



Situational Analysis on Wheelchair and Mobility devices in Tajikistan

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Executive summary

In developing a vision and strategy for wheelchair and assistive device provision in Tajikistan, it is encouraging that three key influences are in place: engagement of a range of stakeholders has been initiated; government funding is allocated to the procurement of products; and support for this situational analysis as part of the World Health Organization (WHO) national disability rehabilitation programme for Tajikistan. Each has a positive impact on the development of a framework for wheelchair and assistive device provision. Further essential elements are integral to the implementation of any wheelchair provision strategy and will be explored in more depth in this report.

The current model of wheelchair and assistive device services in Tajikistan is inadequate, being one of 'distribution' rather than 'service provision'. There is also a lack of awareness of this service and the current systems limit accessibility. The WHO eight step process to wheelchair provision is a logical and practicable approach that can ease the process of shifting to a more service focused model. This process is broken down in more detail in the body of this report.

The range and quality of appropriate products currently available do not meet recommendations set out in the WHO guidelines on the provision of Manual Wheelchairs in less resourced settings. Although there is one workshop providing local production, more investment would be required to improve the quality and quantity of products manufactured. To help meet the need for wheelchairs the focus should be on improving the quality of imported wheelchairs and utilising the skills and experience of staff to assemble and modify the products. This will still maintain employment within the community and improves both the quality of products and service provided. It is possible that local production, particularly of assistive devices, could work in parallel with this change.

The training and retention of staff is a key component of any strategy. Recommendations identify that key technical staff at Dilshod and clinical staffs at Psychological Medical Pedagogical Consultation Centre (PMPC), National Rehabilitation Centre and / or National Orthopaedic centre have skills and experience that would be suitable for training through the WHO

Wheelchair Service Training Package. The involvement of DPOs and parents' associations is also highlighted as an asset, either as core service personnel or to facilitate referral, user training, follow up maintenance and repair within the community.

With the government already providing funds for products, a key recommendation would be to increase the government funding available. This would improve the quantity of beneficiaries reached, the quality of service provided and the quality of products procured in line with the WHO guidelines.

Government funds will also help address the long term sustainability of service provision. Key recommendations are set out within each section of the report, alongside a proposed framework for development of services in the early phase.

Abbreviations

AAR Japan	Association for Aid and Relief, Japan
CBR	Community Based Rehabilitation
CWD	Children with Disabilities
DPO	Disabled People's Organisation
HI	Handicap International
EU	European Union
ICRC	International Committee of the Red Cross
MoH	Ministry of Health
MoHSP	Ministry of Health and Social Protection
MSPP	Ministry of Labour and Social Protection of the Population
NGO	Non-governmental Organisations
NOC	National Orthopaedic Centre
OpM	Operation Mercy
PCT	Parent Carer Training
PGT	Peer Group Training
P&O	Prosthetics and Orthotics
PWD	People with disabilities
PMPC	Psychological Medical Pedagogical Consultation Centre
RFT	Referral and Follow up Training
SASPEM	State Agency on Social Protection, Employment and Migration
TMAC	Tajikistan Mine Action Centre
UNCRPD	Convention on the Rights of Persons with Disabilities
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VTEK	Medical Labour Expertise Commission
WHO	World Health Organization
WSTP	Wheelchair Service Training Package

Introduction

The situational assessment was coordinated by Operation Mercy with financial support from the Disability and Rehabilitation program of World Health Organization, Tajikistan. This report is extracted from the original report submitted from Motivation Charitable Trust in April 2014.

A representative from Motivation Charitable Trust was invited by Operation Mercy to undertake a situational analysis of mobility device provision in Tajikistan. This review will also contribute to the improvement of quality rehabilitation services in Tajikistan being undertaken by the World Health Organization (WHO).

The overall objective was to research and expand the current knowledge of the situation of people depending on mobility devices, especially wheelchairs, in Tajikistan; and to determine a best possible solution for a user-friendly and comprehensive service delivery of such devices, in line with the WHO Guidelines on the provision of manual wheelchairs in less resources settings¹

Specific objectives were to carry out a contextual analysis to:

1. Understand the context of current wheelchair and mobility device provision in Tajikistan and determine the appropriate project partners
2. Review locally available wheelchairs and mobility devices to determine their level of appropriateness or inappropriateness
3. Review the current knowledge of medical and social professionals involved in the identification and prescription of mobility devices
4. Form a framework for provision of wheelchairs and mobility devices.

Methodology

A working group of key stakeholders had been established under the leadership of Operation Mercy in November 2013 and conducted the first national round table on the topic of mobility devices and wheelchair service provision. During this round table the working group agreed to invite Motivation Charitable Trust for an in-depth situation analysis. The working group gathered information on

¹ <http://www.who.int/disabilities/publications/technology/wheelchairguidelines/en/>

the stakeholders and lined up the scheduled meetings. A group of two to three expert participants agreed to accompany the external expert and support in conduction of the situational analysis.

Over a period of five days the researcher met with and interviewed a range of relevant stakeholders. This was important in order to gather a broad perspective and knowledge of wheelchair service provision in Tajikistan. The stakeholders included: people with disabilities (PWDs), including children with disabilities (CWDs), their families and carers; Disabled People's Organisations (DPOs), and parents associations; the government Ministry of Health and Social Protection (MoHSP), the National Workshop for Prosthetics & Orthotics, and VTEK as the institutions who prescribe, and by law provide free mobility devices; two government run Psychological, Medical, Pedagogical Consultation (PMPC) Centres; a local workshop producing wheelchairs and a pharmacy supplying imported wheelchairs; WHO and European Union (EU) representatives; International NGO's who are involved in disability and rehabilitation issues: Handicap International (HI), Association for Aid and Relief, Japan (AAR Japan) and International Committee of the Red Cross (ICRC). Other relevant stakeholders who attended the second round table meeting, where preliminary findings of the situation analysis were presented for feedback, further input and recommendations from the stakeholders, are listed in Appendix 1.

In this report, findings of the situational assessment are compiled and recommendations for future steps for service provision in the areas of mobility devices and especially wheelchairs for Tajikistan are presented.

Background

The WHO estimate that one per cent of a country's population will be in need of a wheelchair, or ten per cent of a disabled population. In Tajikistan, which has a population of approximately 8,000,000 this would suggest an estimate of 80,000 people. In 2012 the Ministry of Labour and Social Protection of Population (MSPP) reported 166,593 PWDs, including CWDs; using the WHO approximation of ten per cent, this figure would indicate that 16,659 people were in need of a wheelchair. There is a significant discrepancy in these figures, and this highlights from the outset that accurate, comprehensive statistics of potential mobility device users are not yet available. These figures

are derived from information gathered through the disability pension system on those who are registered to receive benefits. It can be assumed that the actual number is much higher, with further PWDs unaware or unable to access this welfare system.

A key turning point in both the methodology and access to services for people with disabilities, predominately children, was the polio outbreak in 2010. This initiated a growth in the development of Community Based Rehabilitation (CBR). UNICEF, in partnership with the MoH, OpM and HI initiated a CBR Project establishing CBR support rooms; others were implemented with support from Caritas and the EU. Whilst some of the CBR support rooms established in 2011 worked with health clinics and social services, those working in cooperation with DPOs and parent's associations seem to be more sustainable at this point, it is too early for a long term assessment. The nine PMPC centres were assigned a gate-keeping function to identify alternative means to institutional care and referral to and from educational and rehabilitation services, some of the PMPCs also provide speech and other therapy in-house. The provision of assistive devices is a key component of the CBR matrix², included within the health component; however for those with mobility disabilities it is integral to all five components; health, education, livelihood, social and empowerment.

Mobility is the first step to inclusion; when a person receives an appropriate wheelchair through a service, opportunities for social life, work and education open up³.

In September 2013, WHO launched their 'national disability rehabilitation programme' with the MOHSP, funded by USAID. The aim is to scale up CBR, including human resource development, community-based services, improvement of rehabilitation and mobility device services and the development of a national policy.

Recommendations

- Due to the mentioned discrepancy between national statistics and

² http://www.who.int/disabilities/cbr/cbr_matrix_11.10.pdf?ua=

³ http://www.who.int/disabilities/publications/technology/jpp_final.pdf

international benchmarks a more comprehensive and accurate statistical assessment of the population of PWD and CWD is needed; a sub-component of this assessment should be to determine the need for assistive devices.

- This data should be collected with input from a wider range of stakeholders.

Policy and Planning

The Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted by the United National General Assembly on 13 December 2006. Articles 4, 20 and 26 of the Convention affirm that State Parties shall take effective measures to ensure personal mobility and rehabilitation by facilitating access to good quality mobility aids, devices and assistive technologies at an affordable cost and to encourage entities that produce mobility aids, devices and assistive technologies⁴.

Tajikistan has not yet signed the CRPD, however in August 2013 the Tajikistan Mine Action Centre (TMAC) supported MLSP to develop a State Programme on Promotion of the Rights of PWDs 2014-2015. The objectives of the two year programme are 1) ratification of the CRPD, 2) reduction of discrimination against PWDs, and 3) increase of opportunities and access to services and the physical environment. At the end of 2013 key structural changes were made in the government of the Republic of Tajikistan as social protection was moved from the former Ministry of Labour and Social Protection to the newly created Ministry of Health and Social Protection. While currently many structures are less clear, the long term benefit of having all issues related to PWDs handled by one ministry will be clear. The current discussion around the structure and services of the newly created Ministry is a window of opportunity for input from the international and local stakeholders.

Two key documents support implementation of the UNCRPD (specifically Articles 4, 20 and 26). The Guidelines on the provision of Manual Wheelchairs in less resourced settings set out a framework for wheelchair provision. The guidelines focus on manual wheelchairs and the needs of long term wheelchair users. The recommendations are targeted at those involved in wheelchair

⁴ <http://www.un.org/disabilities/default.asp?id=150>

services, ranging from design, and planning, to providing or supplying wheelchairs and their maintenance. The WHO joint position paper on the provision of mobility devices in less-resourced settings also aims to guide and support countries, especially those with limited resources, in the implementation of relevant articles of the CRPD.

Operation Mercy coordinated a first round table meeting to discuss assistive device provision on 27th November 2013. A copy of the WHO Guidelines in Russian and English were provided to all fourteen stakeholders who represented government ministries and departments, NGOs, a local manufacturer, and DPOs. There was opportunity to raise awareness of the eight step wheelchair service provision model. Communication between stakeholders at this stage is a positive step forwards in developing a vision and strategy for change in the provision of assistive devices.

Recommendations: policy and planning

- Achieve the objective to ratify the UNCRPD by end 2015.
- Use the WHO Guidelines on the provision of Manual Wheelchairs in less resourced settings and joint position paper on the provision of mobility devices to aid implementation.
- Formation of a taskforce group to lobby the TMAC to implement the three objectives of their proposed state programme on the rights of PWDs.

Service delivery

Current situation of wheelchair provision in Tajikistan

In Tajikistan there is currently one model for distribution of a government funded wheelchair. A referral from a polyclinic or PMPC is made to VTEK on their local level, and if appropriate a prescription will be written. This prescription does not fulfil the recommendations of the WHO Guidelines, and is in reality a referral which then places the individual on to a waiting list. This information on the need for wheelchairs is collected at the rayon (local district) level by regional branches of State Agency on Social Protection, Employment and Migration (SASPEM) and consolidated by the MoHSP for

centralised procurement by the National Orthopaedic Workshop. Once procured the wheelchairs are distributed by SASPEM according to the waiting list of recipients. The diagram below illustrates this process.

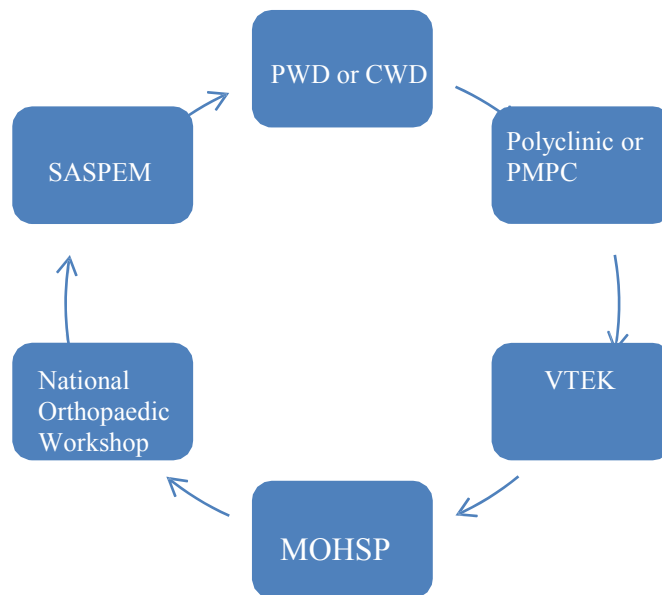


DIAGRAM 1: PROCESS FOR GOVERNMENT WHEELCHAIR DISTRIBUTION

There appeared to be no system for the provision of other assistive devices, with the exception of those referred for the P&O service at the National Orthopaedic workshop.

The two other methods, by which wheelchairs are currently distributed, are through donation or private purchase. Donor funded wheelchairs are distributed to recipients through NGOs. Alternatively referral is made by NGOs, such as Handicap International and AAR Japan, to the Dilshod workshop in Vakhsh, the only local production workshop in the country. These chairs are donor funded, but people with disabilities can also buy from the workshop privately. The pharmacy, “Medical equipment”, in Dushanbe and another in Khujand were visited by the researcher. Both pharmacies sell wheelchairs and assistive devices; but few suppliers are available nationally.

Recommendations for service provision based on the WHO guidelines

The diagram below demonstrates the eight steps typically involved in wheelchair service delivery, as defined by WHO. Each step will be considered in the context of Tajikistan, followed by recommendations on models that should be considered during different stages of the development of a more comprehensive wheelchair service provision.

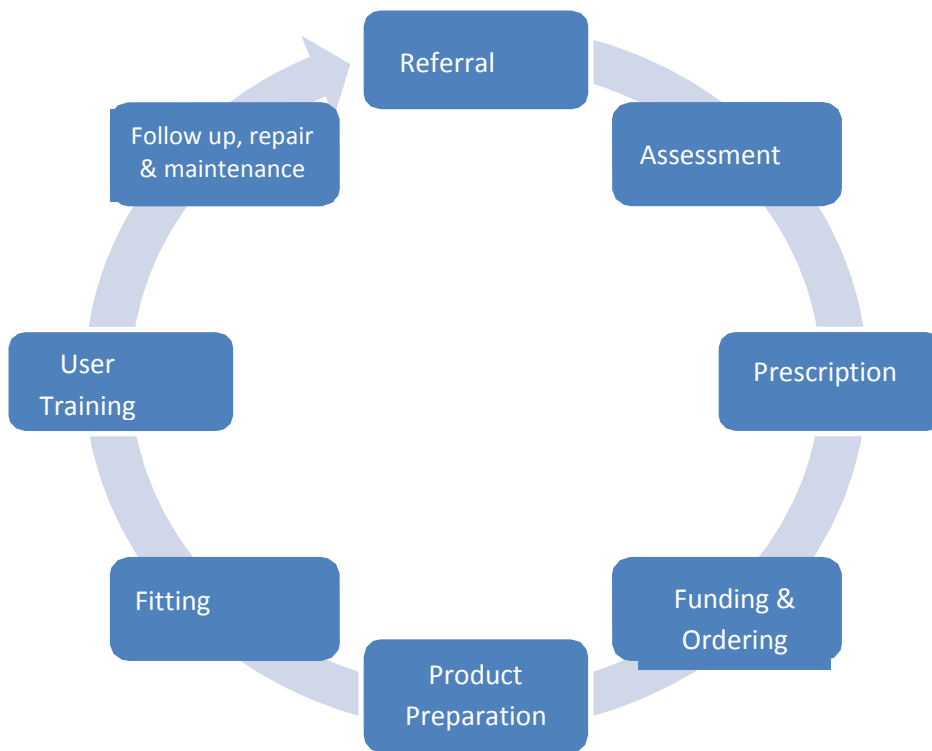


DIAGRAM 2: THE EIGHT STEPS INVOLVED IN WHEELCHAIR SERVICE DELIVERY

1. REFERRAL

The objective of good practice in referrals and appointments is to ensure that users have equitable access to wheelchair service delivery, to increase the efficiency and productivity of the service and to minimise waiting lists. (WHO Guidelines, P. 77, section 3.3.2.)

Referral (defined as prescription within this context), for a government funded wheelchair, is currently made through only one department, VTEK. Those involved at government level, within the National Orthopaedic workshop, PMPC's and DPO representatives were aware of this system though many reported that this was a challenging procedure which worked in parallel with application for a disability card and pension. The reported barriers to application were; a lack of understanding of the official process and cutting it short through means described below geographical issues for those in remote communities in accessing their referral and appointment at VTEK even on district or regional level; a lack of confidence in the transparency of the application process and a lack of awareness by individuals that this was available. These concerns were confirmed when talking to parent association representatives, wheelchair users and their families who had no understanding of how to apply for a government funded wheelchair. Information from interviews indicated that PWD and their families had been contacted to receive a donated wheelchair, had contacts in the community who had sourced a wheelchair on their behalf, or had received products from relatives in Russia. No persons interviewed reported that they knew how to acquire a government funded wheelchair. There was no apparent system of referral for alternative assistive devices unless provided by the National Orthopaedic Workshop. All users interviewed had received these through donation, privately from a pharmacy or from relatives in Russia.

Information from interviews and feedback during the round table discussions supported the need to expand the range of referral sources and utilise the networks they encompass. It should include individuals who have an early connection with PWD, CWD and their families; medical staff, nurses, social workers and teachers; religious and community leaders; NGOs, with a specific example being the Tajikistan Red Crescent Society; and DPOs.

Improving referral sources is the first step to improving access to wheelchair service delivery, but within the current systems for government provision this only leads to VTEK, another referral source. Although referral to VTEK is an essential step in accessing a disability card, it would be recommended in the long-term that this worked in parallel with the availability of direct referral to a wheelchair service. Referral through VTEK leads to a waiting list and the process illustrated in diagram 1 above. There are also no clear criteria for prioritisation of the waiting list. WHO recommend that clear guidelines are used (see WHO guidelines, p 79 box 3.4).

Recommendations: referral

- Expand referral sources to wheelchair services when they become established.
- Allow referral to work in parallel but independent from referral to VTEK for other disability benefits.
- Use WHO guidelines to define criteria for prioritisation of waiting list. This could also be used in early phase for MOHSP waiting list and in pilot service provision sites.
- Referral and Follow up Training (RFT); this equips personnel and volunteers with the knowledge and skills to fulfil a referral and community support role for children and adults who need or have a wheelchair or supportive seat. This also helps to increase community awareness and facilitates inclusion. This training may initially be beneficial for staff working in community based rehabilitation programmes or community health clinics.
- Parent Carer Training (PCT); this is designed to give people the skills to establish and run a parent /carer group, or support those already running groups of their own. It is relevant to the majority of children seen at an intermediate level seating service therefore a large part of the programme is focused on parents and carers of children with cerebral palsy (CP).

2. ASSESSMENT

The objective of good assessment practice is to accurately assess the needs of each individual user in order to prescribe the most appropriate wheelchair available. Every user requires an individual assessment carried out by a person or persons with appropriate skills. The assessment should be holistic,

taking into account the lifestyle, living environment and physical condition of the user. It is important that the user and, if appropriate the family, are fully involved in the assessment. (WHO Guidelines, P. 80, section 3.3.3.)

Assessment is carried out by a number of services; the three rehabilitation units in Chorborg, Macheton and Khujand, PMPC centres where available, VTEK, and the polyclinics. However these are not comprehensive and do not address the assessment of needs specific to the prescription of a wheelchair. Dilshod and Handicap International provided their assessment forms, attached in Appendix 2 and 3. These can be seen to address in more detail the physical component of an assessment required for wheelchair prescription; a step further towards including components of assessment advised by the WHO.

Assessment is predominately undertaken by those qualified in the medical or nursing professions, and there is currently no training available in country for physiotherapy, occupational therapy or P&O. However the experience of staff working alongside PWD and CWD in PMPC, rehabilitation units, the P&O workshop, day care centres or the local production workshop will provide valuable experience on which to build more specific skills in the assessment of potential users. The WHO has developed the Wheelchair Service Training Packages (WSTP) which are designed to train personnel or volunteers to provide properly fitted wheelchairs. This training is designed to be accessible, with no prior qualifications required. More details of these training packages will be discussed.

Recommendations: assessment

- WSTP training for staff involved in wheelchair service provision.

3. PRESCRIPTION

The objective of good prescription practice is to match the need of the user, as identified through the assessment, with the most suitable wheelchair. Wheelchairs need to be available in different types and sizes with different options. The prescription or selection represents the process of matching the needs of the user with the most suitable available wheelchair. The completed prescription form is a full description of the wheelchair required and selected by the individual user. (WHO Guidelines, P. 81, section 3.3.4.)

Prescription (the same terminology used by VTEK for referral) is a step that defines the exact requirements in terms of size, modifications, cushion, and choice in order to match the chair to the user's needs. Prescription does not occur for wheelchairs provided through government distribution. At the Dilshod Workshop, through bespoke local production, the size of the user is taken into account and where possible features are included, chosen by the user. However two key recommendations from the guidelines were not in place; cushions were not standard issue and modifications for more complex postural support were limited.

Products available will be considered in more detail later in the report, but overall there was an inadequate range of types and sizes with few options available.

Recommendations: Prescription

- WSTP training for staff involved in wheelchair service provision.
- Revision of products available in country in accordance with the WHO Guidelines.

4. FUNDING AND ORDERING

The objective of good practice in funding and ordering is to order or procure the selected wheelchair for the users as early as possible. (WHO guidelines, P. 82, section 3.3.5.)

The Ministry of Health and Social Protection is responsible for the purchase of wheelchairs and assistive devices, and these are covered by a specific annual purchase plan. A tender is announced on an annual basis and to date wheelchairs have been purchased from Russia and China; the cost of chairs ranges from \$150 - \$300 each. It was reported that import taxes were waived for delivery of these products. Government funding for the provision of wheelchairs covers only the cost of the products, and currently does not take into account additional funding required to manage facilities, service provision or training that are part of the planning of wheelchair service delivery. The table below summarises known data of government funded wheelchairs, and those distributed within the Khujand region.

	EU data for the country	VTEK data, Khujand
2013	-	248
2012	774 (including 56 wheelchairs for children for the first time)	225
2011	723	212
2010	700	246
2009	-	138
2008	-	114
2007	-	89

It is positive that government funding is in place for the procurement of wheelchairs. Ministry officials also spoke of a system of reimbursement that was available for those who bought their own wheelchairs privately; emphasising that these should be free to the user. However, the amount of financial reimbursement available was not clear, and it did not appear that this system had ever been used. The length of wait is reported to be on average two years, with a significant level of discrepancy noted. Recipients then have to wait a minimum of three to five years as an adult and a minimum of two years as a child before being able to apply for a replacement. This is not an unusual criteria within service provision, however if wheelchairs are to last until a replacement is required, they need to be sufficiently durable, spare parts need to be available, and a follow up, maintenance and repair service is essential.

In developing a new strategy for wheelchair and assistive device provision in Tajikistan, recommendations would be to look at increasing the government funding available; to increase the quantity of beneficiaries reached, gain an understanding of different models that include quality of service provided through an eight step model, quality of products procured, and sustainability through provision of spare parts, follow up, repair and maintenance.

Wheelchairs from the Dilshod workshop retail for an average of \$200. A few years ago the government ordered a number of products, however this has not been repeated. The government stated that they were looking for a company that could fulfil larger numbers within the tender process, 500 units or more, and they also had not received data on recipients who had received wheelchairs from Dilshod through other donors in order to match with their central waiting list. Assessment of the workshop will be considered in more detail on later in the report; but it was noted that there was considerable support from a range of stakeholders for their work. Orders are currently

generated by Handicap International, AAR Japan, and individuals, but without regular more substantial contracts this workshop will not be sustainable. Donations of wheelchairs are intermittently received by INGO's and this amounts to approximately 100 chairs per year.

Most recently Operation Mercy distributed a delivery of 100 ROC wheelchairs (<http://rocwheels.org/roc-chair/>). Operation Mercy started communicating with Motivation to discuss initiation of a project that would propose to import a container of flat pack wheelchair models and assemble them in Tajikistan. Motivation's range includes manual wheelchairs, propelled tricycles and supportive seating. All products are adjustable so that they can be fitted to meet each individual's needs. They are designed to be robust so that they can cope with the potholes and rough terrain, and they are sustainable, providing spare parts or using locally available materials for repair (<http://www.motivation.org.uk/our-products/>).

Recommendations: funding and ordering

- Raise government's awareness on appropriate wheelchairs and the benefits of investing in good quality and durable products.
- Encourage the government to improve their wheelchair tender process and have an open tender process so other wheelchair suppliers can submit a tender bid.
- Government to increase the funding budget for the provision of assistive devices
- Government to order and maintain a stock so there is a constant supply, rather than ordering to a waiting list.
- Government to ensure duty and import taxes associated with assistive devices are waived.
- In the longer term the government should extend funding to accommodate not only products, but spare parts and service provision including follow up, maintenance and repair.

5. PRODUCT PREPARATION

The objective of good practice in product preparation is to prepare the wheelchair for the fitting, including modifications or custom postural support components. (WHO Guidelines, P. 82, section 3.3.6)

The model of government service provision here in Tajikistan is one of distribution; products are not prepared, or modified to the specifications of a prescription which fits the individual needs of a user. At Dilshod, products are manufactured and prepared bespoke for each user, but few postural support components were observed for more complex users and the wheelchair did not match all the requirements to make it WHO compliant. Focusing more on local assembly and modifications over local production can help ensure quality and will introduce good standards of production.

Recommendations: product preparation

- WSTP training for those involved in wheelchair service provision.
- Product Familiarisation Training; a course designed to teach the skills needed to assemble, adjust and modify products.

6. FITTING

The objective of good practice in fitting is to ensure the selected wheelchair has been correctly assembled to make final adjustments to ensure the best fit. Fitting is a crucial step. At fitting, the user and clinical and technical personnel ensure that the wheelchair fits correctly and supports the user as intended. (WHO guidelines, P.83, section 3.3.7.)

Government funded chairs are distributed without fitting. The picture demonstrates one of many observed cases where the wheelchair was inappropriate for the user. Key problems would be poor management of spasticity and progression of deformities and contractures; the risk of pressure sores due to an inadequate cushion; and the inability to efficiently self-propel or utilise upper extremity function. At the Dilshod workshop the wheelchairs and mobility devices are fitted, but further training would be beneficial for more complex cases.



Example of an inappropriate chair

Recommendations: fitting

- WSTP training for those involved in wheelchair service provision.
- Access to a range of appropriate wheelchairs and sizes.

7. TRAINING OF USERS, FAMILIES AND CAREGIVERS

The objective of good practice in training is to ensure that all users are given information and training they need to be able to use their wheelchair safely and effectively (WHO guidelines, P.84, section 3.3.8).

No reports of user training were gathered. The WSTP user training checklist covers the skills the user needs as a priority. The majority of users met had inappropriate wheelchairs, which would have a significant effect on their ability to effectively use their wheelchair. However one user with a spinal cord injury had been prescribed a wheelchair in Russia, and this was an appropriate size and model for her as an active user. During the interview it became clear that despite her seven years as a wheelchair user, she remained anxious that her chair may tip backwards, and this made her reluctant to move around without an assistant. Wheelchair skills training would be the first step to giving confidence for her to move over rough ground and in and out of her wheelchair.

Peer to peer training run by wheelchair users for wheelchair users is an effective and empowering way to teach mobility skills, as well as provide other important health and life skills.

Recommendations: training of users, families and caregivers

- Trainers should be developed at the community level involving DPOs and parent's associations.
- Delivery of user training by those who attend the WSTP training.
- Delivery of a Peer Group Training of Trainers course and thus employment of peer group trainers.
- Parent Carer Training.
- Health and mobility guide. This guide teaches wheelchair users how to care for their wheelchair and about their own health management, such as pressure relief techniques.

8. FOLLOW-UP, REPAIR AND MAINTENANCE

The objective of good practice on follow-up, maintenance and repair is to evaluate the effectiveness of the wheelchair maximising the user's functioning, comfort and stability, and to ensure that the equipment has been maintained appropriately and is in good condition. (WHO guidelines, P.85, section 3.3.9).

No follow-up is available in Tajikistan. WHO advise that this step in the service provision is a priority to the following categories; children (whose needs change quickly as they grow); users at risk of developing pressure sores (e.g. spinal cord injuries); users who have a wheelchair with postural support modifications, and users who have difficulty following the basic user training given at the service. A follow-up appointment also provides an opportunity to gather feedback from the user to help evaluate the quality of service provided.

Interviews indicated that all wheelchairs provided into Tajikistan (government funded, Dilshod, or donated) often break within a year, sometimes after only a couple of months. With the exception of the chairs provided by Dilshod, spare parts are not available, there is no repair or maintenance service available for wheelchair users and users themselves had not been taught how to care for their product. This is a key element of the eight steps of wheelchair provision that can be provided as an outreach, mobile service at community level and there is a role for the CBR networks here. Without provision of this service chairs will become unusable and will be abandoned.



Two unused wheelchairs found hanging from a roof

Recommendations: follow-up, repair and maintenance

- WSTP training.
- Repair Follow-up and Training within community based rehabilitation.
- Repair and maintenance training for community staff.
- Gather feedback from users during follow up.

Models of service provision

A range of different models for service delivery exist – countries need to develop a model which is suitable for their given context and capable of responding to the identified need within the country. Integration and decentralisation of service delivery are important considerations and can help improve the availability, accessibility and affordability of services⁵.

In analysis of the eight steps of service provision within the context of Tajikistan, it can be seen that the service is inadequate and implementation of a selection of these steps is fragmented across a number of different departments, units and organisations. In developing a strategy for change, the benefits of both implementation and coordination of the eight steps must be a priority.

The WHO guidelines suggest a possible model linking a wheelchair service centre with a number of community based wheelchair services. One key issue

⁵ http://www.who.int/disabilities/world_report/2011/en/

to be addressed as the government is reassessing its structure for rehabilitation and social service provision is the cooperation and integration between the two. Traditionally P&O as well as mobility devices are linked strongly with rehabilitation services and clinics rather than the social service. While a social model of disability is welcome, the social service providers currently lack technical knowledge and have a wide and large amount of responsibilities; this will make it challenging for them to engage in the time intensive process of a customer focused service provision. In light of this it might be better to create a stronger link to the rehabilitation units and ensure an understanding of social and medical rehabilitation in those places.

Centre Based model:

The centre based model would be similar to the current provision for prosthetics and orthotics at the National Orthopaedic Workshop. The facilities would have a dedicated area for wheelchair service delivery, including a mobility skills area and a full wheelchair repair and maintenance. The service personnel would include a team trained in wheelchair service delivery. Locations for centre based models could be the branches of the P&O workshop, regional rehab clinics or private locations. It is unlikely that in the immediate term the management of any of the existing places would be able to take on the additional work, so separate management overseen by an INGO or local DPO would be the recommended first step.

Integrated model:

Many centre based models are also 'integrated services', where the wheelchair service is integrated with activities of another service. For example service personnel may have dedicated days for wheelchair service delivery and dedicated days for other services. The old orthotic and prosthetic repair and maintenance centre was visited, and this has the potential to be a good site if sufficient investment is made in the repair and development of facilities.

Alternative opportunities for an integrated service were considered; potential examples were the National Prosthetics and Orthotics Centre with their three repair and maintenance workshops; PMPC centres, Dilshod workshop and Rehabilitation Centres.

The national prosthetics and orthotics workshop in Dushanbe does have the potential to offer an integrated service; an Intermediate service could be

developed at the National Orthopaedic centre, with Basic services then developed to run as part of the regional repair and maintenance centres. However in the short term the priority, with support from ICRC, is to improve current management, facilities, staff capacity for prosthetics and orthotics, and launch of the new centre in Khujand. Although there is endorsement from the director for the concept of an integrated service, it would be recommended that this be considered in a longer term strategy.

During interviews with staff in the PMPC close to the Dilshod workshop, it became apparent that the clinical skills of staff were complementary to the technical skills of their key staff. It would be recommended that they consider a model where they work together to deliver this service; a discussion would have to be raised to whether they extend this service to all PWD, or only CWD. The facilities are not on the same site, but staff commitment and enthusiasm is significant, and a collaborative effort may see a positive model develop. This model could be explored in the early phase of implementation, with dissemination of this model considered within other PMPC's as a longer term strategy.

Integration within rehabilitation units could be considered as part of a centre based model, however interviews with DPO's, parents and potential users of this service highlighted the view that this must be accessible in the community

Community Based model:

A community based model may be available as an outreach model or a mobile clinic. The outreach model suggests that the facilities are temporary, and may be shared with a partner organisation, a small stock of wheelchairs may be stored, and service steps may be shared with the partner and facilities in the community. In the mobile model, products and equipment are transported by vehicle, with service personnel. Once again, taking into account the views of DPOs, parents and potential users, although they wanted to see services placed within the communities they were also clear that they wanted to visit a centre rather than utilise an outreach or mobile model. Looking at the eight steps of service provision it can be seen that steps 1, 8, and sometimes 7 can be effectively implemented within communities as part of an outreach model, whilst steps 2-7 occur in a centre. It would therefore be recommended in regions where services are being implemented in the early phase that relevant individuals from DPOs, parents groups are identified to be trained in RFT, PGT, PCT and repair and maintenance.

Recommendations

Early phase:

- An integrated model comprising a collaboration between Dilshod, the regions PMPC and the national rehab centre should also be explored; again starting at a Basic level but aiming to progress to delivery of Intermediate services (Basic and Intermediate levels are defined in Table 2, p23);
- Exploration of INGO/DPO run (e.g. Operation Mercy proposed) centre-based model in the Khujand region;
- Referral, User training, Maintenance and Repair could be provided within wider community rehabilitation networks following relevant training.

Longer term phase:

- Ideally Intermediate service provision would be provided in the four key geographical regions of Tajikistan, with more Basic service provided at a local level.
- Provision of Intermediate services could be developed as integral to the P&O services currently available in Dushanbe, developing in Khujand, and at the sites of the other two repair and maintenance sites.
- Provision of Basic Level services could be replicated within the other PMPC centres.

Human Resources

The current wheelchair service models that exist in well-resourced settings comprise a team of allied health professionals linked with commercial wheelchair manufacturers. In Tajikistan, as in many less resourced countries, this model does not exist due to a lack of professionals, lack of trained staff and lack of service infrastructure. A second significant and widely reported issue is the retention of any staff who have received relevant training.

A variety of personnel can be involved in the provision of mobility devices, including therapists, medical staff, orthotists and prosthetists, and community workers. However in Tajikistan there is currently no training for therapists, orthotists or prosthetists in the country. Article 4 of the UNCRPD highlights the responsibilities of countries to promote the training of professionals and staff working with persons with disabilities, and investment is being supported

in this area by both WHO and ICRC. WHO are selecting four students from the Diploma in Nursing training and two doctors, to receive physiotherapy, occupational therapy and physical medicine & rehabilitation training in India over the next three years. WHO are also going to organize orientation and exposure visits on rehabilitation and assistive devices for policy makers and service providers, whilst ICRC anticipate the return of seven prosthetists and orthotists from training in Vietnam.

The WHO has developed a comprehensive Wheelchair Service Training Package (WSTP), which can be modified to the context of delivery. The training packages are tools to turn the WHO Guidelines on the provision of manual wheelchairs into reality; designed to increase the capacity of personnel working in wheelchair provision. The WSTP package is made up of three modules. The Basic and Intermediate WSTP modules work in parallel with the basic and intermediate service levels identified in the WHO Guidelines; the service levels are defined by the user's mobility and postural support needs (Table 2), and each successive training would enable personnel to provide wheelchairs for users with increasingly complex needs. The third Management WSTP module includes advice on advocacy for national policy and management of wheelchair provision. Participants from 45 countries have received training in the WSTP Basic and Intermediate courses to date.

Table 2. Definition of the WHO Service Levels

***Basic Service:** Users' needs can be met by provision of manual wheelchairs without modifications. Mobility and postural support provided through a well-fitted wheelchair and seat cushion.*

***Intermediate Service:** Users' needs can be met by provision of manual wheelchairs with supportive seating. Supportive seating provided either through individual modifications to a basic wheelchair, or a specialised seating system.*

World Health Organization (2008) Guidelines on the provision of Manual Wheelchairs in less resourced settings, Chapter 3, P.77

There are no set qualifications to attend these courses although experience of working in the field of disability is helpful; the involvement of wheelchair users is encouraged with a view to them taking on roles and responsibilities within the service team.

Recommendations

Early phase:

- **Managers WSTP:** Key stakeholders from the government, National Orthopaedic Workshop, national rehabilitation centres, INGOs, relevant PMPC, Dilshod, and DPO's.
- **Basic WSTP:** Clinical and technical personnel from PMPC, key Dilshod personnel and staff of the national rehabilitation centres (Macheton, Khujand and Chorbogh).
- **Intermediate WSTP:** Clinical and technical personnel from PMPC key Dilshod personnel and staff of the national rehabilitation centres (Macheton, Khujand and Chorbogh).
- Consider additional training courses such as: **Repair and Maintenance, Peer Training, Parent Carer and Referral and Follow-up Training** for community networks, DPOs, parents associations.

Longer term strategy:

- Basic & Intermediate WSTP to P&O Workshop Dushanbe; & repair and maintenance centres.
- Basic WSTP to other PMPCs.

Products

A wheelchair is appropriate when it meets the user's needs and environmental conditions; provides proper fit and postural support; is safe and durable; is available in the country; and can be obtained and maintained and services sustained in the country at an affordable cost. (WHO guidelines, p.21)

The geography of the country is mountainous in places, providing a beautiful and yet challenging environment for people with mobility disabilities. Within the cities, there were often no pavements, or those present had uneven and broken surfaces. In more rural areas, particularly in the winter months, the tracks consisted of mud and stones. Consistent feedback from users was that the products available were not durable and able to cope with the rough terrain here. An appropriate product would be expected to last three to five years, but users reported that they were breaking within a year, if not a few months.



Difficult geographical context in Tajikistan

Wheelchairs and assistive devices currently available in Tajikistan were briefly evaluated; these ranged from those delivered after prescription from VTEK, what was available in two pharmacies, distributed by donation and, manufactured by the Dilshod workshop.

Imports were from Russia, China and Iran. The cost of these wheelchairs in the pharmacies ranged from \$150 to \$300; this is same cost estimated by the government in procurement of chairs. It would be anticipated that the cost for the government of procurement of a large number of chairs may reduce the cost when compared with a pharmacy; however it is positive that the government anticipates investment of this amount per chair.

The adjustability of certain key features is required to provide basic postural support and fit to the user. In summary these should include: the width and length of the seat and cushion; the backrest; the footplate; calf, foot and heel strap; the position of the rear wheels; and the brakes.

Another key feature of a wheelchair set out in the WHO guidelines is the essential presence of a cushion on every chair. There are three different types of cushion; a comfort cushion, a pressure relief cushion and a cushion that provides some postural support. These features will be briefly evaluated in the wheelchairs seen.

Imported Products

Two key models of chair were available from the government and pharmacy; seen in the pictures below.



Models of wheelchairs

All chairs had slung seats, with no options to adjust the width and length of the seat. A range of sizes was not available, and they were only suitable for an adult, no children's chair being available. One chair had a built in comfort cushion, but the effect of this would have been compromised as the seat also had a commode facility built in. A cushion is an essential requirement, and it is therefore a great concern that no chairs are issued with one, either as part of the product, or as a separate item. Two heights of backrest were available; however no height adjustment was available. A user requiring head support may often present with more complex needs; the chair did have a recline facility, however there were no additional postural support features for the pelvis or trunk. The footplate on some models could be adjusted for height, and on one could be elevated; no calf, foot, or heel straps were observed. The position of the rear wheels were fixed, adjustability is helpful to allow changes to be made to ensure the best stroke push, and dynamic stability for the user. All wheelchairs had brakes.

The key feedback on imported products was that they broke very quickly. No spare parts, repair or maintenance service was available, and it was therefore unsurprising that three unused chairs were observed in people's homes. One mother reported that the chair sometimes enabled her to take her child out, but also reported that the wheelchair was awkward to manoeuvre so this happened rarely.

In summary, none of the imported products met the WHO guidelines.

Recommendations

- Government tenders for the import of products should require products to meet the WHO Guidelines.
- Product assessment tool; this supports the assessment of a product to see if it meets the minimum criteria and could be used in this process.
- A variety of wheelchair models and sizes should be available, including those appropriate for children.

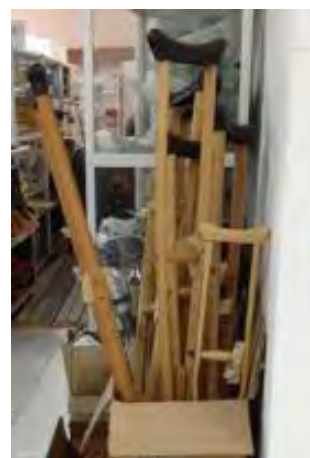
A range of assistive devices were seen; the most commonly used being under arm crutches, rollator frames for children and seating for young children. The key issue appears to be access and availability of these products.

Rollator frames were available from the pharmacy at a cost of \$33 in adult and child sizes. Rollator frames had also been provided through NGO services; though they were adult sizes for use by children. Feedback from the users indicated that they were not functional and used at most intermittently to aid standing. Additional features were adjustments for the height, and to enable the rollator to fold flat.



Available Walker models

Adult under arm crutches were used by a number of people with disabilities interviewed, Most had acquired them privately, some sent from Russia. They were available in the pharmacy for a cost of \$20; and children's sizes were also available. Others would access provision through referral to the Orthopaedic workshop, and the outreach P&O repair and maintenance centres.



Available crutch model

Recommendations

- Referral, funding and service provision of a range of assistive devices needs to be reviewed; ideally provided by the National Orthopaedic workshop, and the P&O repair and maintenance centres. The PMPCs and rehabilitation centres could also be considered.
- Government officials as well as suppliers, rehab centre staff, PMPC, doctors (with a focus on ortho + neuro) etc needs to be oriented on assistive devices and its benefits.
- Opportunities of availability of assistive devices in pharmacy / market should be further explored.
- Linkages need to be made with different suppliers (especially for pre-fabricated products).

Donated products

One donated wheelchair was evaluated by the researcher. It was a ROC Wheels chair which had been distributed in 2013. This is a product designed for children with moderate to severe disabilities; it comes in two sizes and has key adjustability features in compliance with the guidelines.

(<http://rocwheels.org/wp-content/uploads/2013/11/MASTER-ROC-User-Guide.pdf>).



Feedback was largely positive; the wheelchair had enabled them to take their child out with them to visit relatives and friends, and join in the community activities more easily. The children were physically comfortable and many were able to self-propel around their homes, giving them a degree of independence which they enjoyed.

Issues raised were that the wheelchair was quite heavy, and was unable to fold. Many of those interviewed lived in apartments, none of them living on the ground floor; this created significant difficulties when moving the chair up and down stairs. The size and weight of the chair also prevented them from taking it on any form of transport; a stroller was often used when travelling. As with imported products, the same concern was raised as two parents reported broken parts. For one, this made the chair redundant with no spare parts or repair and maintenance service available; whilst the other had managed to fix the problem themselves.



Models of donated wheelchairs

Recommendations

- Where wheelchairs are provided by donation, they must adhere to the WHO Guidelines; have spare parts available, and be suitable for the local environment.
- Donated wheelchairs should also be integrated into relevant services, including prescription, fitting, repair and maintenance.

Dilshod Workshop

A small range of wheelchairs and assistive devices are manufactured at the Dilshod workshop. All materials are sourced locally, although many of these are imported predominately from China. For two years, during 2012-13, AAR Japan provided seven month long visits to provide technical expertise into renovation of the factory building, replacement of old equipment and training from a Japanese specialist on wheelchair production and supplemental services. Collaboration was initiated with the MLSP regional branch in order to identify users from the waiting list and to provide a needs assessment, production, distribution and follow-up service (as required).



Models of Dilshod wheelchairs

The Dilshod chairs are made to the specification of the user and this is very positive. The width and length of the seat is bespoke, however an in built comfort cushion was only seen on a few chairs; this unfortunately was not a consistent feature; those without a cushion were foldable. The backrest on the model shown in the pictures above was adjustable using a system of straps. The footrest was either adjustable, or made bespoke to the individual; no calf, foot, or heel strap were present. The position of the rear wheels was not adjustable, but there were brakes.

Overall this model of wheelchair had many features that met the WHO guidelines and it was the only chair evaluated that could be maintained and repaired locally. However feedback from a few INGO staff highlighted concern regarding the durability and strength of the product. Two beneficiaries visited were rarely using the product; their family rarely taking them out of the home compound, and using an adapted bicycle instead.

The second model of chair could also be made bespoke for the user, but would probably be used for transportation of a user with more complex postural needs; they would be unable to self propel. At this intermediate level of supportive seating additional postural support devices would be required, and these were not observed. The features of this chair would only be appropriate for a temporary use transit chair.



Dilshod wheelchair

Local Production

There are a number of issues to consider regarding the capacity and sustainability of the Dilshod workshop.

Quality

Dilshod has had significant funding input from AAR Japan over the last two years; the beneficial effect is clear; it is the only service in Tajikistan that aims to implement many of the eight steps of service provision. However issues remain regarding the quality and durability of these products. This is a common issue with small scale local production; and reliance on further funding and training would be essential if this was to be addressed.

Quantity and Sustainability

The Dilshod factory reported having the capacity to produce 150 wheelchairs and 40 assistive devices per year. Motivation's experience indicates that local production is rarely sustainable, unless working in parallel with the production of other products, or services. All rely on supplementary funding, usually from external funding sources; a demand from the market is essential. Dilshod has a small production capacity. Although when AAR Japan were involved, there was a government tender for the production of 220 wheelchairs over two years, the government has indicated that they would not be willing to reinstate this as they are looking to put out a tender for 500 chairs, beyond the capacity of the workshop. Demand is currently driven by INGO's and private purchase; this demand is not sufficient to be sustainable as there is limited purchasing capacity.

Experience in Tajikistan also suggests that local production may not be sustainable. Several years ago there was another factory in the North of Tajikistan that produced wheelchairs for government tender; this closed several years ago as it was not able to produce wheelchairs of sufficient quality at a reasonable cost.

Looking ahead, there is considerable support for the Dilshod workshop from INGO's and support within the local community; though there are currently no further proposals for funding or support. The skills of three technicians working at Dilshod would be a significant asset in delivery of the technical steps of wheelchair service provision, and the workshop facilities are also appropriate for product preparation and modification. One model to recommend would be to suggest that the workshop moves to work predominately with assembly and modification of products; with the option of continuing production of assistive devices. As highlighted earlier, clinical input is needed for full service provision, and Dilshod could work in collaboration with the local PMPC to deliver a comprehensive service. Initial funding and support for upgrading facilities, and training would be required, but in the long term this model would produce higher quality and quantity of chairs, and is more likely to be sustainable without external support.

Dilshod, the National P&O centre and the All About Children project in Khujand all produce locally made assistive devices. These currently fill an essential gap in assistive device provision; though production and range of design is limited. User feedback was not available and this would be useful in order to gather information on functionality, quality and durability.



Recommendations: Local production

- Focus on assembly and modification of imported products, to work in parallel with local production of assistive devices.
- Utilise the skills and experience of current staff, providing WSTP and Product Familiarisation Training for technical staff at Dilshod.
- Explore further funding in order to upgrade facilities for full service provision, whilst exploring the model of collaboration and shared facilities with the PMPC.
- When service provision using assembly and modification established; re-establish a commitment from the government for procurement of products and services.
- Implement service user feedback

A Framework for Provision of Wheelchairs and Mobility Devices

Key recommendations are set out within each section of the report. To build these into a framework for the development of services a proposed way-forward will be following.

POLICY & PLANNING Develop & implement policies for sustainable wheelchair provision

Year 1

- Stakeholder conference: to raise awareness of the importance of appropriate wheelchair service provision & support action towards planning & implementing effective wheelchair provision
- Wheelchair taskforce creation and meeting

Year 2

- Stakeholders conference: to report on progress/impact of the wheelchair service programme and discuss next steps
- Wheelchair taskforce meeting

PRODUCTS - Increase the quality & range of wheelchairs available

Year 1

- Order container of a mixed range of WHO compliant wheelchairs

Year 2

- Order container of a mixed range of WHO compliant wheelchairs

TRAINING - Develop the skills & knowledge of personnel involved in wheelchair provision

Year 1

- Delivery of WHO Wheelchair Service Managers' training
- Facilitation of Wheelchair Stakeholder Workshop
- Product Familiarisation Training (manual wheelchairs)
- WHO Wheelchair Service Training - Basic

Year 2

- Product Familiarisation Training (supportive seating)
- WHO Wheelchair Service Training – Intermediate
- Referral and Follow- up Training
- Parent/Carer Training for children
- Peer Group Training camp for wheelchair users

SERVICES - Improve the delivery of wheelchairs for users

Year 1

- Service(s) baseline level determined to review the status of the service, determine strengths & identify any gaps requiring input
- Commence infrastructure of service(s)
- Service delivery commences (after training)
- Gather user feedback

Year 2

- Gather user feedback
- Service evaluation

Notes to Framework

WHO wheelchair stakeholder workshop - This workshop will help to raise awareness of the importance of appropriate wheelchair service provision and support action towards planning and implementing effective wheelchair provision. The workshop is aimed at stakeholders involved in policy and planning including policy makers, planners and implementers, manufactures

and suppliers of wheelchairs, providers of wheelchair services, disabled people's organisations and wheelchair users.

WHO wheelchair service managers training - Wheelchair Service Managers training will give participants good understanding of efficient wheelchair delivery systems and provide them with knowledge and skills that will help them to begin or improve wheelchair provision for PWDs.

Wheelchair taskforce meeting - There has already been a gathering of stakeholders who have been part of the round table meetings to support the improvement of wheelchair provision. It is advisable that this group continues to meet as a wheelchair taskforce group.

Peer group training camp - The peer group training is a recommended course, rather than compulsory. It isn't an essential part of wheelchair service provision but is encouraged in order to provide wheelchair users with a comprehensive service and help them achieve more independence and a better quality of life.

Appendix 1:

Participants at Round Table meeting Friday 21st February

	Organisation	Name
1	World Health Organization	Satish Mishra
2	Handicap International	Myriam, Sandra, Shamsiya
3	Ministry of Health and Social Protection, Republic of Tajikistan	Kurbonov Kudrat, Aziza, Shoev
4	Wheelchair workshop Vahsh	Dilshod org.
5	ICRC	Tigran
6	Orthopaedic workshop	Davlat, Horkash
7	Society of Persons with Disabilities “Imkonyat”	Assadullo
8	Disabled Women’s league "ishtirok"	Saida Inoyatova
9	Parents	Sabohat Hakimzoda, Sharipova
10	Caritas	Nigina
11	Association for Aid and Relief, Japan	Kiyoshi ISHII
12	UNICEF	Shima
13	Chorbog Innovation centre	Soyima
14	UNDP/ Tajikistan Mine Action Centre	Reykhan Muminova
15	Operation Mercy	Andrea Vogt, Sobirjon Safarov
16	Motivation	Rosy Dorman

Appendix 3

ASSISTIVE DEVICES PRESCRIPTION FORM

ID NO _____ Date of assessment ____

Name of person / children with disabilities:

Guardian's Name and Relation:

Date of birth:

Age of the children / person:

Years of education / level reached: none () R&W () primary () SSC () HSC ()

Bachelor /& +

Current occupation: Agriculture () Day labour () Civil service () Business ()

Student () Non-working age () other:.....

Possible Diagnosis:

Type of Disability: PD () H&SI () VI () ID () MI () MD ()

Address: Village:

Jamot:

District:

Brief Description of Impairment:

Name of Required Assistive Device: Additional Requirement / special need:

Measurement or Design



Signature of AD assessor

Signature of final assessor