

Motivation Charitable Trust: The role of CBR in effective Wheelchair service provision
Author: Nikola Seymour **Presented by Charles Kanyi**

People with disabilities (PWD) are amongst the most marginalized groups in the developing world. It is estimated that 80% of the world's PWDs live in developing countries.¹ The WHO notes that they have “poorer health outcomes, lower educational achievements, less economic participation and higher rates of poverty than people without disabilities,” which occur partly as a result of the barriers PWDs experience in accessing mainstream services such as education, health, and employment.² Rehabilitation services, including provision of assistive devices, are a crucial component in breaking down barriers impacting PWDs. However, despite a greater need, low and middle income countries report less availability of skilled health rehabilitation personnel. It is estimated there are less than 0.5 rehabilitation professionals per 10,000 people in Sub-Saharan Africa.³ The WHO Joint Position Paper on the Provision of Mobility Devices in Less Resourced settings (2011) partly attributes challenges to accessing assistive devices to this lack of human resource. Other barriers include lack of policy and legislation; unaffordable devices; and insufficient institutionally-based wheelchair services. The WHO estimates that globally only 5-15% of people needing assistive devices have access to what they need (WHO, 2008)⁴.

Community based organisations (CBO) and workers (CBR workers) working within a Community-based rehabilitation (CBR) framework could play a significant role in overcoming these challenges. However our experience highlights that effective partnerships and decentralised joint services are required to make this happen, but are unfortunately not very common. It is unlikely the situation for people needing wheelchairs will change without targeted strategies to formalise partnerships and improve collaboration.

WHO Guidelines on Provision of Manual Wheelchairs in Less-resourced Setting⁵

The WHO Wheelchairs Guidelines (2008) were developed in response to the need for functioning systems of wheelchair provision in less-resourced regions. The guidelines outline that every child or adult who needs a wheelchair has the right to an 8 stepped process for effective wheelchair provision. This includes referral, assessment, prescription, funding and ordering, product preparation, fitting, user training and follow up, maintenance and repair. Every step must be provided by appropriately trained personnel and training courses have been developed by WHO and key stakeholders to ensure service providers have these skills.

WHO stress that it is not always possible, or appropriate, for all steps to be through one organisation indicating in particular steps one and eight can take place at community level. Important roles for CBR workers are identification and referral, liaison between users and service and advice on environmental accessibility. Additional skills can be developed to reinforce management of health, use of the wheelchair and maintenance and repair⁶. In addition to this the WHO CBR Guidelines place a responsibility on CBR workers to help in identifying ‘funding options for people who are unable to afford the costs associated’. It then

¹ Handicapped International (2011), “Global Situation of People with Disabilities”

² WHO (2011), ‘World Report on Disability’ p.10
http://www.who.int/disabilities/world_report/2011/report.pdf

³ BMC Health Services Research (2011)“Health-related Rehabilitation Services: Assessing Global Supply and Need for Human Resources”

⁴ <http://www.who.int/disabilities/technology/en/>

⁵ Hereafter referred to as the WHO Wheelchair Guidelines

⁶ WHO (2010) CBR guidelines: Health Component

becomes clear that CBR workers can play a role in four of the eight steps of the Wheelchair Service delivery process (Step 1 Referral, 4 Funding, 7 User training, 8 Follow-up, maintenance and repair) and are therefore integral to effective provision.

Challenges with effective wheelchair service provision reaching the community

Motivation Charitable Trust aims to enhance the quality of life of people with mobility disabilities. With experience in over 33 African countries, Motivation has seen the massive need for wheelchairs as well as the establishment of numerous wheelchair services. Experience shows that collaboration between wheelchair service providers and community partners are not always effective evidenced through client feedback, focus group discussions and formal evaluations. A Service Monitoring and Evaluation Tool, with 28 elements, based on the WHO Wheelchair Guidelines is used by Motivation to understand strengths and weaknesses of wheelchair services. Together with the continued difficulty of inconsistent and ad hoc availability of wheelchairs, areas with appropriately trained service personnel continue to experience challenges with specific aspects of service provision including:

- **Appropriate range of service models:** service personnel are often not able to leave their centres for reasons including workload, absence of transport and low resources. Therefore services are commonly only available at a specific centre. Users, particularly remotely located, may not be aware of the service and, if they are, may experience similar challenges leaving their villages; thus a large divide is created. Community organisations may be aware of these people and their needs, however usually the responsibilities lie with the service to overcome the barriers. This is rarely successful and situations remain with inequitable provision systems impacting few who can afford to reach the service.
- **Follow-up:** Effective follow-up programmes are difficult to sustain when small wheelchair services have to also cater for high demand of new clients. Coupled with challenges such as poverty, transport and lack of awareness the service teams who provide PWDs with appropriate wheelchairs often do not see the wheelchair user again. Using a wheelchair or supportive seating device for the first time can open up many opportunities but also exposes new barriers and challenges such as access, storage, transport and attitudes. Regular and ad hoc support to help navigate the new life situations is often needed but absent. A child who once attended school may have to stop when he grows too big for his wheelchair or a self-employed business man no longer earns as he becomes weak and unwell from a pressure ulcer. Isolation and neglect are common and absence of experienced support may cause a manageable situation to become critical.
- **Repair and maintenance:** Some products, in particular those for children, are susceptible to damage and quick wear and tear largely because of the many parts and components and the vigorous use in often rough contexts. Storage facilities are often lacking and parts are commonly stolen. This is usually not noticed or responded to and expensive devices are wasted. Repair services are remote and spares are not accessible leaving users stranded.

Other common challenges expressed by users and community workers relate to accessibility in the home, community and transport facilities. Prevailing lack of knowledge about disability and wheelchairs, as well as negative attitudes, places significant and often insurmountable obstacles to participation and community inclusion for PWDs.

Collaborations to overcome challenges

Focus must be placed on developing the role of CBOs and CBR workers in wheelchair service provision in order to ensure a rights-based and user-centred approach. Examples of current attempts to bridge these gaps in Africa can be used for learning.

- **Training:** A Malawian wheelchair service uses the Motivation Referral and Follow up course. CBR workers and other referral sources learn appropriate identification and referral systems and methods to help use, care and maintain wheelchairs. Parent groups in Uganda learn similar skills to help each other and members of their community. Additional training on how to manage children with cerebral palsy helps to understand the condition, integrate new handling methods and assistive devices into daily activities. New skills and knowledge combined with understanding of the context help CBR workers and community members assist PWDs to creatively overcome daily challenges.
- **Outreach services:** A programme in Tanzania caters for a remote community with a high number of wheelchair users. A partnership initiated by the wheelchair service with a local CBO improves provision to the area, follow-up and sharing of scarce resources. The CBO offices are a temporary service facility and community volunteers responsible for locating clients and arranging logistics for clinic days. The service team assess and provide appropriate wheelchairs and schedule visits every 6 months to follow-up. Training and exposure of the community workers gradually enabled them to increase support to users between scheduled service visits. This reduced pressure on the wheelchair service during their clinics, allowed the wheelchairs to last longer with less damage and enabled more continuous use of products and meaningful participation.
- **Repair and Maintenance:** A national wheelchair supplier is training and equipping 24 repair and maintenance technicians in remote communities in Kenya. Users will have a service point which is easily accessible, reducing the pressure on the main specialised service centres and reducing potential cost implications for clients. In Tanzania, training of select wheelchair users in repairs and maintenance aims to increase options for people closer to their communities. The newly trained technician is linked to new wheelchair users as a resource in their community and is supported by the wheelchair service to fulfil their role.

Summary

Despite both WHO Wheelchair and CBR guidelines making direct reference to the need for collaborative approaches to wheelchair provision it is rarely effectively implemented and the described situations are common. There is a crucial role that CBOs, using a CBR approach, should play in bridging the gap between the community and specialised wheelchair service centres. Through strong collaborations effective and appropriate wheelchair service provision can be established and sustained enabling more people with mobility disabilities to participate and attain their rights. Without this, this marginalised group are likely to be excluded from poverty reduction strategies or activities aimed at achieving the MDGs.

Key recommendations

- CBR to be integrated into national policies and systems and workers to be employed to develop a consistent workforce
- Formal partnerships, joint service approaches and on-going mentoring to be established between health services and community organisations
- Collaborative decentralised systems to be developed to follow-up wheelchair users in particular children, provide maintenance and repair services and to scale up service delivery.