearing-impaired people) in 2015 and 2016 compared with the purchase of standard wheelchairs in previous years. To strengthen wheelchair service provision, a wheelchair service training course was organized in December 2015 to develop the basic skills and knowledge required by personnel involved in wheelchair service delivery (18). To further strengthen the assistive technology sector in Tajikistan, WHO is providing support to the MOHSP to develop a national priority assistive products list in line with the WHO Priority assistive products list (19), which will be used to guide future product development and production, service delivery, market shaping, procurement and reimbursement.

WHO also supported the MOHSP to strengthen rehabilitation services for people with other health conditions that require rehabilitation. For example, information, education, and communication materials on rehabilitation were developed for medical doctors and rehabilitation staff, and training was provided on their use with the aim of providing client-focused rehabilitation services (20). In addition, different capacity-building activities were conducted (described in the sections on human resource development and CBR) to strengthen rehabilitation services for people with different health conditions.

## HUMAN RESOURCE DEVELOPMENT

Institutional capacity-building activities for MOHSP rehabilitation centres were conducted in 2013 and 2014. International experts on physiotherapy and occupational therapy provided on-the-job training for rehabilitation centre staff. Physiotherapists and occupational therapists were also able to attend national capacity-building workshops (21). These initiatives led to the establishment of occupational therapy units within the national rehabilitation centres for the first time (22).

To build long-term rehabilitation capacity, six local staff members are being supported to attend formal long-term training programmes outside the country. All six staff are obliged to return to Tajikistan in early 2019 to support the MOHSP in providing rehabilitation services throughout the country. The staff members include physiotherapists, occupational therapists and therapy assistants. In addition, two doctors have been

trained in physical medicine and rehabilitation and are currently supporting the MOHSP rehabilitation centres to provide quality rehabilitation services to children and adults with disabilities.

Prior to 2014, the existing disability assessment and determination process in Tajikistan did not comply fully with international standards, creating a significant barrier for people with disabilities to access services, benefits and entitlements. WHO, in collaboration with the Government of Tajikistan, conducted a two-day workshop in May 2016 to strengthen disability assessment within the framework of the International Classification of Functioning, Disability and Health (23). From 2017 onwards, WHO will work closely with the MOHSP to strengthen disability assessment and determination in Tajikistan.

## COMMUNITY-BASED REHABILITATION

Prior to 2013, rehabilitation services were inadequate for meeting the needs of the population in Tajikistan (5). The centralized system, with most facilities located in major urban centres, was a barrier to accessing services for the 73.6% of the population living in remote rural communities without means for travel. This triggered the development of CBR, which promotes decentralization of services and contributes to community-based inclusive development. Several different activities have been implemented to strengthen CBR in Tajikistan. The first national conference on CBR, Reaching the unreached in Tajikistan, was organized in December 2014. The WHO CBR guidelines, published in Tajik and Russian, were launched at the conference (24), which comprised nearly 400 representatives from different sectors across the country, making it the largest disability-focused conference conducted in Tajikistan. The outcomes of the conference included establishing guiding principles for implementing CBR and laid the foundation for the initiation of government-managed CBR programmes in Tajikistan.

WHO played a key role in institutionalizing CBR in government policy. WHO supported the development of a Tajikistan CBR network and advocated for the adoption of a CBR approach by the National Coordination Council on Health and Social Protection (an interministerial working group headed by the Deputy Prime Minister). In addition, joint MOHSP–civil society CBR programmes have been established through public–private partnership mechanisms. Over the past three years, CBR programmes have been established in 35 of Tajikistan’s 66 districts, benefiting 6290 persons with disabilities in rural areas. Standards to strengthen CBR implementation, monitoring and evaluation in Tajikistan are under development.

## Policy development: a national programme on rehabilitation of persons with disabilities

WHO supported the MOHSP to develop a position paper on Better health for persons with disabilities for an inclusive society in Tajikistan (25), which was launched on the International Day of Persons with Disabilities in 2013 (26). The position paper assists staff in the health sector to understand their roles and responsibilities in working with persons with disabilities.

In 2015, the Government of Tajikistan created an interministerial working group to draft a four-year (2017–2020) national rehabilitation programme for persons with disabilities, with technical support from WHO. This followed an extensive consultation process with 23 government ministries, state agencies and committees, as well as disabled people’s organizations, the coalition of Parents’ Associations of Children with Disabilities, international and national nongovernmental organizations, United Nations agencies and donor organizations. Approximately 110 different organizations within the country were consulted in preparing the national programme, which was followed by an approval process in the Parliament and the President’s Executive Office. Eventually, the multisectoral National Programme on Rehabilitation of Persons with Disabilities (2017–2020), which is aligned with the United Nations Convention on the Rights of Persons with Disabilities (27), was adopted on 28 October 2016 (Resolution no. 455)<sup>1</sup> by the President of the Republic of Tajikistan.

The National Programme is the first normative document on disability since the country gained independence in 1991. It addresses the rights of persons with disabilities in the spheres of health, rehabilitation, education, livelihood, social protection, culture, accessibility and justice. The National Programme focuses on all people with long-term impairments (physical, sensorial and intellectual), mental health conditions or difficulties in functioning due to NCDs, postoperative impairment, infectious disease, injuries or frailty in old age. The National Programme provides a long-term vision and roadmap to support the rights of persons with disabilities, provide access to quality rehabilitation services and support universal health coverage (UHC) in Tajikistan until 2020.

<sup>1</sup> Available on the Government of Tajikistan Ministry of Health website in Russian and Tajik ([http://moh.tj/wp-content/uploads/2017/07/Tajikistan-National-Program-on-Rehabilitation\\_TAJ-RUS\\_FV\\_WEB.pdf](http://moh.tj/wp-content/uploads/2017/07/Tajikistan-National-Program-on-Rehabilitation_TAJ-RUS_FV_WEB.pdf)).



## DISCUSSION

Globally, there is increasing recognition of the need for adequate rehabilitation services and assistive products, not only in response to the sporadic outbreaks of infectious disease that cause long-term disability (see Box 3), but also for NCD-related and other chronic impairments. However, planning for the required number of rehabilitation professionals cannot focus on individual countries in isolation. Rehabilitation professionals are in very short supply globally (28, 29) and, therefore, active poaching by other countries is a real threat.

### BOX 3. UNANSWERED QUESTIONS

While the incidence of polio has decreased worldwide, the incidence of AFP has markedly increased. At the same time that India was declared polio-free, a total of 59 436 AFP cases were reported in 2012, 53 421 in 2013 and 53 383 in 2014 (30). A new cluster of children, predominantly in the United States of America (173 as of February 2017), have been classified with acute flaccid myelitis (31). The etiology of this syndrome has not yet been determined, although this paralysis may be caused by a polio-like enterovirus. Children with acute flaccid myelitis also require rehabilitation services and assistive products.

In many countries, rehabilitation professionals need better formal training, regulation and recognition. Opportunities to gain experience and to provide and receive mentoring are also required in order to enlarge the cohort of available professionals. Adequate working conditions (including compensation) are important for retaining trained professionals. This is particularly applicable to Tajikistan, where a long-term solution is needed to address the lack of rehabilitation professionals.

Tajikistan has a single ministry encompassing health and social protection which integrates the various issues related to disability. Thus, Tajikistan has the opportunity to demonstrate leadership by coordinating a multisectoral, multidisciplinary response to the need for disability rehabilitation. A key lesson learned from the experience of implementing policy in Tajikistan is that the health and the social sectors required different starting points for the policy dialogue on integrating and strengthening rehabilitation and assistive technology: the health sector required a focus on rehabilitation and assistive products as a part of UHC, while the social sector required a focus on providing specific services for people with disabilities. Given that rehabilitation professionals can contribute to the inclusion and participation of persons with disabilities in society as a whole, rehabilitation services in both sectors are essential for developing a multisectoral governance structure (32).

Rehabilitation and assistive products are essential for meeting the needs of people with different health conditions across the life-course and across all levels of health care. The provision of rehabilitation services and assistive products represents an investment in human capital that contributes to health, economic and social development. Improving the integration of rehabilitation and assistive products in the health system and strengthening intersectoral links can help to effectively and efficiently meet the health needs of the population. It also contributes to achieving Sustainable Development Goal 3 (Ensure healthy lives and promote well-being for all at all ages) (33) and other goals of the 2030 Agenda for Sustainable Development to ensure that no one is left behind. Making UHC accessible to persons with disabilities helps to build a system that is accessible to all vulnerable people, including those living in extreme poverty.

In Tajikistan, work on the National Programme began with service provision to address an immediate need for rehabilitation for people affected by polio, and then moved towards a broader focus on strengthening rehabilitation services and developing a national policy and framework. In low-resource settings, it is important to initially address the service delivery needs in order to engage with the national or local government, as appropriate.

The considerable technical support provided by WHO for polio rehabilitation in Tajikistan enabled service providers to recognize gaps in current practices and to use the guidance provided by international standards of rehabilitation. Rehabilitation services have contributed to the independent functioning and mobility of people with polio, resulting in their increased participation at school and at work (34). These achievements enabled the MOHSP leadership to appreciate the added value of rehabilitation and helped Tajikistan to build a national rehabilitation policy, system and services in line with international standards. By adopting a specific health strategy (that is, rehabilitation) as the entry point – which involves addressing disability issues through national leadership, making the country's needs a top priority and collaborating with diverse stakeholders – WHO was able to influence and strengthen the health system of Tajikistan and work towards achieving UHC for the population. The authors hope that the achievements in Tajikistan can assist other countries in all WHO regions in scaling up rehabilitation services and assistive technology.

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**Disclaimer:** The authors alone are responsible for the views expressed in this publication and they do not necessarily represent the decisions or policies of the World Health Organization.

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