

# Disability inclusion in the Northern Cape: a community-based wheelchair service project

## Authors

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Although a wheelchair provides a person with physical disability with the means to access his or her basic needs, it is still necessary that the environment be prepared in order to facilitate the inclusion process. Without this, the ecosystem remains dysfunctional.

Approximately 70 million people globally require assistive device technology. Many of these people live in low-resource settings, where appropriate wheelchair service provision is poor. Persons with long-term physical impairments require a mobility device to access resources within their communities and to become active members of society. The wheelchair, therefore, serves as a tool facilitating the inclusion of persons with disability into their communities.

Many projects have been implemented globally to reduce the waiting period for wheelchairs and assistive devices required by persons with physical impairments. This chapter explores the effects of a three-year capacity-building intervention undertaken in local rehabilitation departments in the Northern Cape to improve wheelchair service provision and quality, increase access to services for persons with disabilities, and promote social inclusion.

Project objectives included demonstrating positive outcomes of public-private partnership in addressing the need for appropriate mobility devices; building the capacity of local

government therapists to improve access to quality wheelchair services and initiate sustainable systems change; and creating awareness of barriers in the community leading to sustainable systems change, namely identification and actioning of local referral pathways, in order to receive services.

Recommendations for future projects include: training local rehabilitation therapists on the WHO guidelines for wheelchair service provision, plus mentored support to facilitate practical skills development in order for therapists to deliver quality wheelchair services; establishing a standardised mechanism for referral pathways to local services, with the roles and responsibilities of each individual clearly identified to ensure fluidity of referrals and processes from one level of service to the next; and training for parents, community healthcare workers and other healthcare, social and education professionals in order to establish a network of individuals capacitated to identify and support persons with disabilities. Community-based outreach-seating clinics are more effective if offered at venues that are central and accessible to community members.

## Introduction

Wheelchairs improve the health and quality of life of the wheelchair user, as well as the quality of life of the family. A wheelchair facilitates inclusion, and is a basic human right.<sup>1</sup> Appropriate wheelchair service provision programmes support the social model of disability, wherein physical barriers in the environment are addressed to facilitate improved social cohesion of persons with disabilities and their families, and to promote improved quality of life for all.<sup>1</sup>

Once mobile, the individual is able to attend medical appointments, seek employment, attend school, and perform daily activities. It also allows the person to participate in social activities with friends and family, which ultimately builds stronger connections, and thereby lessens the marginalisation and isolation faced by many persons with disabilities.<sup>2</sup>

The purpose of the World Health Organization (WHO) guidelines for wheelchair service provision in less-resourced settings<sup>3</sup> is to promote personal mobility with the greatest possible independence for persons with disabilities; to enhance the quality of life of users in less-resourced settings through improved access to wheelchairs; and to assist member states in developing a system for wheelchair provision.<sup>3</sup> The WHO also recommends the following guidelines<sup>3</sup> to ensure effective wheelchair service provision in low- and lower-middle-income countries (LLMIC):

- Referral and appointment: Best practice would be to start a new client file, and to train the referral network staff, i.e. the staff members involved in identifying the client.
- Assessments: These should be completed by trained personnel, and include a holistic view of client needs, i.e. their physical condition, lifestyle, age, environment and culture.
- Prescription: Trained personnel and the client should choose the final device, as well as the necessary features required. Ideally, the wheelchair user should be able to test different device options.
- Funding and ordering: There should be established ordering and procurement systems and clear agreements with suppliers on ordering and delivery.
- Product preparation: Prior to fitting the device, trained personnel should do a mock set-up of the device to ensure that the fitting process goes smoothly.
- Fitting: This should be done by a trained seating practitioner who discusses the fitting with the user/parent/carer.
- User training: The wheelchair user and/or caregiver should be trained in mobility, safety, usability, transfers, and basic repair and maintenance.
- Follow-up, maintenance and repair: Regular clinical and technical reviews of client and device should be scheduled, especially in the case of children who may develop secondary complications.<sup>4</sup>

a Shonaquip is an NGO working to provide well-fitted, appropriate wheelchairs to children with mobility impairments. The NGO was established 10 years ago, and subsequently expanded to form a hybrid social enterprise known as Shonaquip Social Enterprise (SSE).

This case study describes the process and outcomes of a three-year cross-sectional, blended-funding, public-private partnership that was formed to improve access to appropriate mobility devices for children in the Northern Cape (NC). The partnership between Shonaquip Social Enterprise (SSE) (a subsidiary of Shonaquip,<sup>a</sup> a non-governmental organisation (NGO)), Sishen Iron Ore Company-Community Development Trust (SIOC-cdt), and the Northern Cape Department of Health (NCDoH), arose from a longstanding relationship among the key role players and operated in two clusters (17 towns) in the NC. Some of the issues that the partnership set out to address were the need for assistive device technology, upskilling of professionals, and the non-functional government systems preventing the inclusion of persons with disabilities. The focus of intervention extended to include those elements in the ecosystem of the child, such as the family, community, support services (health, education and social) and policies, which contribute to the inclusion of a person with disability.<sup>2</sup> “Thus an ecosystem that is functional will facilitate the inclusion of a person with disability, while a dysfunctional ecosystem will undermine their ability to access much-needed services, and result in continued isolation, community stigma, health risks, lack of education, poverty and violations of human rights”.<sup>2</sup>

“This ecosystem approach [is] informed by the community-based rehabilitation (CBR) matrix, which identifies five components needed in order to reach inclusion: health, education, social connection, livelihood, and empowerment”.<sup>5</sup>

The service offered by SSE extended beyond wheelchair provision to capacity building among local service providers, family, and community members to remove barriers and enable children to access support services.<sup>6</sup> In this way, wheelchair users were able to use their mobility device as a tool for personal development, and benefit from social inclusion and meaningful community participation.

A needs assessment identified the following challenges: confusion about the number of children on the NCDoH assistive device waiting lists; lack of trained therapists able to provide wheelchair provision services; lack of knowledge on the part of families of children with disabilities regarding which services they needed to access, and/or that they could and should access certain services in order for the child to be included; and parents and caregivers not understanding the child’s condition or how to stimulate and support the child. Additionally, the needs assessment highlighted the presence of systemic barriers in accessing and actioning referral pathways.

## Key findings

This section reports on the findings of a three-year intervention in two clusters in the Northern Cape.

### Community-based outreach seating model

A community-based outreach (CBO) seating model was adopted. Trained wheelchair seating professionals from SSE provided mentoring<sup>1b</sup> and training support to National Department of Health (NDoH) and NCDoh rehabilitation staff. A one-day centralised training workshop was held to upskill local therapists on local tender products, and how to complete a specification sheet and place orders through the government tender. This was followed by a two-day mentored seating clinic. During this time, the NCDoh therapists were able to assess existing clients on their own assistive-device waiting list, and with the mentored support of the SSE clinical team, make prescriptions for appropriate assistive devices. Mentored seating clinics were conducted at six-monthly intervals, and included therapists from all the major hospitals and community healthcare centres (CHCs) in both clusters. On completion of the assessments, another site visit was scheduled six months later to host outreach-seating clinics (ORCs). The purpose of the ORCs was to mentor rehabilitation therapists on the remaining WHO guidelines, i.e. product preparation, fitting, user training, follow up, maintenance and repair. The two-day onsite training was adapted to include a module on repair, refurbishment and technical training, and to optimise used equipment to assist more clients awaiting assistive devices. As most therapists do not have regular access to technical support, they found this to be useful.

Prior to the intervention, 150 children required assistive devices across the two clusters, and 40 therapists were trained on wheelchair service provision. Inclusion criteria for the beneficiaries (children receiving assistive devices) were that they had to have been assessed previously, and be awaiting an assistive device. Some cases were flagged as critical because of the risk of developing secondary complications.

All devices were funded through blended funding streams from the SIOC-cdt, the SSE, and the NCDoh. Written consent for the study was obtained from the physiotherapists and occupational therapists who participated in the workshops, as well as from all beneficiaries or their guardians. At the end of the first year, the intervention had cleared the waiting list, having assisted 159<sup>c</sup> beneficiaries, and trained 40 therapists using the community-based outreach seating model.

b Mentoring = a process or relationship in which a more experienced person guides and advises a less experienced person.

c A further nine children were subsequently identified.

### Impact tools and results

Impact tools developed by the SSE generated pre- and post-intervention data collected from participating occupational therapists and physiotherapists. Primary data-collection tools for the study included:

- A competence and confidence questionnaire to assess how confident therapists felt after being supported and mentored to plan and execute outreach seating clinics.
- An appropriateness-of-device questionnaire, indicating appropriateness of devices prior to and post mentored support from the SSE.
- A training feedback form giving feedback on training experienced post SSE intervention.<sup>2</sup>

Therapists applying the WHO wheelchair service provision guidelines were issued with a questionnaire to assess and measure their competence and confidence on each guideline (the guidelines being: assessment, prescription, product preparation, fitting, user training, follow-up, and maintenance and repair). In each instance, therapists indicated their assumed level of competence and confidence by rating themselves on a scale from one to five, with one meaning that they had a low level/least amount of competence and confidence, and five meaning that they felt fully competent and confident to perform an assessment. The highest achievable score was 35, if the therapist rated him-/herself five on each of the guidelines.

The SSE team also completed the confidence and competence questionnaire in order to rate each therapist based on the skills they demonstrated during the outreach seating clinic. The results indicated that the DoH therapists rated themselves much higher than the SSE team members after the second site visit to both clusters.

After the second site visit to both clusters, the SSE team members recommended continued mentoring support, although there had been a vast improvement in the skills of the therapists post intervention. It was also clear to the therapists themselves that they required ongoing mentored training and support after the first training.<sup>6</sup>

During the initial assessments, beneficiaries may have arrived in an existing device or may have been placed on a waiting list for a device prescribed prior to the training workshop. The results indicate an increased ability on the part of the therapists to prescribe an appropriate wheelchair. In cases where the device was partially appropriate, it was because the children who were originally assessed, had not arrived to receive their wheelchair on the day of the fitting. New children, who had been identified and assessed in the time between SSE team visits, were issued with the devices prescribed for the original group of children. This resulted in children receiving a partially appropriate device, and alterations were required to ensure that the devices would become fully appropriate. It was agreed that the children

assessed originally would be issued with a device at the next seating clinic. In addition, different therapists attended different seating clinics. This situation led sometimes to the prescribing therapist selecting a particular device, and the device later being found to be inappropriate by the SSE team on the day of the fitting.<sup>6</sup>

Comments from rehabilitation therapists post training were as follows:

*I liked being teamed up with experienced therapists to learn from them, and to be in a small group where I could ask questions about the patient being assessed and seated.*  
(RML)

*I learnt a lot. I feel better about assessing, although there are still some issues for me with prescribing and confidence in proper fitting.* (CL)

As many therapists were in their community-service year, this was their first engagement with wheelchair training and it contributed to an increase in both knowledge and confidence. Clients previously at risk of developing secondary complications, and marginalised through not receiving basic health care and support, were identified in order for them to access the next level of care.

### Addressing the environment

Although a wheelchair provides a person with physical disability with the means to access his or her basic needs, it is still necessary that the environment be prepared in order to facilitate the inclusion process. Without this, the ecosystem remains dysfunctional.

Therefore, in parallel with the outreach seating clinics, and acknowledging that persons with disabilities experience barriers in their communities, additional training was provided in the form of 'Let's Talk Disability' (LTD) workshops.

## The twins from Gamorana village

Young identical twin boys live with their mother in a remote rural village in a mining area in the Northern Cape. The nearest small town, Kuruman, is almost two hours' drive away along sandy, potholed roads. The village is deep in the bush, and the families have no local clinic. A mobile van visits the village for social grants. A local community worker brings the outreach team to the family's simple, one-roomed shelter, hand-built with clay. Like other families in the village, the twins' mother has little reason to trust service providers. "Everyone promises to come back, few ever come again". This is a close-knit community and families are an integral source of support to each other. Few comprehend the nature of their child's disability, what their rights are, or how their child's future might look.

To the surprise of the outreach team, both twins have Madiba buggies, very rare in a village like this where children with mobility disabilities are typically carried around on their mothers' backs. Available wheelchairs are unsuited to the terrain, so tyres wear out, wheels break, and brakes soon become faulty. Repairs may take over a year, during which time the growing child is at risk of developing spinal deformities or pressure sores. Children sometimes wait as long as four years to receive a mobility device, by which time the device prescribed is often no longer suitable. Few therapists have the necessary expertise to provide the appropriate postural support for a developing child with advanced needs complicated by secondary deformities. The outreach team notes that the twins' devices have not been fitted correctly. The nearest basic services are about two hours away and can only be reached by donkey cart or by

hitching a ride on the back of a truck. No rehabilitation therapists ever service this remote area. If children are able to get to one of the larger towns they may be seen once off, but there is no regular outreach programme or three-monthly reviews. There is a government-funded multi-disciplinary education support team, which supports rehabilitation in the broader region, but true transdisciplinary services are in their infancy.

Once fitted correctly, there was a noticeable change in the twins' ability to interact with their surroundings. Their mother noted that they were able to eat, breathe, play and communicate with greater ease. She also noted that with her sons now comfortable in their devices, she would be able to find a day care centre for them, so that she could return to work. The physical burden of caretaking was also lessened, as she did not have to physically carry each child while performing household activities.

The SSE team trained the twins' mother on how to manage their positioning outside of their wheelchairs as well. At a later follow-up visit, the SSE team was able to issue the twins with side lying devices, in order to ensure that they were able to sleep comfortably and safely at night, and the family no longer have to share a bed. The family is now able to interact socially with others in their community and the twins are no longer forced to live within the confines of their home.

The team members will never forget the mother's words: "You have built up my trust in the healthcare system again. Thank you".

These were offered to parents of persons with disabilities, as well as disability stakeholders in the community.

The purpose of the LTD workshops was to open a dialogue between departments of Health, Education, Social Development and other local stakeholders on disability, and explore how to identify and reduce barriers. Through connecting stakeholders and establishing functioning referral pathways, SSE aimed to rebuild the ecosystem and drive sustainable change from within.

Key breakthroughs arising from the LTD workshops were that the participants experienced increased awareness of:

- The need to formalise local referral pathways and how to action them.
- Essential services that could support them (the therapists) and/or the children within the community.
- The social model of disability, and how this led to a lessened feeling of shame and exclusion among the children with disability and their families.
- Barriers within the community and how to address them.

## Conclusion

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This project demonstrated the positive outcomes of a public-private partnership in addressing the need for appropriate mobility devices. Through blended funding streams and a public-private partnership, the SSE, SIOC-cdt and NCDoH were able to address the need for assistive device technology, upskilling of professionals, and identification of non-functional government systems preventing the inclusion of persons with disabilities.

Implementation of the community-based outreach model proved to be a crucial factor in beginning to identify and address gaps in the system, and in introducing functional waiting lists. Appropriate costing should be done to address the mobility device needs of all persons with disabilities in a community. As a person with a physical impairment will not use the same device over the full course of his or her life, it is imperative that the budget be allocated to reflect these ongoing needs. For this, a functional waiting list is required, reflecting the assistive device needs of every client over the full course of each financial year and beyond. After a client receives an appropriate device, that client should:

- Be allocated funding for the time spent on the next seating review in 4 - 6 months' time (human resources).
- Be allocated funding for the technical spares/covers/foam components that will be required at the next review (financial and physical resources).
- Be allocated to a waiting list for a new device in roughly 3 - 5 years (financial, physical and human resources).

Budgets should be continuously updated to account for new devices, spare covers and foam components, as well as

technical maintenance, for every client seen or issued with a new device.

Previously, the ongoing costs were not accounted for or reflected in the way in which the waiting list data were reported. Initially, once a client received a device s/he was removed from the hospital database, effectively indicating that no further intervention was needed. As a result of this, the budget allocated to the hospital for assistive device technology stagnated, and was insufficient to provide for or reflect the true needs of the community.

The study found that building the capacity of local government therapists led to improved access to quality wheelchair services for communities, and sustainable systems change. Further, the implementation of outreach seating clinics proved to be crucial in influencing the quality of wheelchair service provision and sustainable systems change in both clusters.

In training existing professionals on the WHO guidelines for wheelchair service provision within the NCDoH, therapists were able to provide quality and sustainable services to clients in need of assistive device technology, as the skills and knowledge required for implementation became embedded within the capacity of local government providers.

As training was provided with the goal of influencing the system (by aligning service delivery with WHO standards), as opposed to providing clinical training in isolation, local therapists were able to utilise a holistic approach when delivering wheelchair services. In addition to this, all outreach seating clinics were hosted at venues within the community, which allowed for improved access to services for the community.

Creating awareness of barriers in the community among local government, the community, and local disability stakeholders, led to sustainable systems change in terms of identifying and actioning local referral pathways.

In hosting the LTD workshops, the SSE and NCDoH were able to further align their practice with the community-based rehabilitation matrix in the community, promoting inclusion through self-advocacy, awareness-raising, and empowerment. Key outcomes included:

- Increased awareness in the community as to which services were available to them, and how to action referral pathways.
- Identification of barriers to inclusion within the community, in order to start addressing these.
- Empowering the community with knowledge and creating open dialogue between local government and the community, in order for the community to drive the change needed from within.

## Adaptations in light of Covid-19

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“South African parents struggle to access health and educational services for CWD [children with disabilities], and many are reliant on state-funded facilities. Continuity of care becomes possible where professionals or trained caregivers transfer skills to family members, to mitigate factors that hinder continuity of care of CWD, by providing home-based visits”.<sup>7</sup> Shifting toward remote clinical support was also found to be of benefit.

Programmes that directly involve parents and carers of persons with disabilities are currently much needed and overlooked. The Covid pandemic has left many families underserved, and parents can be isolated in meeting the daily needs of their children. For this to change, parents must be empowered to ensure the health of their children.

In light of the Covid-19 pandemic, the study and inputs into the project have been adapted. The SSE has undertaken training of NCDoh staff remotely via social media platforms, using the community-based outreach model, as well as community-based play and learning. Therapists and supporting referral professionals (community healthcare workers, community leaders, speech therapists and dieticians) have received training on the principles of 24-hour positioning in the home, defining disability, the rights of persons with disabilities, and adaptive techniques to facilitate play and learning in the home. In training the professionals, these skills can be transferred to parents, in order for parents to continue to provide the necessary care to their children while adhering to lockdown regulations and preventing a rise in Covid-19 infection by not attending their regular therapy sessions. The training also aids in capacitating professionals who are not usually involved in rehabilitation, to identify clients in the community, and act as a resource and referral pathway to families in their community.

## Recommendations

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The underlying thread in all dysfunctional health ecosystems is lack of awareness, absence of training, siloed service delivery, and lack of formal systems. In order to address the needs of a community, understanding and immersion are necessary in the context of that community.

Fresh thinking on how to deliver sustainable services, improved support systems with increased awareness and service access, and fluid processes between service levels, will help persons with disabilities to become productive, contributing members of society.

For change to happen, the SSE recommends the following:

- Establish disability forums for all communities, including all disability stakeholders in the community. This will allow open dialogues to be held on disability-specific challenges in order to identify barriers (relevant to the community) and seek out possible solutions using local resources.
- Establish a standardised mechanism for referral pathways to local services, with the roles and responsibilities of each individual clearly identified, to ensure fluidity of referrals and processes from one level of service to the next.
- Introduce training for parents, community healthcare workers, other healthcare professionals, and social and education professionals, in order to establish a network of individuals who are capacitated to identify and support persons with disabilities.
- Ensure regular community-based outreach seating clinics to address the need for appropriate assistive device technology and wheelchair-related services. Clinics should be delivered at venues that are central and accessible to community members.
- Introduce in-depth wheelchair service provision training at undergraduate level for physiotherapy and occupational therapy students, in order to prepare future therapists for the realities of wheelchair service provision before they enter their community-service year. This will provide students with a base of knowledge to start or continue services in their respective community-service placements.
- Ensure training for local rehabilitation therapists using the WHO guidelines on wheelchair service provision, as well as mentored and remote support to facilitate practical skills development.
- Ensure accurate record keeping and handover to ensure that clients are not lost to follow-up.
- Ensure adequate data capturing to establish a functional waiting list that reflects the needs of clients for assistive device technology throughout their lifespan in order to allocate sufficient budget to address and reflect the true needs of the community.

## Study limitations

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Therapists who attended the community-based outreach clinics managed their time between the training and their daily work commitments. Different therapists attended different training days, and only 35 of the 40 therapists trained received the full training, and completed all the impact tools. The primary data sources were compiled using data from the therapists who attended all the sessions. Although the primary data collected reflect the perceptions of 87.5% of the participants, results may have reflected a degree of variation had all therapists completed the impact tools. Therapists are currently participating in training remotely (via Zoom and WhatsApp), and it has been agreed that clients will be attended to before and after the sessions, in order for therapists to complete the course in its entirety.

The WHO wheelchair service provision guidelines state that a significant step in the process includes that appropriate funding and ordering processes be in place. The standard procedure in all South African government settings is that therapists place orders for assistive devices with the procurement department of their institutions. This step needs to be strengthened. If the procurement department requests alternative quotes from tender suppliers in order to source the most cost-effective solution, the clinical needs of the client may be overlooked.

It is therefore imperative to train all procurement departments in the clinical relevance of equipment. At the same time therapists should be trained in the process of motivating for specialised equipment. This will ensure that clients do not receive devices that are inappropriate in terms of their physical needs and functioning.

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