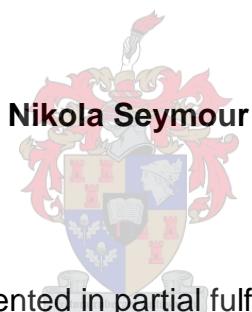


Research assignment

Exploring CBR workers' perceptions of their role in wheelchair provision in three areas of Uganda



Research assignment presented in partial fulfilment of the requirements for the
degree of Masters in Human Rehabilitation at Stellenbosch University

Supervisor: Martha Geiger

March 2016

DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Date: March 2016

Abstract

Background: Wheelchair provision and use in less resourced settings face significant challenges. Global efforts to affect change include the *WHO Guidelines on provision of manual wheelchairs in less resourced settings* and the WHO wheelchair training resources. Multiple stakeholders are required to collaborate to affect improvement, and in contexts where community-based rehabilitation (CBR) is implemented CBR workers have a role to play.

Objectives: The objectives of the study were to determine what CBR workers in three areas of Uganda perceive as the challenges with wheelchair provision and use; the factors contributing to these challenges; the role they can play and what they need to achieve this.

Method: This qualitative, participatory study in the transformative paradigm gathered perceptions of twenty one CBR workers through three focus group discussions, in the north, west and central regions of Uganda.

Findings: Limited availability of appropriate products; financial constraints of people with disabilities (PWD) and wheelchair services; and historical and societal influences on beliefs are perceived by CBR workers to affect utilisation of wheelchair services and mobility of PWD. Participation is further influenced by inadequate skills in wheelchair use; limited durability of products and environmental factors including physical and attitudinal barriers. CBR workers suggested strategies which, if strengthened with training and closer partnership with wheelchair services, can positively impact the provision and use of wheelchairs in less-resourced settings. Findings also indicate the need to address issues related to the position and empowerment of CBR workers.

Conclusion: Contextual challenges to wheelchair provision and use in less-resourced settings would benefit from involvement of CBR workers. However, further efforts are required to increase the availability of appropriate wheelchairs and services, and to ensure the financial resources necessary to enhance effectiveness of both wheelchair services and community-based rehabilitation.

Opsomming

Agtergrond: Rolstoel voorsiening en gebruik in minder gegoede omgewings word deur verskeie groot uitdagings getref. Wereldwyse insette om veranderings te bewerkstellig sluit die Wereld Gesondheids Organisasie (WHO) se riglyne vir voorsiening van gewone rolstoele in minder gegoede omgewings en ook die WHO rolstoel opleidingspakette, in. Verskeie betrokkenes is nodig om saam te werk om die situasie te verbeter in kontekste waar gemeenskaps gebaseerde rehabilitasie ge-implementeer word en gemeenskapswerkers het 'n rol om te speel.

Doelstelling: Die doelstellings van die studie was om vas te stel wat gemeenskapswerkers in drie gebiede van Oeganda sien as uitdagings met rolstoel voorsiening en gebruik; die faktore wat bydra tot hierdie uitdagings; die rol wat die werkers kan speel en wat hulle benodig om dit te kan doen.

Metode: Hierdie kwalitatiewe, deelnemende studie binne 'n transformatiewe raamwerk is uitgevoer om persepsies van een-en-twintig gemeenskapswerkers deur middel van drie fokusgroep besprekings te versamel in die noorde, weste en sentrale gebiede van Oeganda.

Bevindings: Volgens die gemeenskapswerkers het beperkte beskikbaarheid van toepaslike produkte; finansiële beperkings van mense met gestremdhede en rolstoel dienste; en historiese en sosiale invloede op gelowe, impakte op die gebruik van rolstoele en dus die mobiliteit van mense met gestremdhede. Deelname in die gemeenskap word verder beïnvloed deur ontoereikende vaardighede in rolstoelgebruik; beperkte houbaarheid van produkte en omgewingsfaktore insluitend fisiese en houdings stuikelblokke. Gemeenskapswerkers het strategiee voorgestel wat 'n positiewe impak op die voorsiening en gebruik van rolstoele in minder-gegoede omgewings kan hê: indien dit deur opleiding en nouer samewerking met rolstoeldienste, versterk word. Bevindings duï ook aan dat daar 'n behoefte is, om aandag te gee aan ander kwessies in verband met die posisie en bemagtiging van gemeenskapswerkers

Slotsom: Omgewings uitdagings vir rolstoel voorsiening en gebruik in minder gegoede omgewings sou baat by die betrokkenheid van gemeenskapswerkers. Nogtans is verdere inspanning nodig om die beskikbaarheid van toepaslike rolstoele en dienste aan te vul; en om te verseker dat die nodige finansiële hulpbronne om die effektiwiteit van rolstoel en gemeenskapsdienste te versterk, beskikbaar gestel word.

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List of Abbreviations

CBO – Community-based organisation

CBR – Community-based rehabilitation

FGD - Focus group discussion

ICF – International Classification of Functioning, Disability and Health

ISPO – International Society of Prosthetics and Orthotics

NWC – National Wheelchair Committee

NUDIPU – National Union of Disabled Persons Uganda

PWD – Person(s) with disabilities

UNBS - Uganda National Bureau of Standard

UNCRPD - United Nations Convention on the Rights of Persons with Disabilities

WHO – World Health Organization

WHO Wheelchair Guidelines - World Health Organization Guidelines on the provision of manual wheelchairs in less-resourced settings

Glossary

Appropriate wheelchair	A wheelchair that 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 the most economical and affordable price.
Less-resourced setting	A geographical area with limited financial, human and infrastructural resources to provide wheelchairs (a common situation in low- and middle income countries, but also in certain areas of high-income countries.)
Wheelchair provision	An overall term for wheelchair design, production, supply and service delivery.
Wheelchair service	That part of wheelchair provision concerned with ensuring that each user receives an appropriate wheelchair.
Wheelchair service personnel	Persons skilled in the provision of an appropriate wheelchair.
Wheelchair user	A person who has difficulty in walking or moving around and uses a wheelchair for mobility.

(WHO 2008 & 2012)

Chapter 1: Introduction

1.1 Background

Provision of wheelchairs in less-resourced settings is profoundly challenged and not meeting the needs of people with disabilities (PWD) (WHO 2011b). Further to this, the use of wheelchairs for participation in meaningful life activities and community development opportunities is equally challenging. Both situations are globally acknowledged, hence significant efforts in the last decade to initiate change. *The United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD), the World Health Organization (WHO) *Guidelines on the Provision of manual wheelchairs in less resourced settings* and *Guidelines on Community-based Rehabilitation* (CBR) outline individuals' rights, emphasise international and national responsibilities and provide strategies for improvements (UN 2006; WHO 2008; 2010).

The WHO has promoted a rights-based approach to wheelchair provision which recommends users have access to appropriate wheelchairs that meet their needs, through a wheelchair service delivered by trained wheelchair service providers. A service should include, for every user, eight essential steps and evidence-based, standardised WHO training packages have been developed to support this (WHO 2008; 2012; 2015).

Contextual challenges of less-resourced settings are known however to place obstacles to effective provision; similar barriers further influence a PWD ability to optimally use their wheelchair (WHO 2011 a). Effective collaboration of a range of stakeholders is crucial to help overcome barriers to ensure appropriate wheelchair provision and to maximise the benefit for the user. For countries where CBR is a strategy towards rehabilitation and inclusion of PWD, CBR workers are recommended as having a role (WHO 2008; WHO 2010).

Focus on improved wheelchair provision is new in many less-resourced countries; especially where strategies have included use of the WHO wheelchair training packages as a foundation for improving service delivery (ISWP n.d.). Uganda is an example in which certain areas now have access to wheelchair services with trained personnel. Uganda has also adopted a CBR strategy for rehabilitation and is therefore the ideal location to explore CBR workers' observations of the current situation and perceptions of their current and potential roles.

My interest in this topic is derived from my work with Motivation Charitable Trust, an international disability charity organisation with headquarters in the UK. Motivation has worked for the past 25 years with local partner organisations around the world to provide wheelchairs and programmes for people with disabilities (Motivation n.d.). The purpose of my role within this organisation is to contribute to the development of effective and sustainable wheelchair services. Our work in Uganda started in 1999 and our programmes provide an important setting for learning within a context with significant challenges to rehabilitation and for PWD. Learning from this study will hopefully strengthen our work in Uganda and provide points for reflection to enhance our work in other areas.

1.2 Literature review

The United Nations Convention on the Rights of Persons with Disability (UNCRPD) (UN 2006) identifies personal mobility (Article 20) as a right for people with disabilities (PWD) and a responsibility of state parties. Article 20 includes the responsibility to facilitate access for PWD to quality devices ‘at the time of their choice and at an affordable cost’ and states the related importance of ‘training in mobility skills’. Article 26 (Habilitation and rehabilitation) of the convention raises the need for assistive devices as an essential element within habilitation and rehabilitation of PWD and Article 4 (General obligations) calls for accessible information about devices and services. Article 9 and 19 further illustrate the right for PWD to full inclusion and participation in society and highlight that for people with *mobility* disabilities - including wheelchair users - the right to an accessible environment is paramount (UNCRPD 2006).

Assistive technology is defined by the World Health Organisation (WHO) as ‘an umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed’ (GATE 2013). Wheelchairs are one of the most commonly needed devices to assist mobility (WHO 2008). The WHO estimates that people who need wheelchairs comprise approximately 1% of any population (WHO 2008:21). The overall numbers of PWD is however on the rise according to the *World report on disability*, due to factors such as ‘road traffic accidents, natural disasters, conflicts, diet and substance abuse’ and an increase in numbers of children and older people (Mannan, MacLachlan & McAuliffe 2012; WHO 2011a; 2011c). In less-resourced settings the highest prevalence of PWD is reported to be in the poorest communities and rural areas with a vicious cycle at play between poverty and disability (Booyens, van Pletzen & Lorenzo 2015; Eide, Khupe & Mannan 2014; Magnusson *et al.* 2014; WHO 2011).

Access to an appropriate device such as a wheelchair can have a significant impact on the personal health and societal participation of a PWD thereby impacting quality of life and potentially reducing poverty (Banda-Chalwe, Nitz & Jonge 2014; Borg, Larssen & Ostergren 2011 a; Toro *et al.* 2012; Visagie, Duffield & Unger 2015 a; WHO 2011 c:18). Despite this, access to appropriate assistive devices and associated services is limited and not meeting the need (Borg *et al.* 2011a; Eide & Oderud 2009; Visagie *et al.* 2015 a; WHO 2008; WHO 2011 a & b). A study in four Southern African countries (Zambia, Namibia, Malawi, Zimbabwe) between 2001 and 2006 showed that only 17-37% of people needing assistive devices received them (WHO 2011 c:42). The WHO estimates however, that on average, only 5-15% of children and adults *needing* assistive devices in low and middle income countries have them (Borg *et al.* 2011 a; WHO 2008).

The United Nations Children's Fund (UNICEF 2013) estimates between 5 and 15% of all the children in Africa have a disability with cerebral palsy (CP) being one of the most common causes (Bray *et al.* 2014; Donald *et al.* 2014, Zuurmond *et al.* 2015). The need for wheelchairs and other mobility devices is a major challenge for children with CP and other physical disabilities in Africa, resulting in significant consequences for health, development and other aspects of life (Donald *et al.* 2014; Saloojee *et al.* 2006).

In many less-resourced settings international organisations have responded to the gaps by providing high volumes of either mass produced, low cost or second hand wheelchairs. Typically lacking adjustability and hence only suited to few users these wheelchairs also rarely suit the environment and damage quickly (Armstrong, Reisinger & Smith 2007; Jefferts *et al.* 2010; Mukherjee & Samanta 2005; Visagie *et al.* 2015 a; Visagie *et al.* 2015 b). Commonly known as the 'charity model approach', assessment of individual users needs is rare and negative impact on individuals mobility, functioning and empowerment has been found in the literature (Armstrong *et al.* 2007; Mukherjee & Samanta 2005; Visagie *et al.* 2015 a; Visagie *et al.* 2015 b).

In 2008 the WHO and key stakeholders including the International Society for Prosthetics and Orthotics (ISPO), United States Agency for International Development (USAID) and Disabled Peoples' International responded to the situation, following an international consensus conference, by launching the WHO *Guidelines on the provision of manual wheelchairs in less resourced settings* (ISPO, USAID & WHO 2006; WHO 2008). These guidelines aim to 'promote personal mobility and enhance the quality of life of wheelchair users by assisting member states in developing a system of wheelchair provision to support implementation of the UNCRPD' (WHO 2008:9). Since this time the WHO has spearheaded

global initiatives to further improve access to appropriate assistive devices including wheelchairs such as the *Global cooperation on assistive technology* (GATE 2013) and the inclusion of provision of assistive devices in the *WHO Global disability action plan 2014 to 2021* (WHO 2014). The *International society of wheelchair professionals* (ISWP n.d.) established in 2015, further aims to develop and maintain standards, based on the WHO Guidelines, to professionalise wheelchair service provision worldwide (ISWP n.d.).

The WHO wheelchair guidelines define a wheelchair as appropriate when it '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 2008:21). Wheelchair design, production and supply are therefore required to be appropriate to the context and users' needs (Pearlman *et al.* 2008; Visagie *et al.* 2015 a; Visagie *et al.* 2015 b; WHO 2008). To facilitate this further a wheelchair must be delivered through a service (Armstrong *et al.* 2007; Eide & Oderud 2009; GATE 2013; Visagie *et al.* 2015 a; Visagie *et al.* 2015 b; WHO 2008). The guidelines delineate eight service steps essential for any person requiring a wheelchair and provide best practice recommendations for implementation (WHO 2008:76). These eight steps are

Step 1: Referral and appointment

Step 2: Assessment

Step 3: Prescription

Step 4: Funding and ordering

Step 5: Product preparation

Step 6: Fitting

Step 7: User training

Step 8: Follow up, maintenance and repair

Appropriate training of personnel in all stages of service delivery is promoted and has an impact on user satisfaction (Borg *et al.* 2011 a; Mukherjee & Samantra 2005; Samuelsson & Wressle 2008, Visagie *et al.* 2013; Visagie *et al.* 2015 a; Visagie *et al.* 2015 b; WHO 2008). Drawing on the impact that sector guidelines and standardized trainings had on the prosthetic and orthotic sector, the WHO and key stakeholders developed a number of key education packages for personnel involved in wheelchair service delivery (ISPO 2006). The Wheelchair Service Training Package Basic (WSTP-B) and Intermediate (WSTP-I) teach skills to provide wheelchairs to adults and children with minimal to moderate postural support

needs (WHO 2012). The Wheelchair Service Training Package for Managers (WSTP-M) (WHO 2015) aims to ensure that managers support wheelchair service personnel and are able to evaluate and promote the service (WHO 2008).

The packages aim to improve quality of service delivery and wheelchair provision with the ultimate goal of enabling PWD to 'become mobile, remain healthy and participate fully in community life' (WHO 2008; WHO 2015). Acknowledging the enormity of this task the Wheelchair Service Training Package for Stakeholders (WSTP-S) emphasises the need for multiple stakeholder involvement (WHO 2015). In addition to wheelchair users, this includes policy planners, wheelchair manufacturers, wheelchair services, disabled peoples organisations (DPO) and other local and international non-government organisations (WHO 2008). Borg, Lindstrom & Larsson (2011b) emphasise the need to pay attention to the systems of wheelchair provision to ensure a cost-effective, equitable approach. CBR is a suggested strategy and CBR workers are stakeholders that may contribute; hence the focus of this study (Borg *et al.* 2011 b; WHO 2008 & 2011 a & b).

The 2006 International Wheelchair consensus conference points out 'unless CBR is involved in wheelchair provision, we will not reach very far' (ISPO 2006:23). Suggestions of specific roles that can be implemented by CBR personnel, include participating in the referral system especially to locate remote and/or unidentified wheelchair users (Wheelchair service step 1), providing wheelchairs (Wheelchair service step 2 to 6), assisting with training of users (Wheelchair service step 7) and helping with on-going follow up, maintenance and repairs (Wheelchair service step 8) (WHO 2008, 2011 a & b & 2015). Helping users to effectively use wheelchairs by advising on accessibility and providing feedback to services on prescription and use of wheelchairs is an additional potential role for CBR personnel (ISPO 2006).

The following sections introduce the current challenges in less-resourced settings for provision of wheelchairs through the 8 stepped process followed by challenges for PWD in using wheelchairs. The role for CBR is then further explored before the situation in Uganda is discussed. To enhance learning, some observations are borrowed from studies related to the prosthetic and orthotic sector and rehabilitation in less-resourced settings considering the similarities in context and barriers (ISPO 2006) and the limited research on effectiveness of strategies to provision of wheelchairs in less-resourced settings (Borg *et al.*, 2011b; Bray *et al.* 2014).

Challenges with accessing wheelchair services

As discussed, the global community is directing substantial efforts towards improving the situation for people needing wheelchairs (GATE n.d; ISWP n.d.; Rispin & Wee 2014) however, the situation remains that the majority of people in less-resourced settings have significant challenges in accessing the devices they need (Bray et al. 2014; Borg et al. 2011 b; Jefferds et al. 2010; NUDIPU 2013; Rispin & Wee 2014; Visage et al. 2015; WHO 2011 a & b). *The WHO Joint position paper on the provision of mobility devices in less-resourced settings* brought attention to the most common barriers which will be discussed in the following paragraphs. Foremost lack of government commitment to people's right to mobility results in lack of policy and effective legislation and lack of or insufficient financial resources (Borg et al. 2011 b; Visagie et al. 2013; Visagie et al. 2015 a; Weerasingher 2015; WHO 2011 a). In addition wheelchairs are seldom available and local production is often compromised by lack of financial resources (Bande-Chalwe et al. 2013; Jefferds et al. 2010; Øderud, Brodkorb, & Hotchkiss 2004).

A significant challenge in less-resourced settings is that wheelchair services are often not available, affordable or accessible (Bray et al. 2014; Borg et al. 2011 a & 2012; Eide & Øderud 2009; WHO 2011 a). There are many reasons for this however a key reason is the lack of suitably trained human resources (Mannan et al. 2012; Øderud, et al. 2004; Samuelsson & Wressle 2008; Visagie et al. 2015 a & Visagie et al. 2015 b; WHO 2011 a & WHO c:10-11). Rehabilitation professionals such as physiotherapists, occupational therapists and prosthetist orthotists, while not the only candidates, have the background education most relevant for wheelchair service delivery (Greer, Brasuré & Wilt 2012) however in many less-resourced settings are in short supply (Bury et al. 2005; Deepak et al. 2011; Grut et al. 2012; Mannan et al. 2012; Øderud et al. 2004; Wegner and Rhoda 2015; WHO 2011 a and b). The study carried out in Malawi, Zimbabwe, Namibia and Zambia showed that only 23-54% of people received the rehabilitation they needed (WHO 2011 b). Estimates indicate fewer than 0.5 rehabilitation professionals per 10,000 people in countries in Sub-Saharan Africa (WHO 2011 b:40). Other personnel able to develop relevant skills include rehabilitation technicians and CBR workers (Visagie et al. 2015 b; WHO 2008). However the situation is further challenged by the difficulty with accessing the appropriate WHO trainings discussed earlier. While the new courses may exist they are not regularly delivered in most countries (ISWP n.d).

As recommended in both the WHO Wheelchair (2008) and CBR guidelines (2010) and elsewhere, services for people with disabilities should be provided as close to communities

as possible (Grut *et al.* 2012; Visagie 2015 a). Unfortunately the low numbers of trained personnel, further compromised by insufficient resources, mean wheelchair services are mostly unavailable or delivered from centralised locations commonly main cities and towns (Borg *et al.* 2012; Grut *et al.* 2012; WHO 2011a). Outreach services are typically negligible being largely reliant on external donors (Booyens *et al.* 2015). Consequently community members who require input from wheelchair service personnel are required to overcome diverse barriers in order to access the centralised service (Booyens *et al.* 2015; Bury 2005; Hansen, Tresse & Gunnarson 2004, Harkins, McGarry & Buis 2012; Ikeda *et al.* 2013; Toro *et al.* 2012, Wickenden *et al.* 2012). These challenges can have a significant impact on marginalised groups such as women and those living in rural areas hence their specific reference in UNCRPD Article 26 (Rehabilitation and habilitation) (Eide & Øderud 2009, UN 2006).

Accessing available wheelchair services also continues to be exceedingly difficult for users due to financial constraints, few transport options and lack of information on availability of the service (Booyens *et al.* 2015; Campbell, Col & Thurston 2012; Eide *et al.* 2014; Fefoame, Walugembe & Mpou 2013; Mlenzana *et al.* 2013; Rispin & Wee 2014; Schneider *et al.* 2013; Saloojee *et al.* 2006; Øderud *et al.* 2004; Weerasingher *et al.* 2015). Further to this stigma, attitudinal barriers and beliefs influence the uptake of service (Booyens *et al.* 2015; Deepak *et al.* 2014; Eide *et al.* 2014; Grut *et al.* 2012; MacLachlan *et al.* 2014; Magnusson *et al.* 2013; Weerasingher *et al.* 2015; Wegner & Rhoda 2015). This creates a gap in both the referral and follow up process (step 1 and 8 of wheelchair service delivery) where the service may be unaware of and/or unable to reach those in need and those in need may be equally unaware of and/or unable to reach the service.

Trained wheelchair service personnel are expected to assess a user's needs, prescribe the appropriate wheelchair to meet those needs and adjust it to fit comfortably and safely (Armstrong *et al.* 2007; Visagie *et al.* 2015 a & Visagie *et al.* 2015 b; WHO 2008). Accuracy of assessments can be compromised by lack of knowledge of the environment in which the user expects to use the wheelchair, inability to provide the service in the user's local environment and inaccurate information from users themselves (Bray *et al.* 2014; Visagie *et al.* 2013). Visagie *et al.* (2015 a) observed, in studies in South Africa, that therapists only discovered that the gaps in information had resulted in incorrect prescription, when they had the opportunity to follow the PWD up in the home. Wheelchair service personnel are further challenged with limited ranges of appropriate products as insufficient government budget affects choices based on cost (Visagie *et al.* 2015 a) and lack of government budget places a dependency on donors often leading to inconsistent and restricted range.

Products may be manufactured locally or internationally (Jefferds *et al.* 2010; Rispin *et al.* 2014). Local production can be compromised by lack of government commitment and limited resources ultimately affecting quality of the device (WHO 2015). Imported and donated products provided through a service can result in user satisfaction if the design is suitable for the environment with adjustability built in to accommodate various functional and physical needs (Jeffereds *et al.* 2010; Rispin & Wee 2014; Visagie *et al.* 2015 b). The large majority of products donated to and produced in less-resourced settings have historically been and still predominantly are for adult active users (Motivation n.d.). This leaves a significant gap for children and those with complex postural needs (Bray *et al.* 2014; Rispin & Wee 2014; Saloojee *et al.* 2006). Less-resourced settings with challenging environments particularly in rural areas, add significance to the durability of a wheelchair as demonstrated by 95 users in Zimbabwe (Visagie *et al.* 2015 b) who reported this as the most important feature (Armstrong *et al.* 2007; Banda-chalwa *et al.* 2014; Mukherjee & Samanta 2005; Visagie *et al.* 2015 a). As Mukherjee & Samanta (2005) denote, receipt of a non-optimal wheelchair can result in it being discarded.

A further challenge to prescribing an appropriate wheelchair is the range of functions and activities for which it is needed and particularly in less-resourced settings the range of environments it is expected to navigate (Visagie *et al.* 2015 a). Wheelchairs that can travel on rough terrains, be used in small indoor spaces and fold for transport and storage may be challenging to come by and in some instances a user may benefit from two different types (Mukherjee & Samanta 2005; Visagie *et al.* 2015 a). Unfortunately this is recognised as currently unlikely in most less-resourced situations (Visagie *et al.* 2015 a) but places additional challenges for the wheelchair provision sector.

Training a wheelchair user or their carer in the effective and safe use of the wheelchair, is critical and captured in Step 7 in the WHO wheelchair service steps (Hosseini *et al.* 2012; Jefferds *et al.* 2010, Pearlman *et al.* 2008, Sawatzky *et al.* 2012, Visagie *et al.* 2013, UN 2006; WHO 2008). An appropriate wheelchair and relevant skills can reduce the risk of falls and other health complications such as pressure ulcers, bowel or bladder problems, and can enhance functioning and participation (Greer, Brasure & Wilt 2012). The positive impact for children propelling independently was found by Sawatzky *et al.* (2012) to include negotiating potholes, moving over different levels and doing wheelies which help to improve community mobility and are especially important in the rough terrains or unmaintained areas common in less-resourced environments. Users in many less-resourced settings have been found to have insufficient skills to safely and optimally use their wheelchairs (Hosseini *et al.* 2012; Mukherjee & Samanta 2005; Visagie *et al.* 2015 b).

Users who have received a wheelchair need on-going support as recommended by the WHO Step 8: Follow up, maintenance and repair. Follow up is required by all wheelchair users and aims at enhancing fit, comfort and stability of the user in the wheelchair, ensuring the equipment is in good working condition and maximising the user's functioning (Øderud, et al. 2004; WHO 2008, WHO n.d). Follow up is usually on a scheduled basis or as and when needed by the user. Some users may be at a higher risk of complications thus rendering follow up essential and required more regularly. These include those who are at risk of developing pressure sores, have progressive conditions or complex postural needs. All children need to be followed up due to their changing physical and developmental needs as well as users or carers with difficulty understanding instructions (WHO 2008: 85). Reported benefits for the user are reduced pressure sores, reduced risks of accidents and improved confidence in wheelchair use (Fogelberg et al. 2009; Greer et al. 2012; Sakakibara et al. 2015; Visagie et al. 2015 a). Additional benefits for the user and for the service provider are the identification of incorrect product prescriptions and incorrect fittings and understanding the user's living environment and functional needs (Visagie et al. 2015 a; WHO 2008; WHO 2012).

Despite the need and importance of follow up by trained service providers, this is often lacking as stated in the 2013 *Uganda UNCRPD Alternative* report by National Union of Disabled Persons Uganda (NUDIPU 2013). Many studies on provision of wheelchairs and other mobility aids have found this to be a major gap and unsatisfactory to users even though in many circumstances they rated it as important (Ikeda et al. 2013; Magnusson et al. 2013; Samuelsson & Wressle 2008; Visagie et al. 2013, Visagie et al. 2015 a, Visagie et al. 2015 b). This is despite the fact that follow up can be carried out in any location including in the service centre, the user's local community or home environment (WHO 2015). Challenges are surmised as similar to those discussed previously on challenges for users and service connecting such as financial, transport and attitudinal barriers (WHO 2015).

Regular maintenance is a priority for users and essential to ensure durability and safety of the wheelchair (Chen et al. 2011, Fogelberg et al. 2009, Magnusson et al. 2013). Step 7 of a wheelchair service empowers users with education on product use and maintenance however in many situations on-going maintenance remains a problem (WHO 2008). A random controlled study of 216 manual wheelchair users in Sweden found that wheelchair users were not able to determine their own need for adjustments and that regular checks named 'active wheelchair check-ups' by the service helped to prevent problems and accidents (Hansen et al. 2004). Further studies in Taiwan and Mexico showed that, along with an appropriately prescribed wheelchair, the similar 'check-up' approach made an impact

(Chen *et al.* 2011; Toro *et al.* 2012). Both these studies found the age of the wheelchair did not impact the need and Toro *et al.* found that adjustments were required as early as six months after issue (Hansen *et al.* 2004; Toro *et al.* 2012).

Further to the need for maintenance McClure *et al.* (2009) in the USA found in a six month period 44% of over 2000 full time wheelchair users required repairs. Considering the terrain, type of use and numbers of inappropriate devices it is likely, in less-resourced settings, that the need for repairs is as high if not higher. Skilled repair services and access to spare parts are required close to the community which is rarely the case in less-resourced settings, contributing to the high percentage of damaged and discarded wheelchairs (Armstrong *et al.* 2007; McClure *et al.* 2009, Pearlman *et al.* 2008, Toro *et al.* 2012; Visagie *et al.* 2013, Weerasingher *et al.* 2015). Furthermore users often struggle to find the financial resources to access repairs even if services and parts are available (Banda-Chalwe *et al.* 2014).

The need for and benefits of all eight steps are well captured in the literature, however implementing steps effectively, consistently and equally to all is significantly challenged (Accelovate 2015). While each of the steps individually require attention, it is also necessary to strengthen the entire system and engage relevant stakeholders where necessary (Borg *et al.* 2011 b).

Challenges of using an appropriate wheelchair

Wheelchair provision is about ‘enabling PWD to become mobile, remain healthy and participate fully in community life’ (WHO 2008). As pointed out at the WHO consensus conference in some cases a wheelchair ‘*makes very little difference if the core issues are not addressed at the same time*’ (ISPO 2006:126). While the WHO Guidelines put a greater emphasis on provision of an appropriate wheelchair through an appropriate service it is necessary for stakeholders to have a comprehensive understanding of the impact of and barriers to effective use (Borg *et al.* 2011 a). This is the starting point to removing barriers to enhance participation and to further improving products and services to meet users’ needs.

The International Classification of functioning, disability and health (ICF) provides a framework for understanding, measuring and communicating about disability and functioning (Madden *et al.* 20113; WHO 2011). The ICF considers impairment, activity limitations and participation restrictions in which ‘participation’ is considered as involvement in life situations and includes mobility, self-care, interpersonal relationships and involvement in major life areas, community and society (This is not the exhaustive list - WHO 2002). An assistive device is considered an environmental tool which aids functioning and participation. So while

all points raised in the previous section impact a person's ability to function and participate this section highlights other ICF contextual influences, including environmental and personal factors, further impacting a PWD's lived experience in a less-resourced setting (Smith, Sakakibara & Miller 2014; Magnusson *et al.* 2013; Visagie *et al.* 2015 a).

A wheelchair is able to improve a user's mobility and participation. However this is not an automatic result for many users in less-resourced settings and can be difficult to achieve or requires individual support (Banda-Chalwe *et al.* 2014; Bray *et al.* 2014; Eide & Øderud 2009). Physical accessibility of the indoor and outdoor environment is one of the major barriers to participation and independence for wheelchair users (Banda-Chalwe *et al.* 2014; Borg *et al.* 2012, Jefferds *et al.* 2010, Pearlman *et al.* 2008, Scovil *et al.* 2012; Smith *et al.* 2014, Visagie *et al.* 2015 b; Weerasingher *et al.* 2015). For this reason, the WHO recommends accessibility to be a key area of focus for wheelchair service managers (WHO 2008, 2015). Borg *et al.* (2012) also suggested that physical accessibility be considered in provision of wheelchairs when he found no significant difference in school and work participation in Bangladesh between people with ambulatory disabilities who used wheelchairs and those who did not (Borg *et al.* 2012).

Major problems exist in many less-resourced settings for wheelchair users trying to access public transport. Some difficulties relate to the physical accessibility of the vehicle however in most cases this is due to discrimination (Banda-Chalwe *et al.* 2014; Visagie *et al.* 2015 b, WHO 2011a). The impact of cultural and traditional beliefs, negative attitudes and stereotypical assumptions in the community is well documented and can result in behaviours which deter a wheelchair user from attempting to, or continuing to, participate in a desired activity (Banda-Chalwe *et al.* 2014; Borg *et al.* 2012; Smith *et al.* 2014; Weerasingher *et al.* 2015; Wegner & Rhoda 2015).

Coping mechanisms and emotional reactions of wheelchair users and carers to the above barriers, can lead to self-exclusion from activities. Depression, fear, despair, frustration and embarrassment are some of the personal factors influencing a person's desire to continue trying to overcome challenges (Banda- Chalwe *et al.* 2014; Saloojee *et al.* 2006). These and above barriers, which affect the experience of disability in a less-resourced settings, further compounded by the effects of poverty, profoundly impact a person's autonomy of choice (Borg *et al.* 2012; Lang *et al.* 2011; Mitra 2006).

Above factors highlight the need for on-going support for users and carers in overcoming environmental, emotional and societal barriers in order to realise the benefits of a wheelchair for improved mobility and in participating in their chosen life's activities. Long-term strategies

to remove barriers require involvement from multiple stakeholders at national, regional and local level through strategic and sufficiently funded interventions. However, for the immediate situation ‘social help and imaginative intervention’ and solidarity with family and community could empower a wheelchair user or carer in overcoming barriers (Lang *et al.* 2011; Sen 2009). Active, positive and empowered wheelchair users visible in the community may challenge negative stereotypes, support other users and promote the need for and benefit of appropriate wheelchair provision.

Community-based rehabilitation (CBR)

CBR, a rights-based, cross disability approach, is a ‘strategy within general community development for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of all PWD’ (ILO *et al.* 2004:2). CBR, once predominantly health focused, has evolved to include four other domains emphasising the importance of working with disability from a community development and social justice perspective (Booyens *et al.* 2015; Heinicke-Motshe *et al.* 2013). The CBR Guidelines presents these in a matrix as health, education, livelihood, social and empowerment highlighting the comprehensive needs of PWD (Booyens *et al.* 2015; Nganwa, Batesaki & Mallya 2013; WHO 2010; Wickenden *et al.* 2012).

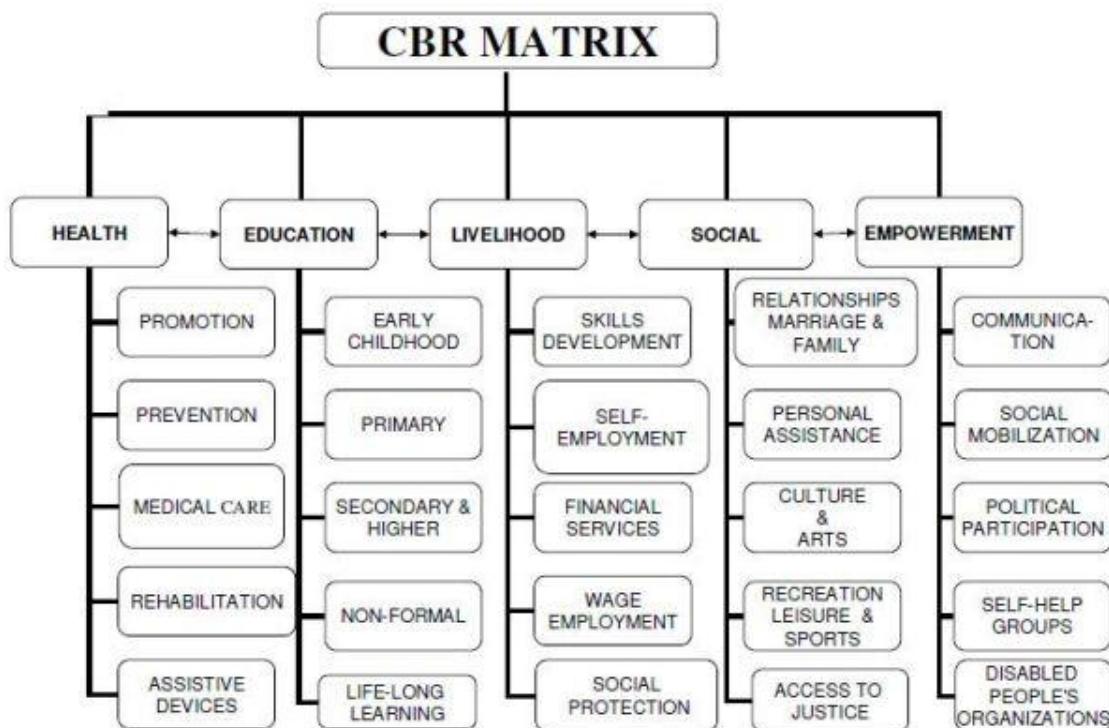


Figure 1.1 CBR matrix

Assistive devices are captured under the health domain which is recognised as cross cutting considering the influence on the other four components. (Bray *et al.* 2014; Nganwa *et al.* 2013). The CBR Guidelines also recognise empowerment of PWD and their families as the foundation of CBR having an influence on all other areas in the matrix (Heinicke-Motshe *et al.* 2013; Nganwa *et al.* 2013; WHO 2010).

CBR is a multi-sector approach requiring involvement from many stakeholders including PWD and their representatives or disabled people's organisations (DPO); policy makers and regulators and services providers such as those in health and rehabilitation (Geiser & Boersma 2013). This usually includes workers or volunteers from the community (from here on termed CBR workers although various titles are found in practice) providing services aimed at facilitating social inclusion of PWD (ILO *et al.* 2004; Booyens *et al.* 2015; Chappell & Johannsmeier 2009, Deepak *et al.* 2011). They may be connected to DPOs, community-based organisations (CBO) or others but they are usually situated close to or within local communities (WHO 2011 c:13). They are likely to be aware of local needs and known to those with disabilities and therefore accessible and available but also able to provide contextual observations of the reality to other stakeholders (Chappell & Johannsmeier 2009; Deepak *et al.* 2011; Grut *et al.* 2012, Ikeda *et al.* 2013; Toro *et al.* 2012; WHO 2008 & 2010). The CBR approach calls for a 'coordinated, comprehensive and inclusive response' (Geiser & Boersma 2013:28) and in particular close collaboration between CBR and health and rehabilitation services to facilitate a continuum of service for PWD (Fefoame *et al.* 2013).

The WHO CBR and Wheelchair Guidelines and other literature promote CBR workers as having a contribution to rehabilitation and provision of assistive devices (Campbell *et al.* 2012; Grut *et al.* 2012; Ikeda *et al.* 2013; Scovil *et al.* 2012; Wegner & Rhoda 2015; WHO 2008 and 2010; Zuurmond *et al.* 2015). CBR workers have a great role to play in situations with shortage of rehabilitation professionals, more commonly found in rural locations (Deepak *et al.* 2011; Mannan *et al.* 2012). Complex and holistic needs of PWD including, as emphasised by Zuurmond *et al.* (2015), children with CP, reinforces the need for more community support through CBR workers and points specifically to low and middle income environments with the high prevalence of multiple barriers to participation (Mannan *et al.* 2012; Saloojee *et al.* 2006).

Strategies employed by CBR workers to promote social inclusion and to empower PWD through reaching rural areas, carrying out home visits, establishing self-help groups and linking with community services enhance their appropriateness in contributing to provision of assistive devices (Ikeda *et al.* 2013). If provision of wheelchairs is to be enhanced for the

benefit of PWD than those working in the service would benefit from ‘activating grassroots knowledge and resources delivered through CBR’ (Fefoame *et al.* 2013: 39). Examples were found to demonstrate their role, however important to recognise these were not necessarily in settings where stakeholders were aware of the WHO Guidelines or where wheelchairs were delivered through the recommended eight stepped process.

Being part of the referral network for services is not an usual task within CBR workers’ scope of work (ILO 2004). This has been shown to have benefits to accessing devices and a study in Thailand demonstrated how the right training impacted this further (Deepak *et al.* 2014; Ikeda *et al.* 2013, Nualnetr & Sakhornkhan 2012). Fefoame, *et al.* (2013) provided an example from Ghana where CBR workers helped wheelchair users use their wheelchairs when training on the device was inadequate. They also helped to adjust the wheelchairs when support was lacking. WSTP Managers course (WSTP-M) suggests training CBR workers to assist with follow up as much possible so referral back to the wheelchair service can primarily be for re-assessment or repairs (WHO 2015). Reminding of regular maintenance of mobility devices and carrying out active check-ups is also recommended as a role to help prevent injuries, accidents and premature breakdown of devices (Campbell *et al.* 2012, Hansen *et al.* 2004, Ikeda *et al.* 2013).

A natural part of their role as CBR workers is to promote inclusion and participation of wheelchair users by identifying and using opportunities and removing community barriers (Booyens *et al.* 2015; Chappell & Johannsmeier 2009; ILO *et al.* 2004; WHO 2008 & 2011b). Scovil *et al.* (2012) recommend that community health workers be more actively involved when they found 93% of wheelchair users in their study in Nepal were unable to access their homes. Booyens *et al.* (2015) reported creative solutions of community workers in changing attitudes of discriminatory transport vendors. They have also been shown to have an impact on levels of independence and empowerment (Mol, van Brakel & Schreurs 2014) and in modifying attitudes and helping to fight prejudice and discrimination (Biggeri *et al.* 2014, Deepak *et al.* 2014). Providing feedback to the wheelchair services on the reality of users’ situation in the community is an additional and very important role for CBR workers (Fefoame *et al.* 2013).

Evidence on specific challenges experienced by CBR workers in implementing a role related to wheelchair provision was not found, however challenges in broader areas of work have been recorded such as insufficient knowledge, frustrations when inputs are not successful, lack of funds for health and rehabilitation systems and too few CBR workers (Booyens *et al.* 2015; Deepak *et al.* 2014). A study including 107 CBR workers across seven

countries identified their perceived training needs across all the domains of the CBR matrix. Fifty one percent highlighted ‘technical aids and appliances’ as a priority and 30% identified making and repairing mobility devices as a learning need (Deepak *et al.* 2011). Training, on-going support, monitoring and closer collaboration with health and rehabilitation services is recommended but identified as a gap (Fefoame *et al.* 2013; Nganwa *et al.* 2013; Wickenden *et al.* 2012). It is equally important to clarify the roles and responsibilities of the different sectors guiding the input from the rehabilitation and CBR workers. This also relates to resources required for manufacturing wheelchairs, enabling access of clients to the services and providing on-going support services (Fefoame *et al.* 2013).

The situation in Uganda

The Ministry of Gender, Labour and Social development (MGLSD) is the leading agency responsible for promoting and protecting the rights of people with disabilities in Uganda (MGLSD 2006). In 1992 the MGLSD adopted CBR as a strategy towards rehabilitation and community development for PWD (ILO, 2006; Øderud *et al.* 2004) and in 2008 they ratified the UNCRPD (Abimanyi-Ochom & Mannan 2014). The 2012 census by the Uganda Bureau of standards estimated that 19% of the Ugandan population has a disability (UNBS 2011) with people with physical disabilities comprising the majority within this group (UNICEF 2014). The 2013 UNCRPD report by the National Union of Disabled Persons Uganda (NUDIPU), the umbrella body for organisations representing people with disabilities, estimated that 80% of PWD are in rural areas (Abimanyi-Ochom & Mannan 2014).

Uganda’s National Policy on Disability (2006) prioritised provision of assistive devices. It draws in civil society organisations and DPOs as being responsible for increasing the capacity of PWD, linking them with existing services, helping to deliver services and mobilising resources (MGLSD, 2006:21 & 24). Despite this, the UNCRPD 2013 report indicates that of the total 30% of people requiring a mobility device only 2% can access them (NUDIPU 2013; Øderud *et al.* 2004).

In 2011 Uganda incorporated principles of the WHO Wheelchair Guidelines into a ‘*Code of practice for design, production, supply and distribution of wheelchairs and tricycles*’ (UNBS 2011). This was updated in 2015 showing commitment to the sector and launched in October 2015. It states that an appropriate service needs to be provided by a health professional who has received training and that this could include medical officers, occupational therapists, orthopaedic officers, orthopaedic surgeons, orthopaedic technologists, physiotherapists, and wheelchair technologists (UNBS 2011). The second

National Health Policy of Uganda (2010) reported however that there is a limited general capacity of health services at all levels in Uganda (MOH 2010:4; WHO 2011 c:13).

Two studies carried out in 2004 and 2005 by SINTEF (*Øderud et al.* 2004) and the National Wheelchair Committee (NWC) (Mukisa & UNAPD 2005) respectively found similar issues and reported the disparity in wheelchairs needed, compared to those available. *Øderud et al.* (2004) highlighted the presence of local production of wheelchairs since 1967 however workshops are unevenly distributed and the few workshops have relatively low capacity. Mukisa and UNAPD (2005) reported that over 75% of wheelchairs in the country were imported but that the prevailing scarcity made a wheelchair seem like a luxury rather than a right. The SINTEF study found a lack of awareness and skills and recommended training and clear definition of roles and responsibilities of stakeholders (*Øderud et al.* 2004). The NWC report called a wider range of community organisations to pay attention to wheelchair provision for their users (Mukisa & UNAPD 2005). Improvements have taken place in some aspects of provision with a small number of service personnel being trained in the WSTP training courses and increased access to a range of donated products being made available through their services. Four of these services have had personnel trained in WSTP-B; WSTP-I and WSTP-M.

The CBR sector in Uganda is more established than many other African countries and its initiation of CBR training through the Community Based Rehabilitation Alliance (COMBRA) in 1994 was progressive. Challenges for PWD however remain and include discrimination from the wider community which often leads to a more damaging effect than the impairment itself (MacLachlan *et al.* 2014 NUDIPU 2015). A paper by Abimanyi-Ochom and Mannan (2014) reviewing Uganda's journey of disability recognised the progress and the prevailing gaps listed recommendations including increased provision of assistive devices, improved data capturing and better community advocacy to change societal attitudes.

Engaging CBR workers

Due to the nature of CBR, the varied organisations that initiate CBR programmes and the domains guiding their focus (Wickenden *et al.* 2012) it is not guaranteed that all workers provide the same input and support. Although the field is now strongly guided by the CBR Guidelines (WHO 2010), and specifically the CBR matrix, training programmes are not standardised and workers may differ in approach due to particular strengths, interests and external factors (Chappell & Johannsmeier 2009; Deepak *et al.* 2011). For this reason, it is important to implement participatory approaches when evaluating and planning community strategies with CBR workers (Deepak *et al.* 2014; Wickenden *et al.* 2012). All opportunities

should be taken to create potential for CBR workers to learn and increase awareness of the scope of their role (Eide *et al.* 2014; Grandisson *et al.* 2014; Nualnetr & Sakhornkhan 2012).

1.3 Motivation for this study

Uganda, having ratified the UNCRPD in 2008, included CBR as a strategy for community development and adopted the WHO Wheelchair Guidelines (UNBS 2011) as a framework for wheelchair provision, demonstrates commitment to improving the situation for PWD and increasing access to appropriate wheelchairs. In line with this the Ministry of Health, other health organisations and international development organisations have started to take steps towards improving access to appropriate wheelchairs in specific areas by training service providers and availing appropriate products. However, as the literature shows, contextual issues commonly found in less-resourced settings add challenges to provision and use of wheelchairs. Feedback from users, CBR workers and service providers in Uganda indicate that improvements are evident but also point to on-going challenges.

CBR workers are referenced in various guidelines and literature such as the WHO Wheelchair and the WHO CBR Guidelines (WHO 2008 & 2010) as well as the Ugandan National Policy on Disability (2006) and Code of practice for wheelchair provision (UNBS 2011) as a role player in wheelchair provision and in supporting wheelchair users. Their role however is not specifically defined. By exploring this role further through the perspectives of CBR workers who are exposed to new approaches to wheelchair service delivery and provision it may be possible to inform future programmes and practice in Uganda as well as other regions experiencing similar challenges.

Research questions

What do CBR workers in three areas of Uganda, each with a wheelchair service, perceive as the challenges with wheelchair provision and use in their communities? How do they think they can assist to overcome this and what is needed to achieve this?

Chapter 2: Methodology

2.1 Aim and objectives

The aim of the study is to explore challenges to wheelchair provision and use in three areas of Uganda, with established wheelchair services, from the CBR worker perspective and to determine if and how the CBR workers can contribute.

Objectives are to determine what CBR workers in the three areas of Uganda, perceive as

- the challenges with wheelchair provision and use
- the factors contributing to these challenges
- the role they can play
- the needs to achieve this.

2.2 Study design

A descriptive, qualitative study within a transformative paradigm was chosen to explore the research question.

The transformative paradigm has the potential to bring about social change, and focuses particularly on vulnerable or less powerful groups in the community (Mertens 2007). While CBR workers may not always be considered vulnerable themselves their work focuses on the most vulnerable and they are likely from the same or similar contexts. They are typically the closest grass root disability workers to the community and may have a disability themselves (Mertens 2007). Assumptions of the transformative paradigm emphasise that reality is a social construct hence the importance of trying to understand an individual's reality and of being interactive in carrying out research. It also raises the importance of justice, awareness of power, respect and beneficence when planning and conducting research (Mertens 2007; Tarsilla 2010). In keeping with a transformative paradigm the literature on CBR evaluation affirms the importance of being participatory for optimal learning and deeper understanding (Grandisson *et al.* 2014; Wickendom *et al.* 2012). While this research was not an evaluation it was felt this paradigm was still useful.

The research was carried out in three settings, representing different contexts, further described under section 2.3. The process aimed at benefitting the participants in each area and the combination of the findings then helped to expose commonalities and differences. This study was not intended to be comparative rather to gather rich information for deeper understanding of wheelchair service provision.

A qualitative methodology was chosen to gather rich stories including perceptions, feelings and opinions allowing for context sensitivity. Focus group discussions (FGD) provided space for sharing diverse experiences and views influenced by different contexts, levels of experience and knowledge. The Freirian approach (1970), commonly used in education, community development and CBR development and evaluation, provided a framework in three phases to guide the discussion (Sharma 2006; Fritz n.d). This approach emphasises dialogue as a tool for ‘freedom’ for group members to express themselves and to be ‘process centred’ and action oriented. The first phase, the naming phase, helped the groups share experiences and get a better understanding of each other’s situations actual challenges observed; the second ‘reflection’ phase encouraged dialogue to further understand the underlying reasons for the challenges observed; and phase 3 elicited suggestions and requirements for how the CBR workers could practically help to overcome specific challenges (Popplewell & Hayman 2012; McNiff & Whitehead 2011; Sharma 2006).

2.3 Study setting

The study took place in three areas of Uganda; Gulu in the North, Kasese in the West and Kisubi in the central region. These areas were identified due to the presence of a wheelchair service delivered by personnel who have attended the relevant WHO Wheelchair service training courses (WSTP-B & I). All services had service managers who are aware of the WHO Guidelines and had participated in related workshops. All services are young and at the time of the study had been active for less than a year and a half.

Convenience sampling was applied in that one community-based organisation (CBO) was chosen per area due to their relationship with the services and their overlap of target areas. A Ugandan work colleague facilitated my access to these organisations and the initial discussions helped confirm the relevance and interest in participation. All three organisations are non-government organisations (NGO) and have activities implemented within a CBR approach targeting adults and / or children with disabilities.



Figure 2.1 Map of Uganda. Stars indicate the three study settings: Gulu in the north; Kasese in the west and Kisubi in the central region

Area 1, Kisubi the central region of Uganda, is considered a mix of urban and rural living conditions. The Wheelchair service and CBR programme are situated within the same NGO, providing surgical, orthopaedic, rehabilitation and CBR services, albeit in different departments. At the time of the study (March 2015) the wheelchair service had three people trained in the necessary skills through formal courses and three learning on the job. The service had been active for one year and eleven months. The target group is primarily but not exclusively children. The CBR department includes eight people with varied training backgrounds including Occupational Therapy, Social work or degrees in CBR. The team work in the community and support a network of CBR volunteers.

Area 2, Kasese in the Western region of Uganda, is predominantly rural including very mountainous terrain. Trained wheelchair service providers are situated in the district mission hospital. At the time of the study there were three trained people (including management), three learning on the job and the service had been active for 1 year 3 months. This is the only wheelchair service available in the district. The community-based partner is a parents association for children with disabilities. The organisation runs a school for disabled children in the town and has a CBR programme reaching out across the district.

Area 3, Gulu, is in the Northern region and is predominantly rural. The Wheelchair service is situated in the district government hospital and is the only wheelchair service in the district.

At the time of the study there were six people who'd attended the formal courses and three learning on the job through mentoring. The service has been active for one year and six months and caters for children and adults when appropriate products are available. The community organisation identified for this study is a DPO focusing on advocacy, with various programmes for PWD including a CBR component focusing primarily on children.

Table 2.1 Overview of the three study settings

	Area 1: Central region - Kisubi	Area 2: Western region - Kasese	Area 3: Northern region - Gulu
Description of area	Mix of urban and rural living	predominantly rural & mountainous	predominantly rural
Location of wheelchair service	Service delivered from NGO hospital with surgical, orthopaedic, rehabilitation & CBR services	Service delivered through local Mission hospital	Service delivered through District Hospital – Ministry of Health
Description of wheelchair service at time of the study	Active for 1 yr 11 months. 3 trained in clinical, technical and management (WSTP and other package). 3 support staff learning on the job	Active for 1 yr 3 months. 3 trained in clinical, technical and management (WSTP and other package). 3 support staff learning on the job	Active for 1 yr 6m 6 trained in clinical, technical and management (WSTP and other package). 3 support staff learning on the job
Details of CBO	Department at the same NGO hospital as the wheelchair service	NGO: Association of parents with children with disabilities	NGO -Disabled Peoples Organisation
Description of activities	CBR programme with workers based at the hospital and network of volunteers in the community	CBR activities with volunteers supporting children and families	Community workers supporting PWD in their homes

2.4 Study population

The study population comprised people working within a CBR approach for, or in collaboration with, the above organisations. The population included those working in the community directly with people needing and using wheelchairs and included designations such as community health workers, CBR workers or volunteers, community facilitators or community-based workers.

2.4.1 Sampling and participants

Following convenience sampling of the three study settings to be included, purposive sampling was implemented to identify participants within those settings to provide the rich information and creative but realistic solutions. To avoid the influence of power in participant selection, each organisation appointed a focal person familiar with other workers and holding positions not considered to be coercive (Mertens 2007). The focal persons assisted with recruitment, planning and logistics.

The participants had to:

- be working in the community and employed by, volunteering for or connected with the identified community organisation
- be working in a catchment area of the identified wheelchair services
- have been working within that setting for over 6 months to ensure experience with the social, environmental, economic situation of the community
- have a role which included supporting people using wheelchairs in the community
- have worked directly with more than 10 people who have needed or received wheelchairs in the past year
- and be willing to participate and share information and perspectives.

I connected with the focal persons via e-mail and telephone and shared information on the purpose of the study and process for participant selection including criteria and ethical issues related to autonomy (see ethics section below for details). Focal persons had approximately one month from uptake of the role to the day of the FGD. I provided some funds to one focal person to purchase airtime for communications. Five to six people were requested per group however the focal persons were asked initially to generate a list of up to eight people to ensure the most suitable persons could be jointly prioritised during a phone call discussion with me. This was challenging in some cases due to bad telephone connections. The focal person was then tasked with engaging with selected participants to ensure five or six were interested, available and willing to participate. Due to the nature of the arrangements it was not possible for me to meet with the focal persons or participants in person before the FGD. Data was enriched by the range of pre-selected participants as well as replacements identified on the day, translators meeting the criteria and in one case an additional unexpected person who had become aware of the group and met the criteria.

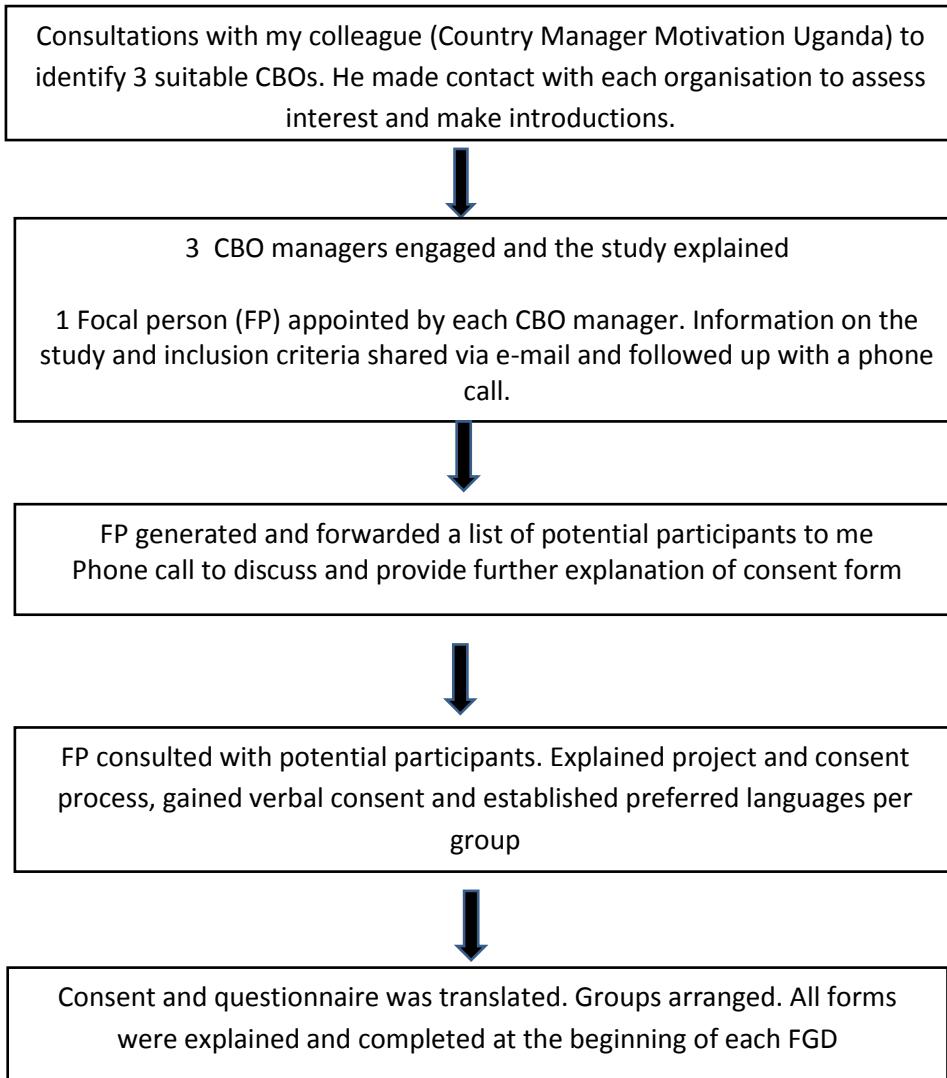


Figure 2.2 Diagram illustrating the process of participant selection per area

2.4.2 Description of participants per area

A total of 21 people attended the 3 separate groups. Selections of the focal persons, which were guided by the selection criteria, resulted in participants with a wide range of training and experience, adding to the richness of the data. Table 2.2 gives a summary of participants.

Area 1: In Kisubi, the focal person, who fit the criteria, invited five other people and a translator, also suitable, bringing the total number to seven. Two people originally selected withdraw due to competing commitments and were replaced by two others fitting the criteria. The final group included six females and one male with a range between three to six years connected to the CBO. Four were employed by the organisation and three were volunteers based in the community. Two represented disabled people in their local councils, and four

had degrees including occupational therapy, social work and CBR, the same four had CBR training. Three had disabilities including one wheelchair user and three had family members with a disability. All worked in the community and four supervised other CBR volunteers covering a number of different communities. Five members had received some training on wheelchairs. Four of these had attended a three day training delivered by the wheelchair service in 2015. Five were very comfortable with communicating in English even though not their first language and one acted as translator for the other two.

Area 2: In Kasese a total of eight people participated: three females and five males; including the focal person, who had initially counted herself as a translator but fit the criteria, and another CBR worker who had become aware of the group and chose to contribute. All those initially selected arrived for the group despite some having to travel over 2 hours to the venue. Three worked directly with the CBO, four worked in CBR programmes in the area with other DPOs and NGOs and one was employed by the district hospital housing the wheelchair service. Time with their respective organisations ranged from one to nine years. Five had attended formal CBR training, one at university level. Two people in the group had a disability, and one used a wheelchair; four people had disabled family members using wheelchairs. Four had some training related to wheelchairs ranging from 2 hours to two days delivered by the wheelchair service in 2014. All eight could communicate in English although some discussions in the local language were summarised and translated for my benefit.

Area 3: In Gulu a total of six people participated, two females and four males. Two of the original selection did not arrive, giving reasons related to cost and length of journey from their remote locations. They were replaced on the day by two community workers closely located to the focus group venue but with the least experience in their roles. Four were connected directly with the CBO and included the coordinator of the CBR programme. The remaining two were from partner organisations; one was a social worker with a CBR role and the other the chairperson of CBR workers in Gulu. Time with their organisations ranged from one to 10 years. One had done a CBR degree, one attended formal CBR training through COMBRA and four had attended various short courses. Four members had a disability and one person had a family member using a wheelchair. Five members had never received any training related to wheelchairs and one had received some. All members chose to communicate in English, not their first language.

Table 2.2 Summary of participants

	Area 1: Central region - Kisubi	Area 2: Western region - Kasese	Area 3: Northern region - Gulu
Total: female/male	M+6F=7total	3F+5M=8 total	2F+4M=6 total
Disability	3 PWD (1 wc user)	2 PWD (1 wc user) 4 family wc users	4 PWD 1 family wc user
CBR organisation	4 CBR workers based as CBO, 3 volunteers in community (local councillors)	3 CBR workers directly connected with CBO; 4 with other CBOs; 1 based at mission hosp.	4 directly connected with CBO; 2 with other CBOs
CBR training and experience	4 have degrees (OT, PT, Social work, CBR), same 4 have CBR training Range of 3 – 6 years	5 CBR training (COMBRA). Range of 1 - 9 years	1 Social worker, 1 CBR degree, 1 CBR training (COMBRA), 4 CBR short courses Range of 1 - 10 years
Details of past Wheelchair training	4 attended 3 day training through the service in 2015. 1 other had 1 day in 2013	4 had training ranging from 2 hrs to 2 days in 2014 delivered by the service	1 person received an orientation.

2.5 Data collection

Data collection was spread over a two week period. I visited each area with my colleague as a research assistant and worked with the focal person in each area on final logistics including arranging a private, quiet venue. Each focus group discussion (FGD) was preceded by an explanation of the purpose, reiteration of ethical considerations such as autonomy and confidentiality and signing of informed consent forms (see Appendix A). Each participant was asked to complete a structured self-administered questionnaire with open and closed questions, provided in English or in the dialect of that specific region. This was to record demographic and descriptive information (See Appendix B).

Each FGD was semi-structured, framed around a Freirian question approach process with four open questions (Freire, 1970; Martinez n.d.). A schedule of one focus group discussion can be seen in Appendix C. The four questions were written on flip chart papers and placed on the walls before the group discussions began. The questions were:

1. 'what are the challenges for people needing or using wheelchairs in your community?'
2. 'what are the reasons for these challenges?'
3. 'what can you do about it?'
4. 'what do you need?'

The research question aimed at exploring challenges to wheelchair provision and wheelchair use. In keeping with a rights-based and user-centred approach I decided to ask the first question placing the user at the centre and to ensure words chosen were simple and easy to translate. In my introduction to the group, I explained the broader purpose of the research as improving wheelchair provision in line with the WHO Guidelines, so while the question drew in observations of wheelchair users the discussions related to both the service provided through the wheelchair service and the use of a wheelchair. To help the group start the dialogue they were asked to think of a scenario of someone who needed or used a wheelchair in their community and experienced challenges. As members presented stories challenges and reasons were exposed. My research assistant was tasked with capturing these in the separate sections on the flip chart as conversations continued. At the appropriate time I reflected back to the group on the challenges and reasons before moving onto the third question.

The aim of the third question was to gather examples of their current practice which were perceived to have a positive impact on tackling the reasons but also to hear other ideas for what they felt could work. This approach allowed a freedom of ideas but then the fourth question acknowledged the challenges to and needs for effective implementing of the suggestions. Prompting questions periodically reminded the group to be mindful of the contextual realities and to bring focus to what *they* (CBR workers) could do rather than other stakeholders.

I encouraged active participation and ownership by allowing the natural flow of conversation and group dynamics to guide the pace, content and depth of discussion. This allowed flexibility for the different contexts and space for reflexivity (Popplewell & Hayman, 2012:3; Wickendon *et al.* 2012; Grandisson *et al.* 2014). It was however also important to ensure all three phases and four questions had adequate time. The flip chart with the four questions proved useful as a reminder of the process and I used prompting questions to subtly move the group on following adequate discussion. There was a natural shift backwards and forwards between questions as group members were reminded of situations or had no new

information to share. This was captured in point form by my research assistant on the flip chart and rich detail was recorded via voice recorder.

Description of focus group per area

Area 1: The FGD was held on a working day at the organisation. The discussion started late due to transport challenges of the CBR volunteers and late arrival of the CBR workers based at the organisation possibly due to other work pressures. The discussion was two hours in length and in English with translations to and from Luganda.

Area 2: The FGD took place on a Saturday in Kasese town in an independent venue. The discussion was mainly in English with occasional conversation in Konja. The discussions continued for three hours and were followed by the group making a decision to formalise their association and setting next meeting dates.

Area 3: The FGD took place on Saturday on the property of the CBO in Gulu town. It started an hour late due to cancellations and waiting time for new participants. The discussions took two and a half hours and were in English.

Data gathered in the FGDs was reflected back to focal persons in e-mail communication. This was responded to by each focal person to clarify ambiguous points and to verify information. Additional data collected in my field notes and journal entries captured my observations and thoughts before, during and after the focus groups.

2.6 Data analysis

Data collected from each group was managed in 5 different formats. Data collected in the questionnaires was managed by transferring it to a password protected excel table (Appendix D: Focus group database). Data produced during the FGDs was recorded verbatim and transcribed into one document per group. Data from flip chart notes was transferred to electronic word documents. Data from the respondent validation e-mail from the three focal persons was maintained in a separate word document and data from my journal and field notes were maintained as they were. As pointed out by Carter, Lubinsky & Domholdt (2011) managing data collected during qualitative research often involves a large degree of analysis to understand in order to code and group into smaller and larger themes.

For this reason I will describe the process of data management and analysis simultaneously in the next section.

Braun and Clarkes' (2006) six phased process of thematic analysis was used first with a focus on individual areas before looking at findings across the three areas. The 6 Phases of thematic analysis are listed here and then described, as they relate to my study. A descriptive illustration of this process can be found in figure 2.3 on page 30.

1. Familiarise yourself with the data
2. Generate initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

I became familiar with the data by repeatedly listening to the verbatim and reading the transcriptions of all three FGDs as well as reflecting on the electronic flip chart notes and journal entries.

Steps 2 to 5 were then focused on the first focus group before moving to the other two. First round analysis coded data from the individual transcriptions (Figure 2.3: Area 2: FGD Transcriptions) and electronic flip chart notes (Figure 2.3: Area 2 Electronic flipchart notes) and manually sorted into the four main questions which were later set as the overarching themes. Simply put, this is: perceived challenges (theme 1), perceived reason (theme 2); CBR worker role (theme 3) and CBR worker needs (theme 4). A code was given for each piece of data which referenced the area and one of the four main themes as well where the data could be found i.e. K(Kasese)/Chal(challenge)/pg11. The flow of dialogue during the discussions meant information was not entirely presented in a linear manner according to the four questions but rather interconnected for example some topics explored a particular challenge, presumed reasons and the CBR role in overcoming it, before moving on to another point. In addition to this certain points given as reasons for specific challenges were also presented as challenges themselves being caused by other factors. This was especially challenging for coding data which fell within theme one and two (challenges and reasons).

As sub-themes started to emerge through inductive analysis I was able to define and name them which aided in further understanding of the relationship of the data under the four main themes. It was at this stage that sub-themes under theme one and two were exposed as being reflective of the ICF categorisation system. Theme one, *challenges*, reflected

participation restrictions and activity limitations experienced by wheelchair users. While theme two, *reasons*, related to contextual factors. Theme three, which focused on what the CBR workers' perceived *they could do* about the issues raised, resonated elements of the 8 steps of wheelchair service delivery and different aspects of a CBR workers role in empowering PWD as described in the CBR Guidelines. The final theme focusing on *needs to achieve this* did not have a specific framework for analysis and sub-themes were exposed at a later stage in the analysis when cross referencing data of the three areas. Table 2.3 shows how the objectives, questions and frameworks for analysis relate.

Table 2.3 Table showing link between objectives, questions, themes

Objectives	Questions	Frameworks for analysis
To determine what CBR workers in the three areas of Uganda perceive as:		
- the challenges with wheelchair provision and use	1 'What are the challenges'	ICF Participation and activity limitation
-the factors contributing to these challenges	2 'what are the reasons'	ICF Contextual factors: Environmental factors including wheelchairs and wheelchair service steps; personal factors
-the role they can play	3 'what can you do about it'	8 Wheelchair service steps CBR strategies: Empowerment (CBR matrix)
-the needs to achieve this.	4' what do you need to do this'	

Mayring (2000) and Schwandt (2001) explained many qualitative studies comprise a combination of inductive and deductive analysis similar to this study. Following analysis of the first set of data from the first FGD sub-themes identified were then used for deductive reasoning for the second two sets of data. However as mentioned in the previous paragraph sub-themes under theme four (needs) were again derived through inductive reasoning.

Once themes and sub-themes were identified the electronic flip chart notes were categorised accordingly, confirmed against the manually sorted transcription data and finally prepared into a set of notes per area for respondent validation (Figure 2.3: Area 2 FGD notes). This generated further responses which were included for analysis along with my

field notes and journal observations (Figure 2.3: Field notes and journal) to form one comprehensive document for that focus group (Figure 2.3: Area 2 *Final FGD notes*).

The idiographic nature of this research means findings are specific to the individual contexts. However a table which can be found in Appendix E was developed to consolidate the final FGD notes from the three areas including themes and sub-themes and to expose through a degree of triangulation similarities and differences useful for analysis (Figure 2.3: Consolidated findings table). Data from the focus group database (Figure 2.3: FGD database) was used to further enhance understanding and analysis. In keeping with the flexibility of the transformative paradigm, I was consistently open to new sub-themes emerging during analysis and included these in reflection and discussion (Mertens 2007; Tarsilla 2013). To aid the final step of analysis I developed pictorial diagrams displaying interaction of themes and sub-themes as example of which can be found in Appendix F.

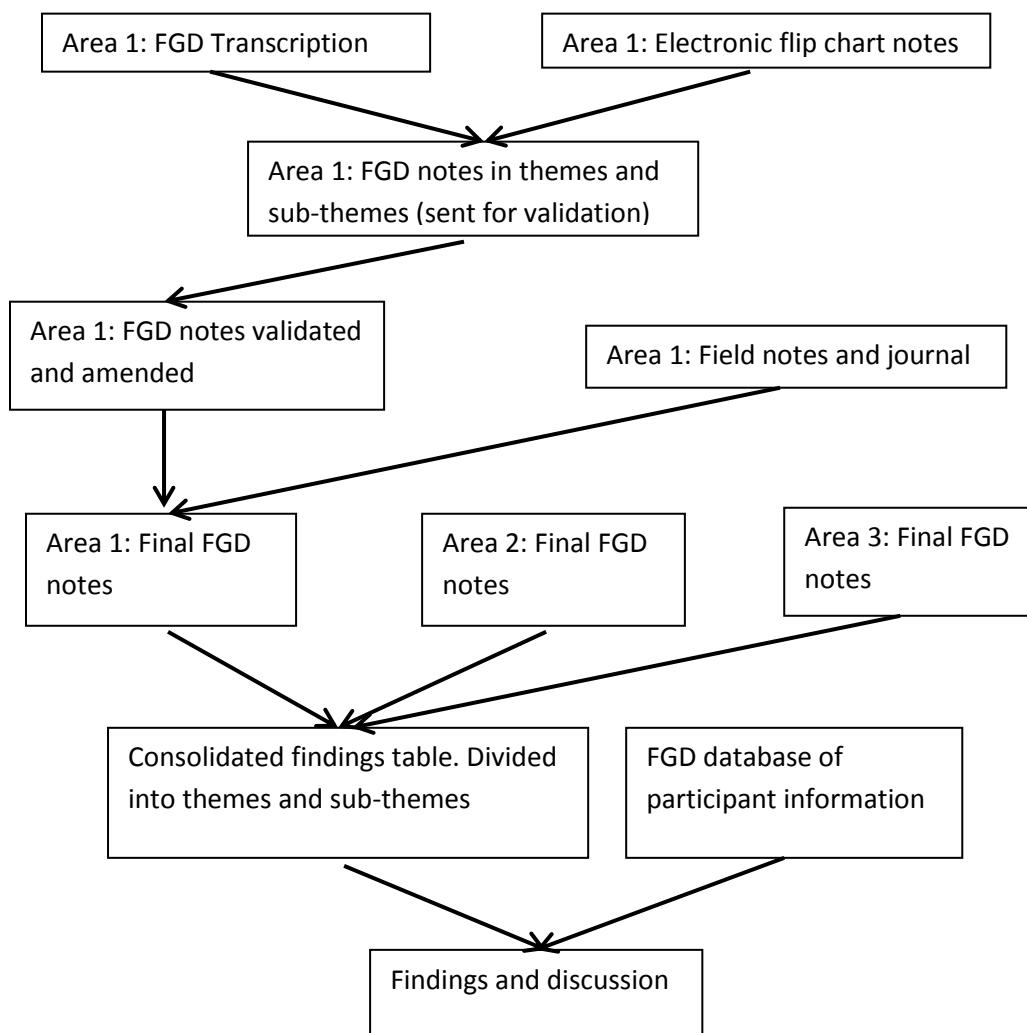


Figure 2.3 Illustration showing data analysis process

2.7 Ethics

This research process was guided by the principles of ethical research of the South African Medical Research Council (MRC) Guidelines (MRC 2004). Stellenbosch University Health Research Ethics Committee approval S14/10/210 and appropriate permissions from the Uganda National Council for Science and Technology SS3687 were obtained as well as the regional organisations involved in the study and my employer.

The principle of beneficence and non-maleficence was upheld through the very nature of the transformative paradigm and the study design. At the start of the discussions I explained the intended progression through the four questions so members were aware of the importance of sharing challenges but also of moving towards other questions. This was useful as there were many challenges to share but participants themselves guided the progression on to other points of discussion. The reflective process provided a chance to share and to listen and all participants took this opportunity. Some members were more talkative than others and this was tactfully and respectfully handled. Space was deliberatively created for translations and contributions in other languages as needed however most groups were very inclusive to those members who understood less English. When the group felt it necessary, discussions continued in the local language and summarised in English for my benefit.

The phase of the group during which participants generated solutions was positive, and allowed members to see their potential to contribution. On occasion I reminded the group to maintain focus on a CBR workers role and encouraged them to stay realistic so as not to generate grossly unachievable ideas. The wrap up of the group included suggestions on what to do with the information gathered in the group. Group two has since followed through with this by holding subsequent meetings to take forward suggestions.

The flow of the discussion was guided by the group and this ultimately dictated the length of the session. I was flexible with this to ensure participants time was respected however also their need to connect and share, as was particularly the case with group two. I had prepared for how to manage emotional reactions of participants to sad stories however it seemed as if they were very familiar with the difficult situations.

The principle of justice which is aimed to prevent discrimination was considered through the inclusion criteria and confirmed by the lack of exclusion criteria. Richness of data was intended with the purposive sampling design and decisions for who was appropriate beyond this was up to the focal persons. Two people invited to group three withdrew on the day due

to distance however this was not a predetermined exclusion and could have been overcome with prior notice. Transfer of benefits from the group discussions is up to each individual to share. However subsequent conversations with different stakeholders have raised awareness to the perceptions of these groups.

It was important that my **position as researcher** did not influence discussions or levels of participation. It was made clear to the participants and organisations that participating in the focus groups will not influence future opportunities with my organisation. At the time of the group I used the introduction to help people settle and get to know me and each other. I also expressed my genuine interest in hearing their inputs considering their expertise and experience. My approach to the group was purely in posing questions, occasional prompting to encourage equal participation and reiterating points to see if further reflection or suggestions were offered. As I progressed through the groups I also reflected some points, as seemed appropriate, from subsequent groups to determine its relevance to others. Additional facilitation skills were used to help group two draw together their thoughts and ideas and to help me understand.

All participants were made aware before and at the outset of the discussion that there was **autonomy** in their decision to participate or stay the duration and decline or withdrawal would have no negative consequences. This information as well as full details of the study was captured in a written **informed consent** (appendix 4) document which was explained and provided in the language of their choice for signing. A full explanation was provided with expectations of participation and methods for capturing data. All but two members chose documentation in English however the translator and group members helped each understand the documents. All groups took a significant amount of time to complete this process which I was hesitant to rush. All participants consented and gave permissions for all forms of data collected to be used for the benefit of the study and publications.

Considering the study is situated in the transformative paradigm and is intended to lead to social change meant **confidentiality** and anonymity was considered but not always appropriate. Each organisation was aware of who participated in the focus group in their area and all participants were aware of other group members and individual contributions. I ensured the organisation and participants were clear that each individual has the right for their contributions to be anonymous outside the group. All written and verbal accounts of the process and outcomes have respected anonymity. Names of people and organisations raised during the discussions were omitted from transcriptions and this paper and terms such as district hospital, wheelchair service and community organisation used instead.

Ethics in data management

The participants' details were captured on the consent form and the questionnaire. During the focus group my research assistant allocated each person a reference number based on the position they were sitting in the group. I retained all the hard copy documentation and uploaded information myself onto a database. One database was retained with all the information including names but password protected and only accessible by me. An additional version with the names removed from retained for quick reference. Transcriptions of verbal contributions to FGD were recorded anonymously and so confidentiality of input was maintained.

2.8 Trustworthiness

Qualitative data capturing methods benefit from careful consideration to ensure they are trustworthy and contain elements of truth, authenticity and reality (Holloway& Biley 2011). The process must also allow for individuals' experiences, perceptions and feelings to be shared and explored. It is for this reason that focus groups were used but that numbers were kept small to allow the space to share. Beyond the inclusion criteria, the purposive sampling method allowed for interpretation by each focal person. Trust was placed by the organisation in the focal person's ability to identify appropriate people. The diversity and suitability of most participants and the efforts to arrange and arrive showed a respect for and possible interest in the process. No incentives were provided. Discourse during the focus group exposed the areas of strong correlation and difference between participants.

Qualitative research is by nature idiographic (Carter *et al.* 2011:158). Triangulation, useful in enhancing credibility in qualitative research, was used to increase transferability. Data from three focus groups and three verification processes from three areas of the country were generated. This was combined with flip chart notes, reflective journal and field notes. Analysis identified common sub-themes across the three areas which are likely to be more externally transferable. Those only reflected in one or two areas but by many participants in the group have been highlighted and together with descriptions of the sample groups may render them more transferrable. Comparing results to existing literature also assisted in providing a basis for transferability. Considering the qualitative nature of the research rich stories and experiences were captured regardless of transferability.

The data may also be influenced by my direct involvement and affiliation to my organisation involved in a project related to wheelchair provision in Uganda. I however did not know the majority of participants and was clear through my introductions about my independence with

this study. Participants were encouraged to use this opportunity to their advantage with the view to improving the situation.

Trustworthiness was enhanced by doing a verification step. Data was reflected back to the focal persons via e-mail and the opportunity was offered to provide confirmation or comment via e-mail or phone. All focal persons responded and chose e-mail. Data was clarified and some points explained. The response time and apparent effort put to the responding e-mails directly correlated with the rate of correspondence in preparation for the group. One group took prompting to elicit a response whereas another responded swiftly with a number of informative e-mails. This may have been influenced by other pressures on the specific focal persons or the benefit they derived from the FGDs.

2.9 Summary of methodology

What do CBR workers in three areas of Uganda, each with a wheelchair service, perceive as the challenges with wheelchair provision and use in their communities? How do they think they can assist to overcome this and what is needed to achieve this?

To answer these questions a descriptive, qualitative study design framed within a transformative paradigm, was used. Three FGDs took place with CBR workers from three areas of Uganda each with a wheelchair service. The Freirian model guided the discussions and helped CBR workers reflect on the situation and consider their role. Four questions posed to the CBR workers linked directly with the objectives and further formed the main themes used during thematic analysis.

Chapter 3: Findings

The findings presented in this section answer to the four questions posed which relate directly to the four objectives. The four main themes correspond accordingly as shown in the table below. Each theme had between four and eight sub-themes capturing rich data from across all three focus groups.

Table 3.1 Table showing link between objectives, questions, themes and sub-themes

Objectives	Questions	Themes	Sub themes
- To determine what CBR workers in the three areas of Uganda perceive as the challenges with wheelchair provision and use	What are the challenges for people needing and using wheelchair?	Theme 1: Perceived challenges 4 sub-themes related to ICF participation and activity restrictions	<ul style="list-style-type: none"> • Wheelchair users' lack mobility • Wheelchair users are not consistently benefitting from or participating with their wheelchairs • Wheelchair users are dependent on others • Wheelchair users are challenged to maintain or improve health and well being
-the factors contributing to these challenges	What are the reasons for these challenges?	Theme 2: Perceived reasons 6 sub-themes related to ICF environmental and personal factors (including reference to the WHO 8 wheelchair service steps)	<ul style="list-style-type: none"> • Wheelchairs are either inappropriate or inconsistently available • Services, systems and policy are not meeting the need • Negative attitudes and cultural beliefs about disability • Inaccessible physical environments • Lack of peer role models • Poverty
-the role they can play	What can you do about it?	Theme3: Perceived CBR worker role 4 sub-themes Related to WHO 8 wheelchair service steps and CBR matrix: empowerment strategies	<ul style="list-style-type: none"> • Facilitate PWD to benefit from available wheelchair services (step 1) • Support wheelchair users in continued use and optimal benefit of a wheelchair (steps 7 & 8) • Empowerment and inclusion activities • Gather statistics

-the needs to achieve this.	What do you need to do this?	Theme 4: Needs to achieve this 8 sub-themes	<ul style="list-style-type: none"> • Training related to wheelchairs • Communication with wheelchair services • Resources • Opportunities to meet • Legitimacy of CBR workers • Increased trained CBR workers • More and decentralised wheelchair provision and repair services • Comprehensive rehabilitation programmes for wheelchair users
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3.1 Theme 1: Perceived challenges

The first theme is based on the first question ‘What do you see as the challenges for people needing or using wheelchairs in your community?’

3.1.1 ‘Some parents don’t want wheelchairs’: Wheelchair users lack mobility

Despite the availability of a wheelchair service all areas explained how many PWD in need of wheelchairs were challenged by lack of mobility. Limited supply of wheelchairs was a reason but users and carers’ not accessing the wheelchair service was equally common. This was because they were not aware of the service, unable to access it or unwilling to. Decisions not to utilise the service were often influenced by uninformed, prevailing beliefs and ignorance of benefits. A CBR worker from Area 3 explains *‘If one is afraid [of the hospital], this means they won’t turn up for the wheelchair even if they are in need’*. CBR workers from Area 1 stated that wheelchairs are seen as a *‘symbol of reporting that someone has got a disability’* and that *‘some parents don’t want wheelchairs’*.

Examples also showed how at times wheelchairs are promised but then not availed and at other times they may be available to some but not all.

Area 3 ‘Politicians have promised PWD wheelchairs but after not succeeding to elective positions they don’t come to fulfil such promises.’

Area 2 ‘When these parents see people are moving on wheelchairs, those people who have got are really proud. But when they see their children not getting, it becomes a challenge for them. They’re in need of wheelchairs.’

A participant from Area 2 explains that as a consequence parents and PWD are let down; they *‘feel they have wasted time’* and she used the words *‘demoralised, stigmatized, segregated, inferiority complex, disrespect of human rights’* to describe their feelings.

Further points related to the reasons for lack of mobility are captured under findings in section 3.2.

3.1.2 '*They find themselves forgoing it some days*': Wheelchair users don't consistently benefit from and participate with their wheelchairs

All groups reported wheelchair users who, for different reasons, struggled to participate in age appropriate, family or community activities. The level and regularity of involvement appeared quite variable. Challenging environments and situations meant that choices had to be made prior to each activity resulting in haphazard and fragmented engagement such as in Area 1 where '*they find it very tiresome, using it every day*' and '*they find themselves forgoing it some days*'. For instance when a wheelchair can't be transported between school and home due to inaccessible transport the parent is forced to make the decision whether to send the child to school or not, or to send them but without the wheelchair.

Area 1 'It's the parents to decide which is more beneficial, him staying with the wheelchair at home, or the wheelchair being kept at school; because it can't be in two places [] it means he won't have to move places [] so he doesn't engage in play. He can't interact with peers.'

Area 3 'Sometimes they don't go to school, because the roads are bad and a long distance [] for them to push those kids'.

Some children in area 2, who used wheelchairs during school term time, were said to have difficulties when returning to their villages during holidays. The villages are often inaccessible due to the mountainous terrain and the wheelchairs could either not reach the homes or not be used in the home. The wheelchair would therefore be left behind and the child may spend the entire holiday period without mobility and lacking the other health and functional benefits of their wheelchair.

Area 2 'Like someone who lives in the mountain [] the only solution will be carrying him on my back. That's why they'll even abandon new chairs.'

In some instances according to the group in Area 2 the families don't see the benefits of the wheelchair or may be uncomfortable being seen with it in public and so avoid using it. The result is the community never becomes aware and the family is prevented from realising the benefits. This can result in them abandoning or selling it. On the other hand some people tried desperately hard to be actively engaged in their lives but various challenges led to a level of uncertainty and disappointment.

Area 1 'She stopped over six taxis, but they were all leaving her because she had a wheelchair.'

Area 1 'She was very excited when she was told that she's going to be given a wheelchair, [] we thought having a wheelchair is something very important [] but then they are not able to use it [] when they are inside the room, the room is small'

The positive impact of the wheelchair was also mentioned such as enhanced participation however increased levels of wear and tear were often the result. This is a common challenge reported in all areas. Examples related to products provided through the services as well as mass produced imported products distributed through other mechanisms.

Area 1 'Given that some of the kids are now active they are gaining their strength. They become playful or active or engage in a lot of activity and gaining the other stages and end up, breaking down tables on their chairs; sometimes screws coming out'

Area 3 'The adult say the wheelchair has greatly eased their mobility, however the challenge with some of them is on maintenance of the wheelchair.'

In some instances it sounded as if using the wheelchair may not be providing the added benefits for the carer. It seemed that it was not unusual for the wheelchairs not to be used, only used sporadically or only when the CBR worker arrives '*then they will run and put the baby in the wheelchair*'. This could be due to ignorance of the benefits, difficulty using it or other reasons but the result is that the child does not benefit from the device and is excluded.

Area 1 'In the home you find the wheelchair in the corner of the house, with clothes packed on it and it's never been used. [] It feels like an extra effort for them to put this child there.'

Area 2 'They just lock the house and they leave their child inside the house and they go there and they do their own activities. So after finishing those activities, then they come back and then they open for a child.'

3.1.3 '*Take it! I don't have anyone to help me*': Wheelchair users are dependent on others

In many instances wheelchairs users were dependent on others either because of their impairment, age, type of wheelchair or environmental barriers. Mobility was often the main reason for assistance however others included moving in and out of the wheelchair and

managing personal needs such as toileting. The interconnectedness of challenges can be understood when a CBR worker in Area 1 speaks of a man returning his wheelchair and becoming immobile: '*He give me the wheelchair back. 'Take it! I don't have anyone to help me,*' or the following example when a boys school attendance is interrupted.

Area 1 'If this child has to be wheeled to school, [and] the mother has so many other commitments, he won't attend school; because she's the only person to wheel the boy to school'

Support systems seemed small and most often limited to one's family. Competing influences of poverty, fatigue and life roles were examples offered making it difficult for carers to prioritise needs of the wheelchair user. Difficult decisions resulted in situations often not in the best interest of the PWD but also at times not easy for the carer.

Area 3 'In some instances I've seen two children who go to school – they have wheelchairs, but they have to be carried every day by their father to school, because the wheelchair cannot travel along the narrow roads.'

Area 2 '... their parents regard it as a tiresome exercise because now they say they have a lot in terms of looking for survival. And now getting time to spend on this child....?'

In addition to the strain on families of providing on-going support there are times when they are not able to provide this support and other support systems are absent leaving the child or adult vulnerable.

Area 1 '.... but because the mum is sick, and the child is not able to wheel herself, she finds herself not going to the hospital, even when she was supposed to get medication.'

Area 2 '... if the child is going to defecate he is pushed up to the latrine door and thereafter he's lifted []. When the children [are] at home [] their parents sometimes go in the field; [] and they cannot get any other person [to help].'

There was a common feeling especially in Area 1 that some people are willing to assist but that this is not lasting. Either the novelty wears off or it becomes tiring and time consuming as seen in the following example. This can result in people avoiding to go out in an attempt to prevent inconveniencing others or being abandoned in the middle of an activity when the helper fatigues.

Area 1 'At first some teachers were willing to do so, but then their attitude changed. I think because he was new [] but after he had stayed for a year, it feels like it's a lot of work for them. Now no-one feels interested to do so'

Area 1 and 3 elaborated how some choose to keep outside support to a minimum considering the vulnerability of the wheelchair user in particular women and young girls who are at risk of abuse.

Area 3 '.... because of such support many especially the females have been objects of sexual abuse. Many because of these will want support from their parents or close relative. Most parents are very protective of the girl child.'

On the other hand participants in Area 1 reflected on how parent's perceptions of disability impacted treatment of their child. This differed to the other two areas and may be due to increased pressures in a more urban context.

Area 1 'Here it's not like abroad, where there's that special attention. It's very few parents who love their own children. [For] most of them, that kid becomes a burden. So in the long run, they are left there.'

3.1.4 'Actually ulcers are my biggest problem': Wheelchair users are challenged to maintain or improve health and well being

Potential health and developmental benefits of a wheelchair are not always realised as was alluded to in all areas. Area 3 noticed some children with complex postural needs still looking uncomfortable even though they had been fitted by trained service providers. They also observed a child's physical needs changing over time however no adjustments were made to the chair. A further story from Area 2 explained a child being in the same seated position all day without being moved as '*this caretaker will just assume that [this is] now a comfortable place*'. This has serious implications on the child's body structures and especially on hygiene as highlighted by the CBR worker's questioning of the parent: "*Are you taking care of the boy when he urinates in the seat?*"

Wheelchair users are at risk of secondary health complications due to their impairment, late diagnosis or lack of treatment, unsafe, inaccessible environments and inappropriate products. The ability for a user or carer to maintain health and prevent complications or illness is reportedly challenging in all three areas.

Area 1; 'Kids who are using wheelchairs [] have to transfer from a wheelchair and then use their hands and enter in a latrine which is already a very dirty. They end up getting secondary infections'

Area 1 'The road is not wheelchair friendly. [] So they end up sometimes getting accidents and being crushed.'

Area 1 'And the last challenge is these materials they use are very weak. In the long run the back aches.'

A reflection from one of the participants who is a wheelchair user shows how she has to make the choice of not eating to prevent having to access inaccessible toileting facilities while moving through the community. The short term impact of headaches and long term development of ulcers highlights the significant impact of common barriers.

Area 1 'If I am to move [around the community] I don't eat because I fear the afterwards answers. So, in the long run, you suffer from headache, ulcers. Actually ulcers are my biggest problem.'

One participant reflected on the vulnerability of female PWD who become visible and an easy target when they are in a wheelchair. She explained that it wasn't uncommon for women to be impregnated and then abandoned leading to further difficulties for them with looking after themselves and their child.

Area 1 'So, there is no privacy when you are using the wheelchair, because you are seen from a distance. A very big challenge to most people who are using wheelchair, like me, they are impregnated by men, of course, and they leave you like that [clicks fingers]. You can't really sustain yourself. That means you are now going to another level of just being a beggar.'

Summary of theme 1

Theme 1 captured CBR workers' observations and perceptions of some of the challenges experienced by PWD needing and using wheelchairs. The four sub-themes emerged in relation to the ICF framework sections: participation and activity restrictions.

- Wheelchair users' lack mobility
- Wheelchair users are not consistently benefitting from or participating with their wheelchairs
- Wheelchair users are dependent on others

- Wheelchair users are challenged to maintain or improve health and well being

3.2 Theme 2: Perceived reasons for challenges

Theme 2 relates to the second objective and question: ‘What are the reasons for these challenges?’ The question called for reflection and deeper understanding of challenges presented in the section above. Six sub-themes emerged in relation to the ICF framework’s environmental and personal factors influencing the situation.

3.2.1 Wheelchairs are either inappropriate or inconsistently available

A range of wheelchairs were mentioned however not all were considered by the CBR workers to be appropriate. Wheelchairs provided through the services, which were all imported, were described as being stable and having adjustability and options to modify.

Area 3 ‘This one [] issued at the hospital has lot of adjustment and modification on the chair before one receives one [] These not made here in Uganda – they are good.’

All three areas emphasised the needs of children. A CBR worker in Area 3 pleaded ‘*but we need to focus on the children*’ and raised concerns regarding the impact of inconsistent supply of a range products through the wheelchair services for adults and children.

Area 3 ‘For the last two years, we have not had supply in the wheelchair service for the adults.’

Area 3 ‘There are times when wheelchairs get finished. People need to wait’.

Locally produced products which are available in Area 3 are not appropriate. They reflected on the durability and stability of the products at times being unsafe for users. Lack of financial support for wheelchair manufacturers was presented in Area 1 as affecting their production.

Area 3 ‘But the ones that are made locally, the wheelchair is really unstable,[] my concern is the quality of wheelchairs.’

Mass distributions of donated and inappropriate wheelchairs were familiar to CBR workers in both Area 1 and 3 and many wheelchairs remained in the communities.

Area 3 ‘..just a plastic chair that is modified and put on a wheel. They don’t last, because of the nature of the plastics.’

Area 3 'There are so many products for adults in the community – they are out of use, they can fill 2 rooms.'

A CBR worker, also a councillor, in Area 1 was offered unassembled wheelchairs from a church. She struggled to find technicians to assemble and explained how a '*child fell off [because it] it was poorly assembled.*'

CBR workers from Area 1 and 3 demonstrated better understanding than those from Area 2 of wheelchairs, in particular how design and materials impacted durability, function and health. The fact that Area 2 has no local producers, apparently also fewer distributions of donated products and a small wheelchair service active for less than 18 months, contribute to the CBR workers and community's uncertainty with wheelchairs. 'Fear' was a term used to describe feelings of some users and parents. Fear of damaging the wheelchair results in keeping it for special occasions. An additional concern raised in Area 2 was related to the complexity of the wheelchair and fear of being 'imprisoned' in it.

3.2.2 Services, systems and policies are not meeting the need

All point related to the 8 steps of wheelchair service provision are captured under this section even though the CBR workers were not directly referencing the steps.

3.2.2.1 Wheelchairs are not always provided through a service

Participants from Area 1 and 3 have observed that wheelchairs are still provided through the charity model approach without considering the needs of the client which in Area 1 is reportedly the reason why 'you find even kids are falling off the wheelchairs'. It was pleasing to hear they are recognising the difference between this and those provided through a service

Area 1 'Some organisations say I've got 50 wheelchairs. Then the issue of not being measured and assessed also comes in, because it's a gift. Have that one! If it fits you – good! If it doesn't fit you, you still have it.'

Area 1 'Here (hospital with wheelchair service) it is different to outside they take appropriate measurements and give out appropriate devices; but in communities [] I see so many kids in wheelchairs too big for them [] you find a kid of eight years using a wheelchair of somebody around 30 years.'

3.2.2.2 Wheelchair services are not being accessed by all in need

Access to wheelchair services raised many challenges for people in particular in Area 2 and 3 and affected people in rural areas tremendously. The reasons varied and were perceived as follows:

- a) **Too few wheelchair services and trained personnel result in many users' needs not being met**

This was raised as a challenge in all areas however was most significant for Area 2 and 3. The wheelchair services are the only ones in their respective districts and services are integrated into existing rehabilitation departments in district hospitals. Time available to deliver the service was said to be limited.

Area 3 'They say they are few and their workload is high, particularly for wheelchairs and service provision. They are only allocated one day per week.'

It was evident through the discussions that the wheelchair services are carrying out assessments and doing product modifications prior to fitting, but that this process is time consuming.

Area 3 'There is assessment [] they take measurements, [then] they make modifications. If they are fitting one chair in the hospital, they are spending a lot of time because they make sure it is modified to fit the child.'

The low number of service providers, few days for service and duration of the process mean that numbers of users benefitting from the service are low and not meeting the need.

- b) **Wheelchair service providers are challenged to deliver close to communities**

The service providers also struggle to bring their services closer to the community (outreach service). This was presumed to be due to insufficient time and low staff capacity as discussed above but also lack of resources for transport and challenges with carrying products.

Area 2 'Transporting those wheelchairs, [] and two technicians from [the service] to the outreach is difficult to manage.'

c) Many users don't hear about the service and are impeded by distance, transport and finance

Poverty affected the ability for many people to access the service. The overwhelming majority of PWD live in very remote rural areas which don't receive information easily and they have long distances to travel to wheelchair service locations. The requirements for accessing an appropriate wheelchair can become too expensive and time consuming for poor families to afford.

Area 3 'But there are very many who are not being reached. They are there in the community. There is nobody in the community to connect them.'

Area 3 'You may need to travel to the hospital, maybe twice or even three times to access the chair, and most of the parents give up.'

d) Ignorance of benefits, assumptions and fears of users and carers prevent access

Participants reflected on this as a major barrier in accessing wheelchairs.

Prevailing attitudes towards disability result in a fear of visibility in Area 1 and particularly in Area 2. Wheelchairs are seen in Area 1 as a '*symbol of reporting someone has got a disability*' so '*some parents don't want wheelchairs*'. Traditional beliefs and assumptions about disability cause some parents and carers to neglect and even discard their children believing them a curse and valueless. This impacts decisions on use of resources which may already be scarce.

Area 1 'They don't see any value in a person with disability, so they can't waste any money on buying a wheelchair [or sending] them to school.'

In all groups there were examples of users and family's ignorance of the benefits of a wheelchair and so not taking up opportunities. This was explained in Area 1 where a CBR worker paraphrased a parent saying '*I stood on my feet and said no, my child won't get a wheelchair. That would mean they would never walk again.*'

Negative perceptions of health institutions prohibit many in Area 3 from accessing wheelchair services. Experiences of discrimination by health workers, said '*to despise PWDs*', cause some PWD to forego the chance to become mobile. In area 3 a CBR worker explains '*If one is afraid, this means they won't turn up for the wheelchair even if they are in need.*'

Disappointments from unmet promises and expectations related to receiving, paying for and using wheelchairs in Area 1 and 3 were also said to influence willingness to accept new opportunities.

3.2.2.3 Lack of clarity of policy, regulation and government funding

Differing messages from government, service providers and other donors on the right to a free wheelchair also make it difficult for people to make decisions best for them. These formed the basis for a lot of discussion in Area 1 and 3, areas which have commonly receiving mass distributions of donated products.

Area 3 'Our community has for many years been accessing this facility at no cost by charity organisations [] now they charge a small charge. [] People are against the idea of paying [they] are used to the culture of free things.'

Area 1 'In Uganda the law says the government should assess PWD and provide them with movement facilities. So I think maybe people [] know their rights, and that's why they won't pay.'

Area 3 'Our situation is not that we have very few wheelchairs – the wheelchairs are there - or that the need for the wheelchair is not there – it is there. But they are not given out as fast as possible because people think that is has to go for free.'

Area 1 and 3 commented on lack of political will from government in providing and implementing policies and regulations, and lack of funding to support the sector.

Area 1 'in Uganda we are supposed to produce wheelchairs, but because the government doesn't have a goodwill there's no proper funding.'

Area 1 'We have a National wheelchair committee in the Ministry of Health, but it is not so effective. They tell you they have no funding.'

3.2.2.4 Wheelchair users and carers lack training on use

The CBR workers in all areas reported that they have observed the wheelchair services giving training to users after receiving their wheelchairs. Training should relate to use and care for a wheelchair (**Wheelchair service step 7**). However all areas referred to situations where users and carers do not have the necessary skills. Newness of the skills required, significant information to be absorbed and training delivered at the end of a long day were assumed reasons. Often users forget what they have learnt. At times the person receiving the training is not the main or only person needing the skills and transfer of skills doesn't

appear to happen. This was suggested as one of the reasons why products are misused or not maintained well.

Area 2 ‘...parents are trained but on a small scale because of limited time and few service providers, and they don’t remember everything.’

Area 3 ‘Sometimes even the family members are not aware of how to maintain the wheelchair and how to take care for that person. That’s why we find that the wheelchairs get destroyed.’

Area 2 ‘The toolbox might be there but there is only a grandmother - don’t even know a spanner – you need someone who has a skill. [] Supposed to be regular training, not only one day, need deep training.’

Area 3 ‘I have a client, but each time we go for a home visit, you’ll find that they don’t have skills and the knowledge of how to care for the wheelchair. At times they leave it outside in the rain, sometimes [] when the child needs to eat they forget to fix [the tray].’

3.2.2.5 Wheelchairs are not lasting

Product durability was a major concern for all groups. Discussions pointed to products which were more and less durable than others and largely related to the appropriateness of the product discussed in 3.2.1. However a number of other points were raised. Product durability was reduced by them being stored outside, because they are mishandled or not maintained and cleaned.

Area 1 ‘They keep it outside their room []. It wears off very fast.’

Area 3 ‘General negligence around maintenance... a simple problem on a wheelchair that could be fixed is usually not done till the problem gets worse.’

In area 3 societal poverty played a role where stealing of parts was not uncommon.

Area 3 ‘....members of the communities, stealing their spare tyre, even their pump, especially to use on their [] ordinary bicycle.’

Repair services are mostly at the wheelchair services, too distant and costly for many users to reach. Those available closer to users charge for their services and have no spare parts available preventing them from being a realistic solution.

Area 2 ‘This repair has to be done in the (service). This parent has no money and the distance is too long. It becomes a problem for [the trained service technicians] to

move, because it's a long way to go from [the service] to these places we are getting clients.'

Area 1 'So first of all they're very expensive and the spare parts are not seen.'

Area 3 reported that due to the challenges above, they often experience pressure from wheelchair users to repair the wheelchairs but they are aware they lack the expertise. They are equally challenged to provide realistic advice to users.

Area 3 'they expect someone else like (CBR organisation) to fix problem on their behalf. You find that we don't have skill as facilitators for repairing'.

3.2.2.6 Wheelchair services are not following up users

Another point of concern raised particularly in Area 2 and 3 was the lack of follow up by the wheelchair service providers to the users once they had received the products (**Wheelchair service step 8**).

Area 2 'Those people who have been getting follow ups, are getting their relief and guidance []. But you find the wheelchairs are taken but getting a person to go and make follow up on how they should go on using it, then also becomes a challenge.'

All groups felt however that this was not consistent and resulted in wheelchairs being misused or neglected. Quotes pointing to the lack of follow up are included in 3.1.4 i.e. situations where the fit of the wheelchair for the child was not correct initially, growth of the child impacting fit of the wheelchair which has not been identified and adjusted to lack of follow up.

3.2.2.7 Lack of statistics on wheelchairs provided and needed

Discussions in Area 2 and 3 pointed to high numbers of people in need of wheelchairs however there was no confidence in availability of specific statistics. Participants could mostly give numbers in the areas they were covering of who needed a wheelchair, but not who already has. There also seemed no central place where numbers are collated to reflect the overall situation. Area 2 suggested that government officials are unaware and in all probability underestimating the true need for wheelchairs.

Area 2 'Those people who don't reach into the community think there's not many disabled persons. Most of these parents hide their children in houses. We as CBR

workers know about these people because we've been deep in the village to search for them.'

However the CBR workers in Area 2 and 3 also explained how they prefer to not gather the information in an attempt to avoid raising expectations only to disappoint again when wheelchairs are not provided.

3.2.3 Negative attitudes and cultural beliefs about disability

Negative attitudes and abusive, discriminatory and disempowering treatment of wheelchair users and other PWD was common in all three areas. Traditional belief systems and lack of knowledge result in negative treatment from a range of people from close family and carers to the community, service providers and leaders. This was significant for all groups and impacts all areas discussed in theme 1.

Area 2 'They will just imagine that if you touch somebody who is disabled, you are likely to produce the same disability and pass it on.'

Community attitudes transfer easily to others in particular to children thus influencing the experience for school going disabled peers.

Area 1 '(children's) negative attitudes stems from their home because they've heard their parents talk about different issues surrounding disability.'

As raised in previous points Area 1 and 3 expressed how attitudes of service providers have significant influences on wheelchair users experiences in school, with health institution and transport vendors.

Prevalence of negative attitudes towards PWD in rural areas was specifically highlighted.

Area 3 'But if you go far in the villages, that is where the problem is, that is also where CBRs should concentrate because from there is negative attitudes about people with disabilities, so I think there is much work needed in the villages.'

3.2.4 Inaccessible physical environments

Challenges caused by inaccessible environments were highlighted by all groups. Challenges in rural areas related to long distance and rough and inaccessible natural environments with mobility being further and significantly hindered in bad weather conditions.

Area 1 'School going children find a problem to reach schools. [] they are [] very distant from their homes.'

Area 3 'We don't use the road, we use the path and the path is very narrow. At times we have to cross the river, and there is no bridge, so you have to carry the wheelchair on your back or on a bicycle.'

Examples from urban areas included unsafe roads and inaccessible pedestrian routes. People's houses, whether local huts or concrete built, were often small and cramped affecting proper indoor use of a wheelchair.

Area 3 'The nature of houses we have here are grass hut houses and the doorway is very narrow.'

Public places were also difficult to access. Area 3, with a history of unrest and subsequent international and national attention, felt there had been some improvement in the past few years. Area 2 however told of situations where new building work had not taken into account accessibility needs or regulations.

Accessing public transport able to accommodate a wheelchair is also a challenge.

Area 1 'It's very expensive for someone who is very poor []. These wheelchairs are bulky. [] If you use a Boda,(motorbike taxi) then that means you have to get three, one for you, one for the wheelchair and one for your guide."

3.2.5 Lack of peer role models

The benefits of empowered peers can strengthen a support system and contribute to self-esteem.

Area 1 'you identify a positive role model [] sometimes they [children] listen when a person in the same situation gives them their experience.'

Area 1 'The parents are even the best because they have walked that path and they know everything.'

Adults and children in all the areas have very few role models who are wheelchairs users

Area 3 'Most disabled children that have had limited exposure and mentorship from adult disabled person look at themselves as valueless in the community. For them to

gain self-esteem it requires lots of support by the community like teachers, adult disabled person and parents.'

3.2.6 Poverty

Poverty of wheelchair users and families was a cross-cutting theme raised throughout discussions as having significant influences for PWD in accessing required services and in overcoming environmental barriers. Carers, said to be single mothers or grandparents, were said to be challenged by the need to earn an income and look after other children, thus reducing the time and energy available for a child with a disability. Resources necessary to acquire and maintain a wheelchair are out of reach for many.

Area 1 'Due to rampant poverty existing around Uganda, you find even when a kid is supposed to get a wheelchair, she or he is not able to access it, because there is a contribution a parent is supposed to make, and because a parent is not able to get that money, the child is going to end up not having a wheelchair.'

Having a wheelchair may also lead to increased need for resources e.g. home modifications to accommodate a wheelchair or transport money for three when distances are too great for pushing a wheelchair and drivers charge extra for wheelchairs. Considering the complexity of disability and poverty receiving a wheelchair may overcome one challenge but may not lead to an actual change in the person's life.

Area 1 'Sometimes we give wheelchairs to these people, but then it doesn't change a lot in their quality of life. For example, if a child is school-going, and you give them a wheelchair, but still they stay at home?'

Summary of theme 2

The CBR workers were effective at capturing a range of reasons for challenges expressed in theme 1. Sub-themes relate to ICF contextual factors. The discussions bought to life how the different factors impact each other and interact leading to more significant and complex situations for wheelchair users and their carers.

Perceived reasons were:

- Wheelchairs are either inappropriate or inconsistently available
- Services, systems and policies are not meeting the need
 - Wheelchairs are not always provided through a service
 - Wheelchair services are not being accessed by all in need

- Lack of clarity of policies, regulation and government funding
- Wheelchair users and carers lack training on use and care
- Wheelchairs are not lasting
- Wheelchair services are not following users up
- Lack of statistics on wheelchairs
- Negative attitudes and cultural beliefs about disability
- Inaccessible physical environments
- Lack of peer role models
- Poverty

3.3 Theme 3: Perceived role of CBR workers

This theme was a response to the third question 'What can you do about it?' Following discussion on challenges and reflection on reasons the groups provided ideas based on current methods, which they felt were beneficial, and made new suggestions. Group discussions explored practicality of ideas and while not all data was generated through consensus the process allowed perspectives to be shared.

3.3.1 Facilitate PWD to benefit from available wheelchair services

3.3.1.1 Identify users and support them to access the wheelchair service (wheelchair service step 1)

Considering the factors affecting uptake of services under theme 2 this role will have benefits for users especially those remotely located, poor or influenced by misinformed perceptions and fears. However this will also aid in developing an efficient system to help the wheelchair service put energies into appropriate assessment and provision of an appropriate wheelchair. This role was emphasised by all groups and was also noted as an existing activity for many in the responses in the pre-focus group questionnaires (appendix 3: FGD database).

Identify: All groups felt they could identify those needing referral; they also reported cases where people are isolated or remotely located and are dependent on a CBR worker either to find them or to connect with the right networks to get information to them. The CBR workers knowledge of disability, community services and existing networks were factors justifying this role.

Areas 2 'You go to meet those groups of people with disabilities, as you tell them they will go and tell others in the community. By doing that, those people in the community will get to know about where to get the services.'

Inform, reassure and change attitudes: Considering the major barrier that users and carers fears and assumptions have in accessing available services, this is an important role.

Sometimes many visits are necessary to change attitudes towards a child and to encourage a carer to take advantage of an available service.

Area 2 'You find that a caretaker can say that this child of mine was cursed. So changing him from that belief to the actual belief takes long.'

Area 2 'it gives an impression [] 'this disabled person of mine, is also liked by many people'; that impression alone helps to stimulate the mind of this caretaker.'

Area 3 included sharing information on the benefits of a wheelchair as well as information on what to expect from the service in order for informed decisions to be made.

Area 3 'We need to explain at an early stage 'we are sending you for assessment, from then the child may get or may not. []. They need to know before they go.'

Further information on the costs helps some users put it in perspective and be prepared to pay the fee.

Area 3 '...you say that you pay some small amount of money, but the real cost of the wheelchair is almost a million [Uganda Kwacha] [USD280]. [] If they have understood, then people will start paying that money.'

Agreeing to accompany a user to the service at the hospital was also expressed in Area 2 and 3 as helpful for users in overcoming the fears.

Make arrangements: Area 2 and 3 put a great emphasis on facilitating the connection between users and service providers. Negotiations with a service provider may lead to them serving a group of users together during an outreach community visit. On the other hand sharing appropriate information with a PWD may ensure they overcome possible financial and environmental barriers to reach the service on a day they can be served rather than to be turned away.

Area 3 'We tell the community, [] Tuesday's the day. [] If someone comes on other days, they are going to waste their transport.'

Area 2 'We talk to [the users to see if they] are able to afford the transport that can make [them] reach [the service]? Then we again talk to the technician. [] So, if all are agreed [] it is on that day [] we access that service.'

Good understanding of the service processes can enable the CBR worker to contribute further by not overloading the service with unreasonable number of clients on any one day. Such as below where a client was identified as having complex needs which could result in pressure on the service and incomplete service provision if too many clients present.

Area 2 'Since this difficulty of this client is heavy instead of going three you go two'

3.3.1.2 Assisting during service provision (steps 2 to 7)

Area 2 provided examples of how they thought they could be helpful to the wheelchair service. An example in Area 2 described how clients may not always be relied on to provide accurate information during assessments and presence of a CBR worker has helped the service providers with gathering accurate information about the clients' situation.

Area 2 'CBR worker is well known to the parent, [] then the parent will feel that environment that I'm at home, then he can be able to elaborate more.'

Area 2 suggested they could assist with preparing products at the service or providing training to users during the service to help the service meet the needs of more clients.

Ares 2 'If we are trained in that technicality, then you can be able to help, [] and then try to assemble other wheelchairs, in order the service to reach all the people that has come, ja.'

3.3.2 Support users in continued use and optimum benefit of a wheelchair

All groups presented examples of the need for and impact of carrying out regular home visits to follow up the client once they have received the wheelchair. This activity was explained as having multiple purposes including to reinforce training learnt (wheelchair services step 7), to carry out some aspects of wheelchair service follow-up (wheelchair services step 8) and implement the CBR strategy of care giver support and social inclusion.

Reinforcing training about care, maintenance and use of the wheelchair was suggested considering the challenges in all areas with users and families remembering instructions (wheelchair services step 7). On-going mentoring is needed.

Area 3 'Because those parents, those mothers, can have enough time with you to ask what they don't know, and you also have enough time to explain to them and demonstrate what they don't know physically, so it is very important.'

Area 2 'As I kept making follow ups, [] I find that they have started [to catch] up with my message.'

These opportunities can help to identify the need for transferring knowledge and skills to other family and community members to ensure a larger, continuous and knowledgeable support system.

Area 2 'Caretakers, some of them [] get tired. So, when they get tired, ah, CBR workers make some follow-ups. You can train another one to carry on with the activity.'

CBR worker can help to identify on-going challenges in using the wheelchair such as with health or accessibility.

Area 2 'although you are sitting in a wheelchair that doesn't mean you should sit and relax. [] You can sit in the wheelchair and make other activities.'

Area 2 'So at least if you reach the home and find out the difficulties in that home [] you can make a proper bathing place for him.'

Considering the environmental barriers and challenges to participation encouragement and support from a CBR worker can empower users and carers with information to negotiate difficult decisions prohibiting social inclusion.

Area 2 '...their child knows how to speak but not to walk and wanted to go to school but couldn't go, and had a wheelchair. So I sensitised the caretakers. This time they are taking their child to school [] and [] even to church.'

Area 1 'we need to enlighten them about the importance of this child going with the wheelchair [to school]. To them they might not look at the bigger picture, if my child has no wheelchair, it means they are going to do their toileting from the classroom.'

Follow up is a time when the CBR worker can check the condition of the wheelchair and encourage the user and family to continue caring for and maintaining the product to help it stay safe and functional for as long as possible (step 8).

Area 2 ‘You can check whether some nuts have fallen off. You talk to the family member on how to maintain. If maybe their doorway is too narrow [] you can know the reason this chair is sleeping in the rain.’

Area 3 ‘Most of our communities are ignorant – you find the wheelchair is already broken and thrown away. There is need for regular follow-up.’

Area 3 ‘You don’t need to wait until the wheelchair is broken and then take it for repair – you can keep it still in working condition. It does not need a specialist. You should have a spanner.’

During the home visits CBR workers in Area 2 felt they can help to ensure the wheelchair continues to meet the users’ needs by doing adjustments (wheelchair services step 8). It was encouraging that they acknowledged the needs for specific skills to do this.

Area 2 ‘You may reach in a home, and then the parent may tell you [] my child [] is not fitting in the wheelchair. [] The technician from the service [] say, [] we are busy []. But if a CBR worker is well skilled in that, then you could have worked on that and make sure that it fits.’

Both Area 2 and 3 agree that the visits could be used to identify the need to refer back to the trained service providers for a comprehensive follow up by the wheelchair service (wheelchair services step 8).

3.3.3 Empowerment and inclusion activities

Numerous examples were provided for how CBR workers could use their CBR strategies to help with wheelchair specific issues. This included spreading information, increasing knowledge and bringing about attitude shifts in order for PWD, communities, service providers and leaders to initiate improvements towards an inclusive society. It was also apparent that the CBR workers were aware when they needed support of specific role players in order to influence others and showed how they could strengthen one side such as a peer role model to influence another. The range of stakeholders and levels shows the holistic needs of wheelchair users and potential impact of CBR workers.

3.3.3.1 Empower role models

All groups spoke about the impact that persons with disabilities have on others either as CBR workers or strong role models in the community. Area 1 and 3 felt there was a role for them in identifying and empowering individuals to become strong role models and representatives for others. This was an area in which the groups particularly in Area 1 felt could strengthen their work.

Area 3 'If you can identify the one whose self-esteem is high, who can talk, [] from the community, and maybe you build their capacity to understand how to address their issues.'

Area 1 'You give them exposure. Like if you get leaders [role models] from village W they come and visit [experienced role model] in village X. They observe, appreciate. It begins like that.'

Area 3 also suggested helping to connect strong representatives with community platforms in order to give voice to people with disabilities.

Area 3 'If we empower a wheelchair user they will be able to explain their own experience and they [community leaders] will listen more to him because they know he is talking out of his or her experience. [] CBR role in this is [] to connect them with those leaders, to allow them [leaders] to give them time to explain what they want.'

Area 1 suggested role models can also be used on a larger scale than for one to one support.

Area 1 'Using role models [] at a bigger level [] for example a big meeting. We can use these role models to still come in and talk to the parents and so we can improve what we've already been doing.'

3.3.3.2 Empower user support groups

Participants in Area 1 and 3 conveyed their links with parent support groups could be used to increase the flow of information and also the support available to wheelchair users and families. This included using and caring for the wheelchairs and accessing the community.

Area 1 'They could do the identification because sometimes we don't know all the children within that community, if they have the knowledge we have.'

Area 1 'Within the parent support groups, we can have, like, a committee in charge of wheelchairs, so they can be responsible for guiding other parents.'

Area 1 'Parents find a common voice so they can [] improve wheelchair service for their kids. [] Since the schools are very far, they can look for schools which are nearby.'

3.3.3.3 Empower the community

All groups provided suggestions on their role in increasing the communities' knowledge about disability and needs of wheelchair users by sharing information through various platforms.

Area 1 'We work with the District health teams, [] when the immunisation dates run [] and we give a talk about disability and inclusion issues.'

Area 3 'It will take the community time to understand, as we dialogue some of them [] get to realise [and say] "oh, our members are missing this" '.

Area 3 felt it important for them to help locate disability issues within the community rather than PWD being the responsibility of specific organisations and sectors.

Area 3 'people think that this child has a disability should be the concern of (the CBR organisation) or the hospital. But you sensitise that that person should be integrated in the community.'

Participants in area 2 discussed the impact that engaging in public with a person with a disability can have on breaking down community barriers.

Area 2 'I went to demonstrate eating to that child on the same place when the community are seeing. They said, 'oh, epileptic person' []. A good number have come up and they are now [] able to sensitise others in the community.'

Area 2 'That one alone can help and say, 'oh but these people are like us'. That barrier can be removed. And in that way the love can be extended to this person and all of a sudden he's enjoying his full potential.'

Area 3 provided an example of how the community would help if they were empowered with information

Area 3 'The community will act as vigilantes to see that assets, wheelchairs for people with disabilities, are protected. If the community is aware they will severely punish whoever causes problems with people with disabilities'.

3.3.3.4 Empower local service providers

A multi-pronged approach to changing attitudes is required in some settings such as school. Area 1 and 3 gave examples how they had educated school management, teachers and pupils on issues regarding individual children, general disability as well as accessibility.

Area 1 'disability awareness are not just for the teachers, eh, we also go down to the pupils []. Disability is not contagious, because so many of them think I might also contract the same disability.'

Area 1 'there is one school that we use as a model school, where most of the accessibility was done and there was quite a very big change, because now those parents do want to take their children to that particular school.'

Area 1 'We found that some schools were not taking proper care of these wheelchairs, but now that the teachers have been sensitised they can help prevent other children from mishandling'

Both Area 2 and 3 explained how they could also share their knowledge with other service providers including village health teams.

Area 2 'We can really go and impart those skills to the service providers; those who are having clients [] who are using wheelchairs. And even, train those who don't have any client, because they may come across a client who is needing that service.'

3.3.3.5 Share information with local leaders

The importance of engaging local leaders was recognised in all groups. Area 2 felt it was important and possible to help increase understanding and thus change attitudes towards disability. This was vitally important considering the influence of the elders on the broader community.

Area 2 'the cultural leaders [] are taught this different point of view. [] With a scientific point of view you can easily trace the origin, and they get it.'

Area 2 and 3 discussed this point at length and some felt attending relevant community meetings would provide a platform to transfer information and share responsibility for removal of community barriers to participation.

Area 2 'in those meetings, some of them may not be knowing about the wheelchairs coming. By meeting them, you can tell them, [] [and] they will tell the community.'

Area 3 'As CBR workers we have to take our chance, and bring in all these issues like the roads, paths, [] issues of school.'

3.3.4 Gather statistics

Gathering statistics, identified as useful to support wheelchair services, is an activity CBR can assist with. Area 2 and 3 felt CBR workers could use their location and connections to gather details on who had and who needs wheelchairs. This was challenged by their wish to avoid disappointment and raised expectations; however the agreement was that this was important.

Area 2 'We can also do the identifying those people who really need those wheelchairs. You can also identify those who have already got, and you at least have a good record of them, in case there is someone coming from the district [] I have this number which already has wheelchairs, and this number needs wheelchairs.'

Summary of theme 3

A range of suggestions were provided for how CBR workers can assist in overcoming elements of the challenges they observed. Some suggestions were based on current functions and others were ideas generated during the discussion. The list below is not based on consensus between groups but rather capture main suggestions from individual groups.

Perceived CBR worker roles include:

- Facilitate PWD to benefit from available wheelchair services
 - Identify users and support them to access the wheelchair service (step 1)
 - Assisting during service provision (steps 2 to 7)
- Support users in continued use and optimal benefit of a wheelchair (steps 7 & 8)
- Empowerment activities
 - Strengthen role models
 - Empower user support groups

- Empower the community
- Empower local service providers
- Share information with local leaders
- Gather statistics

3. 4 Theme 4: The needs to achieve this

Theme 4 is drawn from the question ‘what do you need to be able to do this?’ which followed directly on from their suggested role and contributions (question three). The data under this theme was generated throughout the group discussions as a natural part of conversation but a particular focus was paid to this once they had fully discussed the role they could have.

3.4.1 Training related to wheelchairs

All groups regularly mentioned the need for training such as a CBR worker from area 3 who said '*I need to know everything about the wheelchair*'.

When asked specifically to generate a list, they provided the information summarised in Table 3.2

Table 3.2 Training needs

Area 1	Area 2	Area 3
What is an appropriate wheelchair	Same training wheelchair users receive	Identifying disability early
How does a wheelchair function	Measurements for follow-up	How to access a wheelchair
How it feels to use a wheelchair	Assembling	Why a wheelchair needs to be accessed through a trained professional
How to check comfort and fit, check pressure	Some repairs	Types of wheelchairs at the service
Maintaining a wheelchair	Access and environmental adaptations	Repair and maintenance
Safety issues	Simple budgeting and fundraising	Adaptations
Accessibility and adaptations of the home	Nutrition	

Training was requested to enable implementation of the roles however there was also a sense in Area 2 and 3 that by receiving additional training the CBR workers could assist the wheelchair services in sharing tasks and achieving more.

Area 3 'We have people who are actually willing and they are able also to work, so instead of only two people getting all the patients, they will also need many other people, and the work will become easier.'

The CBR workers from Area 2, with less exposure to wheelchairs, showed great interest in enhancing skills and a number of them had accompanied users to the wheelchair service to increase their knowledge. They felt unable to support users if they knew less than them. Some participants had received some training from the service however this was not deemed useful for their role. The service had trained them on doing measurements which is not sufficient to prepare them to play a greater role in assisting the wheelchair service and inappropriate to enhance their existing CBR role.

Area 2 'But now, for us when there only one day, that one day, we are given some help for measuring [?], eh? We are helping everyone for measuring, but now, measurement will not make us work with the spare parts'.

Knowledge of the different types of wheelchairs available as well as their features and functions was raised and it was clear through the discussions that this varied dramatically within the groups. It largely depends on an individual's willingness and ability to reach the wheelchair service to explore what's available.

Area 3 'They see them in the community, but some of them think these wheelchairs cannot be adjusted. But the reality is if you go to hospital, like most of us – if you're taking people to the hospital, you are taking time to see how these modifications are done.'

Area 1 had experienced a training in which they sat in and propelled wheelchairs themselves. They recommended this as an activity for others to experience in order to better appreciate some of the challenges with using a wheelchair.

Area 1 'It got me thinking this is not really something easy, I really got in their shoes, I must confess it was really hard.'

Area 1 'It helps you to assimilate how people are living in wheelchair – appreciate the challenges – so when you are lobbying for service delivery you know the issues you are talking about not like guess work.'

All groups identified the need for training in maintenance and repairs however there was debate in Area 3 on the level of repairs they should be doing. This is an important point as there is an obvious need to improve the repair services available but it is important to determine what can be expected of CBR workers and which may require advanced technical skills and equipment. It was clear that some felt they could do some repairs and sounded confident when talking about relevant tools and techniques but others were significantly less comfortable with this idea.

Area 3 'You find that we don't have enough skill as facilitators for repairing, if some of the part of the wheelchair might be breaking or not in a good position – we don't have the skill of training those parents how to repair it.'

Training on fundraising and budgeting was suggested. Some discussions in Area 2 centred on the role of the group in overcoming lack of resources for themselves to fulfil their role and for users to access the service. After some discussion they realised they needed to increase methods to raise funds but first needed to know the associated costs.

Area 2 '...because if you do the budget you will get to know how much you will have [] on certain number of clients who will go for wheelchairs'

A review of the individual questionnaires captured on the FGD database (appendix 3) indicated how varied the trainings on wheelchairs had been. Only 12 of the 21 participants had had any training on anything to do with wheelchairs. Of these, 9 were since the wheelchair services began and only 8 had been delivered by or in collaboration with the wheelchair service providers. The durations ranged from 2 hours to 3 days of training.

3.4.2 Communications with the wheelchair service

Groups referred to the ad hoc communications with service providers. This was mentioned less with the members in Area 1 where some of the CBR workers are based at the same location as the wheelchair service. Communications that take place relate to referrals and arrangements for service. However there was also discussion about needing information on wheelchair availability and some mentioned they have to visit the service to establish this. The members were sure not all CBR workers within the communities did the same. Most

communications with the service were initiated by the CBR worker and it sounded as if this was very dependent on the individual's interest.

Area 2 'We shall get problems if we mobilise people when they come here and they don't get wheelchairs []. You need to go to the hospital to find out if there are wheelchairs. Or we can coordinate through our boss.'

Some group members in Area 1 felt they were unaware of where to refer while others in the group had clear systems.

Area 1 'She is saying, if they are kept informed, the volunteers, then they will at least be aware of where to refer the different people.'

Area 2 suggested that the service be consulted with the aim of establishing regular meetings with an appointed CBR worker who could then share information with the others and feedback information to the service.

3.4.3 Resources

All groups raised the need for resources whether this was for their own costs such as transport for home visits or funds to carry out training or awareness activities. There was a common feeling that inadequate resources prevented them from targeting the appropriate people to influence change.

Area 1 'If you don't facilitate [pay] them (parents and carers) and you call them the next time, they will not come.'

Area 2 'If we are really empowered with the facilitation [funds], we can as well train more and more people within their localities.'

Area 3 '[CBR workers] around the town may be many because if you say you need to go that distance, you need [] some facilitation [funds]. It is far'

They also felt that with resources they could solicit assistance from others to help change attitudes. Suggestions were made of an empowered wheelchair user, trained wheelchair service provider and leaders.

Area 2 'When we call them [leaders] they need to spend some money, transport and lunch. Now we who is very poor, where will we get the money'

Area 2 explained how they try to raise funds to implement activities such as assisting users to reach the service. This is not commonly successful and can be disappointing and demotivating influencing future attempts.

Area 2 'Maybe we get discouraged after failing [to raise money]. After not succeeding, then you say [] this [next] one maybe will not succeed.'

They also shared how in some instances they cover costs with their own resources however they felt that their own economic situation made this challenging for them.

Area 2 'if you feel that you have that something and you can donate then you can go with him [to the service]; but if you have an empty pocket, you just send him there and call the doctor.'

Area 2 'making their [CBR worker] personal contributions; [] for facilitation in case there is an emergency.'

It was also interesting to hear some opposing sides of the debate in Area 3 on whether CBR workers should be volunteers or not and whether they should receive compensation for expenses incurred.

3.4.4 Opportunities for CBR workers to meet

All three areas discussed the need for CBR workers in the same area to meet to share information and ensure they are all working with the same knowledge. Area 1 was the only area in which the CBR workers had scheduled meetings. Area 2 and 3 felt this was necessary.

Area 1 'for the CBRs,(workers) we meet almost every month, [] and then with our volunteers [] we meet them and then we share with them.'

Area 3 'What I know is there is a need for capacity building, regular sitting and having meetings and sharing all these things together. Then we can have uniform knowledge. We may be doing different things, so there is a need for capacity building for community-based workers.'

The participants in Area 2 reflected on the current focus groups and identified the benefits of meeting with other CBR workers. During the meeting they agreed to continue to formalise their affiliation and have met three times since with an on-going plan to meet quarterly.

Area 2 'We planned to be meeting twice a month. This was our arrangement to complete our tasks [] with the constitution. We have now met three times. We now plan to be meeting quarterly' (July 2015)

3.4.5 Legitimacy of CBR workers

Area 2 and 3 raised many additional challenges related to the situation of CBR workers which impact the effectiveness of their work. One of these was related to the attitudes of community and service providers towards them. The participants felt that the community was often suspicious about their intentions when they tried to carry out their role.

Area 2 'maybe this one, he want some money. They have some problem and adversity with some people.'

Area 3 'You know when you go to the community by yourself, you start creating things like "I want to do this" – it will bring a lot of questions, they will start saying maybe you are a politician who wants votes.'

They made suggestions for overcoming this such as having registration documentation or working in teams with other CBR workers or PWD to increase impact and legitimacy.

Area 3 'CBR workers should be given [] a sort of document so they can enter the hospital. Like for me it is easy, I can come in and see the different wheelchairs. But for someone from far they need to be given something.'

Area 2 '(If) a CBR worker is not disabled [] they say, no, this one is lying. But if he comes [pointing to CBR worker with a disability] that one will cause a change to the parent or the caretaker.'

3.4.6 Increased availability of trained CBR workers

Area 2 and 3 expressed the need for training of more CBR workers. Area 3 suggested a CBR worker in every community.

Area 3 'it is true that the CBR worker is not everywhere they are few. So you need someone from that area, to help in supporting, providing information, attending community meetings. The person should be based there but attached to us [CBR organisation] so we know so and so has a disability.'

However group members in Area 3 explained that the levels of knowledge and training of CBR workers differ quite dramatically.

Area 3 ‘training of CBR workers is still an issue as majority have received short training through hiring the service of COMBRA. But those who have gone on a four months training at COMBRA have in depth knowledge of CBR work as compared to those who underwent 1-2 weeks short training.’

3.4.7 More and decentralised wheelchair provision and repair services

Area 2 and 3 also expressed the need to increase the number of service providers and to bring wheelchair services and repair workshops closer to the community. They also expressed the need for increased availability of durable wheelchairs.

Area 2 ‘If only they could get another centre where those people having the wheelchair can easily come and be repaired. Maybe in the village there and not in town, [] where you don’t need to make an appointment first.’

Area 3 ‘At least if there was a way of building the capacity of the staff, [], then we decentralise this service points. So that [wheelchair service] will not have the bulk of workload of people coming in.’

3.4.8 Comprehensive rehabilitation programmes for wheelchair users and carers

A participant in Area 1 explained the need for comprehensive rehabilitation programmes for wheelchair users and their families inclusive of opportunities for economic empowerment. Considering the many contextual factors affecting participation and quality of life, highlighted in theme 2, overcoming one barrier such as receiving a mobility device is often insufficient to affect change.

Area 1 “If we give a wheelchair and the mother is able to contribute towards school then we’ll get a comprehensive rehabilitation programme.”

Summary of theme 4

Theme 4 focuses on what CBR workers felt they needed to fulfil the role and functions raised in the previous section. CBR worker needs include:

- Training related to wheelchairs
- Communication with the wheelchair services
- Resources
- Opportunities for CBR workers to meet

- Legitimacy of CBR workers
- Increased availability of trained CBR workers
- More and decentralised wheelchair provision and repair services
- Comprehensive rehabilitation programmes for wheelchair users

Summary table of all themes and subthemes can be found at the beginning of this chapter on page 35 Table 3.1

Chapter 4: Discussion

The purpose of the study was to explore challenges to wheelchair provision and use in three areas of Uganda as perceived by CBR workers and to hear the role they think they can play. The three areas were identified specifically due to the presence of a wheelchair service. The services, all active for less than 2 years, are managed and delivered by personnel who've attended relevant training as recommended by the WHO and other stakeholders (Borg *et al.* 2011; ISWP n.d; Visagie *et al.* 2013; WHO 2008). All the CBR workers involved in the focus groups were working with wheelchair users in the target areas of the new services. The perspectives of these CBR workers are important considering their links with PWD, wheelchair services and communities. Many of the CBR workers had been working in the same context for a number of years enriching their perspectives on the current situation. As pointed out in other evaluations involving CBR workers, participation is important to build local capacity (Eide *et al.* 2014; Grandisson *et al.* 2014; Nualnetr & Sakhornkhan 2012).

The Freirian approach used in each focus group was useful for eliciting participation and for guiding the conversation. The ICF domains were applied in sorting and categorising the data showing the complexity of factors interacting to influence the wheelchair user's participation and quality of life (Smith *et al.* 2014). The overall purpose of wheelchair provision is to enable PWD 'to become mobile, remain healthy and participate fully in community life' therefore it was an appropriate framework to draw on (WHO 2008:23). Further to this, the ICF is recommended as a support tool for CBR and rehabilitation (Madden *et al.* 2013).

Participation and activity restrictions were captured under theme 1 as the main perceived challenges. The two most prominent participation restrictions related to lack of mobility and sporadic engagement in various major life areas such as school and other community life. Maintaining health and well-being under the 'self-care' domain was a constant challenge and for many the potential health and developmental benefits of an appropriate wheelchair were not being realised. A further challenge to participation was the high dependency on small support systems.

Environmental factors captured under theme two demonstrated the range of challenges for wheelchair users especially when interacting with issues of rural living and poverty. Of particular emphasis was the role that negative attitudes and beliefs play in utilising services but also on-going use of wheelchairs (Wegener & Rhoda 2015; Smith *et al.* 2014). Of specific interest was the impact of previous experience with wheelchairs and other models of provision primarily the charity model approach. Challenges observed with the 8 steps of wheelchair provision were captured under this section but in no way were an evaluation of

the wheelchair service but rather reflections necessary to identify potential areas of CBR worker support.

CBR workers felt they have a role to play in provision and use of wheelchairs. The different activities and strategies exposed some variations but key trends were identified. Most input was in line with typical CBR strategies such as being an active part of the wheelchair service referral network, supporting and empowering wheelchair users and families through home visits and linking and empowering wheelchair users and community stakeholders for enhanced community integration. As Chappell and Johannsmeier (2009) point out, an important benefit of CBR workers' involvement is 'how' they work which is highlighted in this study as crucial, considering the many and varied challenges experienced.

Participation domains will be further explored in combination with the different contributing factors in the two sections below. The first will focus on 'Perceptions of challenges found with accessing wheelchairs' followed by 'Perceptions of challenges found with wheelchair use'.

CBR workers' perceptions of challenges found with accessing wheelchairs

Identified challenges included lack of consistent availability of appropriate products, lack of policy clarity and government support and insufficient trained wheelchair service providers working with too few resources in central locations. Poverty and rural living play a key role however very prominent was the impact of negative attitudes and beliefs of PWD largely influenced by previous wheelchair experience. Lack of available statistics was also noted.

CBR workers discussed the high prevalence of children and adults needing wheelchairs in their communities as was reported in the Uganda UNCRPD 2013 report (NUDIPU 2013). They were not however able to provide or refer to more specific details. Lack of differentiated statistics has been recognised as a weakness in Uganda (Abimanyi-Ochom & Mannan 2014). While they are likely not to hold this level of information they did show how their knowledge of the community and the 'hidden' PWD would be useful to generating an impression of the need. There was a common feeling that collecting statistics would raise expectations of PWD to the possibility of receiving a wheelchair; the CBR workers typically chose not to gather information for this reason to avoid this disappointment. They report however that local government officials are not aware of the true need and are largely underestimating it.

Some political will towards ensuring access to wheelchairs were recognised including the *National Policy on Disability* (2006), the '*Code of Practice*' for *Wheelchair Provision* (UNBS 2011) and the oversight role of the National Wheelchair Coordination Committee (MGLSD 2006; Mukisa & UNAPD 2005; UNBS 2011). However, most references related to inconsistent implementation and lack of regulation. Local production is promoted by the government but is not funded, resulting in apparent challenges with quality and availability, as observed previously in Uganda (Øderud *et al.* 2004; Mukisa & UNAPD 2005) and in other less-resourced settings (Banda-Chalwe *et al.* 2014). In Uganda, the UNBS (2011) indicates that wheelchairs should be provided through a wheelchair service however the CBR workers accurately pointed out that wheelchair services are too few and most wheelchairs are provided in other ways. From the CBR workers perspectives the lack of funding for wheelchair services impacted their activities and ability to reach more people. The situation is further confused by government messages speaking to the right to *free* mobility while in reality some wheelchair services had to charge to overcome lack of government support. Visagie *et al* (2013) point out the damaging effect that not implementing policy can have on wheelchair users and service providers. Frustrations were evident in these groups as well as lack of agreement on the meaning of policies and the role and responsibility of government.

Common to all areas was the inadequate availability of appropriate wheelchairs. One CBR worker commented that often children would benefit from two wheelchairs reflecting on the different environments and places a wheelchair needs to be used in e.g. one for home and one for school. Visagie *et al.* (2015 a) and Bray *et al.* (2014) concur with this however as Visagie et al (2015 a) points out it is unlikely that accessing two products is possible for many and instead emphasis needs to be placed on the design and features of the wheelchair. Diverse types of wheelchairs were seen in the north and central areas provided through local producers, charity model distributions and the wheelchair services. Information from the west indicated less availability with the new wheelchair service being the main provider. As mentioned, locally produced wheelchairs were reportedly affected by quality issues. Imported wheelchairs, designed with consideration of the rural context and provided through the wheelchair services, were reported to be more suitable, but not always available which is a common challenge with imported products (Banda-Chalwe *et al.* 2014; Jefferds *et al.* 2010; WHO 2015).

Mass produced, low cost wheelchairs distributed through the charity model were reportedly not suited to the rural environment reflecting findings from South Africa, Zambia and Zimbabwe (Banda-Chalwe *et al.* 2014; Visagie *et al.* 2013; Visagie *et al.* 2015 a; Visagie *et*

al. 2015 b). The many wheelchairs observed to be available for adults were not appropriate so the gap prevailed. Observations by the CBR workers of the charity model approach to wheelchairs pointed to the disadvantages of high volumes of damaged products, not designed for the terrain, clogging storage areas and products provided inappropriately, usually adult products given to children, causing injury through falls, pain and discomfort (Motivation 2015). The negative consequences of this approach for users' health and function have been reported through studies in India, South Africa and Zimbabwe (Mukherjee & Samanta 2005; Visagie et al. 2015 a & Visagie et al. 2015 b). A further important observation in this study is how experience of this approach affects the willingness of users to pursue opportunities through the newly established wheelchair services.

Transition from the charity model approach, indiscriminately handing out wheelchairs, to a professional service model approach, based on individual users' needs, raises challenges for PWD. The free supply of wheelchairs, fuelled by messaging during political rallies, cause PWD to continue expecting free wheelchairs and hence resist meeting the cost required by some wheelchair services. A SINTEF report on the Ugandan wheelchair situation in 2005 suggests free products are unsustainable and that charging an amount is a more sustainable approach (Øderud et al. 2004). Contributions may be small and required to cover service overhead costs but indications were that this was rarely understood. Another shift for PWD in these areas is that wheelchair are now provided by trained rehabilitation personnel based at district hospitals rather than given out by community-based organisations. Discussions showed how some people resisted this change due to fears of discrimination and abuse from health care providers and the CBR workers reflected on the prevailing attitudinal barriers. Influences of past experiences of the medical model approach to disability have been found to affect PWD utilisation of health and rehabilitation services (Grut et al. 2012; Walker & Gilson 2004). Participants from the CBR organisation in the north explained the continuing pressure by the community for *them* to provide wheelchairs and related support.

People with little or no previous exposure to wheelchairs were also not utilising wheelchair services. Ignorance of the benefits of a wheelchair and fears of the technical complexity of the device were reasons provided. In some instances scarcity had resulted in wheelchairs being treasured rather than used (Mukisa & UNAPD 2005). Fears, compounded by cultural beliefs and stigma are well documented and commonly found to affect PWD in rural areas (Deepak et al .2014; Grut et al. 2012; Harkins et al.2012; MacLachlan et al. 2014; Magnusson et al. 2013; Wegner & Rhoda 2015). Using a wheelchair in public is perceived in some instances to increase discrimination. A wheelchair user in the group expressed her increased vulnerability when in the community because of her wheelchair. A study in South

Africa suggested that visibility of physical disability made people more open to discrimination (Wegner & Rhoda 2015) but a study in Bangladesh showed that using a wheelchair actually resulted in better attitudes from neighbours than not using a wheelchair (Borg *et al.* 2012). It is likely that the experience of discrimination is less about the wheelchair but more due to increased visibility of the PWD in the community. The CBR workers in the west felt that increasing visibility of wheelchair users engaging in everyday activities would challenge negative stereotypes and may ease the path for others needing to use wheelchair in the future.

Previous disappointments further impacted utilisation of wheelchair services as found by Grut *et al.* (2012). Examples included situations products promised but not received, or only made available to a certain group of people. Other situations emphasised people's disappointment when provided with a wheelchair that, for different reasons such as physical barriers in the home, turned out not as useful as expected. Multiple societal, political and historical influences and change from one approach of wheelchair provision to another play a fundamental role for PWD in accessing services. Grut *et al.* (2012) emphasises the need to understand to improve plans to enhance wheelchair provision. Without this cost effectiveness of the wheelchair service may be impacted such as indicated in the following quote '*Our situation is not that we have very few wheelchairs – the wheelchairs are there. Or that the need for the wheelchair is not there – it is there. But they are not given out as fast as possible because people think that it has to go for free.*' A cross-sectional approach to changing attitudes is needed to ease the path for new users (Chappell & Johannsmeier 2009; Wickendon *et al.* 2012). Empowering people with the right information can help to develop agency and the ability to make good choices; and support from a CBR worker was recommended by these groups and in other literature (Biggeri *et al.* 2014; Deepak *et al.* 2014; Grut *et al.* 2012; Zuurmond *et al.* 2015).

Lack of financial resources in combination with living remote from wheelchair services was a further barrier in accessing the wheelchair services (Grut *et al.* 2012; Schneider *et al.* 2013; Saloojee *et al.* 2006). As found in other studies, interaction of factors common to rural environments such as scarcity of information, unavailable or inaccessible transport, long distances and inaccessible physical environments combined with high levels of poverty resulted in many PWD choosing not to, or trying and failing to, access the wheelchair services (Grut *et al.* 2012; Machlanlan *et al.* 2014; Magnusson *et al.* 2013; Schneider *et al.* 2013). The CBR workers explained that at times the wheelchair service required a user to visit a number of times prior to finally receiving their wheelchair; and that often they would give up. Booyens *et al.* (2015) and others found in rural areas of Africa, poverty and rural

living affect the time and money available to take up and fully benefit from these services (Booyens *et al.* 2015; Eide *et al.* 2014; Fefoame *et al.* 2013; Grut *et al.* 2012; Mlenzana *et al.* 2013; Schneider *et al.* 2013; Saloojee *et al.* 2006; Øderud *et al.* 2004).

Access to an appropriate wheelchair was further compromised by scarcity of trained wheelchair service personnel and wheelchair services being far from communities. This is not altogether surprising considering rehabilitation personnel are designated for this role in Uganda (UNBS 2011), but are in short supply; similar to what is found in other less-resourced settings (Borg *et al.* 2012; Grut *et al.* 2012; Mannan *et al.* 2012; NUDIPO 2013). During discussions many contributions referred to service providers not easily or regularly able to deliver services closer to communities but that there was an advantage and need to do this. This is a common challenge for health and rehabilitation services and often due to limited resources (Grut *et al.* 2012; Ikeda *et al.* 2013; Wegner & Rhoda 2015). Visagie *et al.* (2015 a) further reflected on difficulties with accurate assessment and prescription of an appropriate wheelchair when a user's home environment is not known pointing to the advantages of delivering services as close to users communities as possible (Bray *et al.* 2014).

The multiple, complex and interrelated factors discussed impact a wheelchair user in overcoming challenges in accessing the available wheelchair services. The WHO Wheelchair guidelines capture this as step 1 of the wheelchair service steps: Referral and appointment. CBR workers are important stakeholders in the referral network and the significance of this role is made clear by the diversity of challenges affecting individuals' decisions and capability. Fefoame *et al.* (2013) acknowledges the CBR workers as the 'gate-keepers' and often the first contact points for users, hence their need to be adequately equipped to ensure effective referral.

Wheelchair users who were able to access the wheelchair service were, according to the CBR workers, being provided with an appropriate product. This leads us to believe the WSTP trainings are being used: '*At least here (hospital with wheelchair service), we refer, they take the appropriate measurements and give out appropriate devices*'. Those CBR workers who had also experienced the charity model approach to wheelchair provision made positive observations of the new wheelchair service approach of users assessed and products modified to meet their needs. The Wheelchair service approach was noted to be lengthy due to the complexity of the process, the nature of clients' impairments and the types of products (Bray *et al.* 2014). It was interesting to hear how CBR workers acknowledged this but were not critical of it. One might assume that considering the high volume of PWD

needing wheelchairs, that CBR workers would prefer a speedier process. Contrary to this, those who had observed the process from step 2 to step 7 of the WHO wheelchair service steps, were more appreciative of the thorough efforts and the good outcome. Rather they provided suggestions for how they could support, including more accurate identification, more logistics support in making and following through on user's appointments and in some cases even providing some support during service delivery. This is further discussed in the section discussing the role of CBR workers.

Perceptions of challenges found with wheelchair use

A wheelchair has the potential to enhance quality of life; however, as also found in other studies, in these three this was not automatic and often challenging (Borg *et al.* 2012; Bray *et al.* 2014; Eide & Øderud 2009; Teerink *et al* 1999). Benefits of a wheelchair in relation to health and participation were difficult to achieve or inconsistent. This was partly due to the use of inappropriate wheelchairs already discussed but also due to the interaction of other factors including lack of appropriate knowledge on use of the wheelchair, wheelchairs not lasting and attitudinal and environmental barriers.

Optimal use of a wheelchair is enhanced through appropriate training. Feedback from CBR workers in this study indicated that users and carers tend to display insufficient skills in using and caring for their wheelchairs. As pointed out in other studies this could be due to insufficient training or lack of compliance with advice and instruction (Hosseini *et al* .2012; Mukherjee & Samanta 2005; Visagie *et al.* 2015 a & Visagie 2015 b). Most discussions focused on lack of care of the product however challenges observed with maintaining health, appropriate use of the wheelchair and optimal participation were also connected to training (Fogelberg *et al.* 2009; Sakakibara *et al.* 2015; Scovil *et al* .2012, Smith *et al.* 2014; Visagie *et al.* 2015 a). Wheelchair services had been observed to provide advice and instruction as recommended in step 7 of the WHO Wheelchair service steps (WHO 2008), but reasons for the lack of skills noted, included the shortness and timing of training as well as the complexity of information provided. In most instances education levels of users and carers are low, which according to Mol *et al.* (2014), is linked with little knowledge of basic health further impacting comprehension and retention of new information. Feedback also showed how the person receiving the training is often not the main carer but rather someone who was available to spend the often long period supporting the user at the wheelchair service. This may be a grandparent or another community member who is usually not working, and often the skills and knowledge gained is not transferred to the relevant people.

Sawatsky *et al.* (2012) and other literature suggests that training be delivered in a number of sessions over a period of time to allow consolidation of knowledge. It appears that in the study context alternatives are required to the current strategy, which is largely reliant on the wheelchair service providers. This is especially relevant for wheelchairs for children with complex needs in situations such as this, where further rehabilitation support is in short supply. At times when the child's support system changes, skills need to be effectively transferred to others as soon as the need arises to ensure safety and on-going benefit – this was apparently rare and users were left vulnerable and wanting. CBR workers can play an important role in providing this support or equipping peers and parent support groups to do the same.

Repairing products, similar to reports in other studies in less-resourced settings, was also observed as a significant challenge (Ikeda *et al.* 2013; Magnusson *et al.* 2013; Smith *et al.* 2014; Visagie *et al.* 2013). The need for repairs was high, exacerbated by inappropriateness of products, type of use and storage, lack of maintenance and care and theft of parts (Pearlman *et al.* 2008). Similar to other findings in other studies', repair services in less resourced setting are hard to find, spares are unavailable and costs are unmanageable (Banda-Chalwe *et al.* 2014; Magnusson *et al.* 2013; Toro *et al.* 2012; Visagie *et al.* 2013).

Home visits by the CBR workers were described the opportunities where most observations were made. Problems related to fit, function and condition of the wheelchair were identified and presumed to indicate need for further input from the wheelchair service providers. It was evident in many cases that follow up services, prescribed as step 8 in the WHO wheelchair service steps, were not consistently taking place. This is not dissimilar to findings in Uganda a decade ago (Mukisa and UNAPD 2005; Øderud *et al.* 2004) or in other less resourced settings (Ikeda *et al.* 2013; Magnusson *et al.* 2013; Visagie *et al.* 2013; Wressle and Samuelsson 2004; Samuelsson & Wressle 2008). An important benefit of follow up for newly trained wheelchair service providers is the opportunity to check the appropriateness of the prescription and fit of the wheelchair (Visagie *et al.* 2015 a) and to gather information on product and maintenance issues (Mukisa & UNAPD 2005). The CBR workers indicated that this was included in their activities when they had opportunities to visit wheelchair users. While a follow up from a wheelchair service provider will provide specialist input, home visits and interim checks by CBR workers was said to have benefits to the wheelchair user and can assist in alerting the wheelchair service to problems identified.

Further to the challenges experienced with on-going use of a wheelchair, the prevailing and debilitating impact of other environmental and attitudinal barriers were highlighted. Serious accessibility issues from one's own home to public spaces are well reported barriers to

participation (Banda-Chalwe *et al.* 2014; Borg *et al.* 2012; Jefferts *et al.* 2010; Pearlman *et al.* 2008, Smith *et al.* 2014, Weerasingher *et al.* 2015). Negative attitudes from the family, community and leadership as well as public services such as health, education and transport were prevalent in all areas and have a profound impact on support offered to wheelchair users and their ability to engage positively in life. The impact of societal attitudes is well captured in other disability studies in Africa (Banda-Chalwe *et al.* 2014; Booyens *et al.* 2015; Hansen *et al.* 2014; Wegner & Rhoda 2015).

Participation and life experience was further impacted by high levels of dependency on often small, unpredictable and transient support systems. Increasing a support system was at times possible but not always lasting or desired. It appeared as if some of those initially willing to assist became fatigued by the efforts required or weary with the routine. Vulnerability for women and girls was a reason for parents to be more protective and deliberately restrict support provided from outside the home. This result was reported as avoidance of activities in an attempt to forego the need for support or to inconvenience others.

The complex interaction of these multiple barriers results in inconsistent and fragmented levels of participation. A child would go to school on some days but not others if the parent was too tired to push the long distance; or a person would reach town one week when a taxi accepted them on board but not the next when they were barred. A major impact was on fatigue levels and sense of control and autonomy of the user or support system. This has been found to relate particularly to carers of children with disabilities (Hansen *et al.* 2014; Zuurmond *et al.* 2015). Banda-Chalwe *et al.* (2014) found similar factors in Zambia often led to cessation of activities which was the same as reported in this study. Banda-Chalwe's study along with a study on children with disabilities in Zambia (Hansen *et al.* 2014) found resilience, determination and resourcefulness to make a difference. This was reflected by a CBR worker, also a wheelchair user, in this study: '*it is very difficult for someone using a wheelchair in Africa to be happy; but you have to be happy, because you have to live*'. So while crucial for multiple stakeholders to work together to change societal attitudes and remove environmental barriers input from CBR workers can help motivate individuals and surrounding communities to find solutions to ease their situation and overcome barriers.

A further challenge for wheelchair users was around their health and sense of safety and security. Health problems result from the interaction of the impairment and complex factors already discussed, and concerns with maintaining health further lead to avoidance of meaningful life activities. Similar to a study in Zambia inaccessible environments were

reported to cause health issues, such as illness from forced unhygienic practices like crawling on the floor in inaccessible public toilets (Banda-Chalwe *et al.* 2014). Another story explained how a woman tried to avoid using public toilets by not eating which led to stomach ulcers and other health complication. Attitudinal barriers led to school going children being too afraid to share concerns of pressure ulcers with teachers. On the other hand lack of knowledge of risks for wheelchair users caused some teachers to discipline children when safe practices were attempted. Inappropriate wheelchair designs, misuse of wheelchairs and badly fitted wheelchairs were additional reasons provided for health concerns similar to that found by Scovil *et al.* (2012) in her study on people with spinal cord injury. Compounding this, recognising health issues and seeking medical care is further impacted for PWD in less-resourced settings and is well-documented (Grut *et al.* 2012; Schneider *et al.* 2013; Wegner & Rhoda 2015). The role for CBR workers in helping to maintain health of wheelchair users was raised in this study which supports recommendations from others (Scovil *et al.* 2012).

The study participants indicated that there was a dearth of empowered wheelchair users in the communities who could act as role models. Observations on the benefits of peer support were in line with the WHO Wheelchair and CBR Guidelines and other literature, and refers to increased levels of self-esteem, knowledge and self-representation of adult and child wheelchair users (Campbell *et al.* 2012, Chappell & Johannsmeier 2009, Ikeda *et al.* 2013; WHO 2008 & WHO 2010). With few examples of how to be empowered and how to live a good life in contexts with persistent attitudinal, emotional and contextual barriers may cause decisions to be based on what they think is possible rather than what is (Lang *et al.* 2012; Sen 2009). CBR workers felt they could play a role in identifying potential role models and further building their capacity to support and advocate for others.

Role of CBR workers

The participants reflected on how their role as CBR workers could strengthen both the provision and use of wheelchairs in the areas in which they worked. In line with other studies, a significant role relates to identification, referral and making arrangements to connect wheelchair users with the wheelchair service, that is, Step 1 of the wheelchair service steps (Deepak *et al.* 2014, Ikeda *et al.* 2014; Nualnetr & Sakhornkhan 2012; WHO 2008 & WHO 2010). Overcoming considerable attitudinal and knowledge barriers needs time, knowledge and varied approaches. The CBR workers referred to different strategies and approaches used: '*changing him from that belief to the actual belief takes long*'; '*we need to explain*' and home visits will help to demonstrate to a carer the value of that person. Knowledge of the CBR worker on how to relay fears and inform accurately is crucial (Grut *et al.* 2012; Nganwa *et al.* 2013).

To ensure effective referral CBR workers are well placed to ensure information reaches those in need and particularly those most remote (Nganwa *et al.* 2013). Beyond the CBR workers' knowledge of hidden PWD they are linked to community networks, such as parent support groups and community leaders enhancing their effectiveness with the function of information dissemination (Fefoame *et al.* 2013). They reflected on efforts to make arrangements suiting both the user/s and service providers. Considering their observations of time spent by the wheelchair service providers with each user they suggested their role could help match the number of users with the services time availability. They also suggested support in arranging outreach visits to ensure wheelchair service personnel are not overwhelmed with high numbers and users not disappointed. While arranging for PWD to access different services is not an unusual role for CBR workers it was evident how specific knowledge on wheelchairs, wheelchair users and the wheelchair service enhanced understanding of requirements and how regular planning with the service helped to ensure the best outcome for the user and the service (Fefoame *et al.* 2013). Considering the limited resources of users and wheelchair services the CBR workers especially in the west felt they had a role in mobilising local resources concurring with Fefoame *et al.* (2013) and Booyens *et al.* (2015). This was either from the user, or themselves however often it involved engaging with other community stakeholders however they acknowledged their weakness in this area and requested training to improve this.

Suggestions were made to overcome specific challenges for people from rural areas who were less comfortable with engaging with health personnel (Deepak *et al.* 2014). By accompanying users to the service the CBR worker could reduce fears, encourage patience until the service was complete and help with providing accurate information during the user's assessment. Grut *et al.* (2012) points out the importance of creative solutions to overcome low resources of health and rehabilitation services in impoverished setting. So while not a replacement for the benefits of service providers delivering services closer to users communities it does help to ensure some understanding of a user's living circumstances to aid in accurate prescription. This will also prepare the CBR worker to provide more appropriate support to the user when back in the community (Fefoame *et al.* 2013).

Through home visits to wheelchair users a CBR worker can ensure a continuum of service as pointed out by Fefoame *et al.* (2013) and support in continued use and optimum benefit of a wheelchair. With the right knowledge and skills they can monitor and if needed provide advice, educate or refresh and transfer skills related to use and care of the wheelchair. Using these opportunities to check up on the health of the user was demonstrated through many examples to be important as was checking on maintenance and care of the wheelchair.

and functioning of the wheelchair user. Hansen *et al.* (2004) and others reported on the benefit of regular check-ups in continued suitability and durability of the wheelchair and safety of the wheelchair user (Chen *et al.* 2011; Toro *et al.* 2012). Identifying the need for the service to follow up (step 8) was highlighted as an important function made even more vital considering the challenges with ensuring this step. Home visits are times for CBR workers to identify and address barriers in physical accessibility, also suggested by Scovil *et al.* (2012) and Bray *et al.* (2014). It was interesting to note that only few specific examples were provided by the groups on actual adaptations made to environments to enhance access despite it being raised as a significant barrier. Discussions in one group indicated some uncertainty and little exposure to different solutions but all groups raised this as a training need.

Identifying and strengthening role models and linking people to peer groups and support networks was discussed in all areas as having considerable benefits resonating with findings by Chappell and Johannsmeier (2009). Building the skills of parent support groups to identify others in need of wheelchairs and to enhance use and maintenance of their wheelchairs was suggested and will further aid in increasing community involvement for wheelchair users. They also suggested how this could empower people to advocate for their rights such as parents requesting for accessible schools to be closer to communities (Biggeri *et al.* 2014, Deepak *et al.* 2014; Mol *et al.* 2014). As pointed out by Booyens *et al.* (2015) this is an important role, especially in resource poor settings, required to influence leaders and other community actors to make the changes needed. CBR workers who are wheelchair users have a significant role to play as reflected during a stakeholder consultation in Uganda (Wickendon *et al.* 2012) however it must be recognised that similar environmental barriers discussed in this paper may prohibit them from reaching those most in need.

Complex and prolific factors affecting participation and community inclusion of wheelchair users, especially when linked with poverty and rural living, benefit further from CBR input (Booyens *et al.* 2015; Geiser & Boersma 2013). Increased knowledge of wheelchairs, wheelchair use, new approaches to wheelchair provision and common barriers experienced to participation were suggested to strengthen the CBR strategies employed to empower PWD and communities (Heinicke-Motshe *et al.* 2013; Nganwa *et al.* 2013). Awareness raising, education and information transfer were some of the strategies discussed to empower users, caregivers, peer support groups as well as communities, service providers and leaders (Chappell & Johannsmeier 2009; ILO *et al.* 2004; Scovil *et al.* 2012; WHO 2008; WHO 2011 b). Smith *et al.* (2014) says the complexity of participation and the interconnectedness of influencing factors means more than one factor should be addressed

at one time to make a difference. This was reflected in one group which engaged school management, teachers and pupils to relay fears of disability, advice on accessibility and train on care of the wheelchair. Others suggested providing communities with information to empower them to build their own mechanisms towards a more inclusive community (Geiser & Boersma 2013). For example sharing information on theft of wheelchair parts would cause the community to '*act as vigilantes to see that assets, wheelchairs for people with disabilities are protected*' and sharing information on the wheelchair service with leaders empowers them to inform communities.

Although children with disabilities were not a specific focus of this study it was evident through the study that the situations for children and their carers were particularly difficult. Bray *et al.* (2014) already highlighted the complex nature of children with CP requiring wheelchairs and raised similar concerns on the lack of appropriate wheelchairs for children (Rispin & Wee 2014). Zuurmond *et al.* (2015), Saloojee *et al.* (2006) and Bray *et al.* (2014) also highlighted the complex needs of carers of children with disabilities which were similarly reflected in this study. Wheelchairs have the potential of enhancing quality of life of children and their families; however this study showed that this can lead to further difficult situations. Considering the holistic nature of the needs of children with disabilities and their families more comprehensive rehabilitation programmes are required. An important element of this is support from a CBR worker as highlighted in this paper.

The CBR workers were asked to describe what they felt they needed in order to fulfil the role they had suggested. During these discussions it became evident that they were experiencing many challenges in meeting these needs negatively influencing their work. Training, on-going mentoring, monitoring, resources and closer collaborations with health services were raised and are needs consistent with the literature (Chappell & Johannsmeier 2009, Wickenden *et al.* 2012, Zuurmond *et al.* 2015).

Specific knowledge and skills related to wheelchairs and new approaches to wheelchair provision are required. All participants in the group regardless of background and experience suggested the need for training, as already recommended in the World Disability report and other literature (Chappell & Johannsmeier 2009; Fefoame *et al.* 2013; Mannan *et al.* 2012; WHO 2011b). Different levels of knowledge on wheelchairs displayed by participants, indicated that transfer of information from newly trained wheelchair services is not consistent (Fefoame, *et al.* 2013; Nganwa *et al.* 2013; Wickenden *et al.* 2012). There was overlap in training needs between the three groups pointing to the benefit of a specific training module for CBR workers. They suggested: definition and information about appropriate wheelchairs,

basic information on wheelchair types and features, purpose and function of a wheelchair service, skills to use and care for a wheelchair and environmental adaptations for the home. Processes to link with a specific service were also raised as important. Other items raised by one or two of the groups indicate that modules may be useful for different contexts (Fefoame *et al.* 2013) i.e. skills for repairs were raised by two groups; and measurements, technical skills for assembly of products, identifying disability early, nutrition and budgeting and fundraising by one group each.

As suggested by Geiser & Boersma (2013) coordinated mechanisms are necessary and in this case a more formal link between CBR workers and wheelchair services would increase efficiency of their joint activities and would provide a platform for transferring information about the service and product availability, and use of the wheelchair in the community (Chappell & Johannsmeier 2009, Fefoame *et al.* 2013; Wickenden *et al.* 2012). The WSTP Managers workshop raises the importance of wheelchair services collaborating with relevant community organisations however the observed lack of this may indicate the need for on-going mentoring of wheelchair service managers following training (WHO 2015).

In addition to the needs raised above the groups in the north and west raised fundamental challenges to implementing their perceived role. Challenges related to too few CBR workers, lack of financial resources to implement activities, lack of acknowledgement of their role in many communities and health institutions and feelings of isolation due to limited opportunities for peer support leading. These challenges are well recognised in Uganda as well as other less resourced setting (NUDIPU 2013; Fefoame *et al.* 2013; Wickendon *et al.* 2012). Despite this, as found by Booyens *et al.* (2015), the passion and commitment towards PWD was very evident and it was disheartening to observe how these challenges affected them. They shared feelings of disappointment when their assistance was rejected or when unable to raise funds to support PWD. Some CBR volunteers told how they used their own limited resources to help PWD overcome challenges such as reaching the wheelchair service and other stories demonstrated how cessation of CBR activities resulted from lack of financial assistance. In most instances the resilience, determination and creativity of the CBR workers came through in their various strategies to overcome challenges. These traits position them well in their support function to PWD however it is essential to empower CBR workers if their benefit to wheelchair users and other PWD is to be realised. Their important contribution needs to be acknowledged by national and local stakeholders and a robust strategy to strengthening this sector developed (Mannan *et al.* 2012, Wegner & Rhoda 2015).

Borg *et al* (2011 *b*) recommends reviewing systems of provision to ensure cost-effectiveness. In situations such as in this study, with high levels of poverty and rural communities, and where wheelchair service provision is further challenged with few trained providers and limited resources for outreach, this study suggests CBR workers may contribute to enhancing cost-effectiveness of the system. If empowered to fully implement the role identified they suggested they can increase the numbers of users accessing the wheelchair service (step 1) and help with transferring accurate information between the service the user to ensure more accurate assessment (step 2) and prescription (step 3). Helping with development of skills and knowledge on care of the wheelchair will contribute to durability and use of the wheelchair thereby facilitating increased participation (step 7). Identifying needs for further wheelchair service support will facilitate the wheelchair service in implementing follow up to users when needed (step 8). Empowering users and communities to overcome barriers to participation will increase the use of wheelchairs and hence increase opportunities to further strengthen appropriateness of the service delivered and the wheelchairs provided. Further demonstrated through the discussions, and emphasised during the Wheelchair consensus conference, was the advantage of the CBR workers' position in the community, for gathering and feeding back valuable observations to help wheelchair services to bridge the gap between themselves and the community (ISPO 2006).

However, as highlighted in the WHO CBR and Wheelchair guidelines multiple stakeholders are required to effect change needed for PWD and wheelchair users (Wickendon *et al.* 2012; Chappell & Johannsmeier 2009). This study highlighted the need for greater advocacy efforts to be employed in areas where strategies to improve wheelchair provision are being implemented. This should aim to mobilise community support and clarify ambiguous situations related to historical approaches to wheelchair provision.

Additionally, this study highlights the crucial need to increase the number of trained wheelchair service personnel. In this study some CBR workers showed interest in increasing their skills in order to support technical and clinical wheelchair service tasks in response to the inadequacy of the reach of existing trained personnel and services. This highlights the need to increase the capacity of existing wheelchair services. In a context such as Uganda with few rehabilitation professionals identifying other suitable cadres for training is an important point of consideration for decentralising services. However strategically planning the expansion of wheelchair services is essential to avoid creating an even further fragmented sector. More formalised involvement of CBR workers in wheelchair provision such as suggested in this paper will prepare for an enhanced role if indicated.

A final observation is the lack of cohesive strategy for enabling wheelchair users to reach wheelchair and repair services. Findings of this study point to the difficulty for wheelchair service providers delivering services closer to communities in part due to limited financial resources. Wheelchair users were equally challenged to reach remote services also in part due to limited resources. Even if appropriate wheelchairs were made more available through wheelchair services, without acknowledging this gap and providing financial support to overcome these barriers, significant challenges for wheelchair users in less-resourced settings is likely to continue.

Chapter 5: Conclusion

5.1 Conclusion

'What do CBR workers in three areas of Uganda, each with a wheelchair service, perceive as the challenges with wheelchair provision and use in their communities? How do they think they can assist to overcome this and what is needed to achieve this?'

The findings of this study suggest that, in less-resourced settings such as in Uganda, CBR workers' perception is that they have an important role to play in enhancing provision and use of wheelchairs. The perspectives of CBR workers indicate challenges for PWD in accessing the wheelchairs they need and in using the wheelchairs they have been provided. Influencing factors included inconsistent availability of appropriate products and financial limitations of both PWD and wheelchair services providers. Previous experience with wheelchairs, exposure to different models of provision along with cultural beliefs presented major attitudinal barriers of PWD, caregivers and communities. Trained wheelchair service providers providing appropriate products were recognised as having a positive impact. However benefits of receiving an appropriate wheelchair was not always fully realised due to lack of skills, durability of products, impacted by low maintenance and unavailable repair services, and complex environmental barriers impacting participation.

Empowering CBR workers with specific skills and knowledge and closer collaboration with wheelchair services was suggested to strengthen their CBR activities to enhance their support of wheelchair services and wheelchair users. This could increase numbers of people accessing the wheelchair service, enhance use and care of the wheelchair and empower wheelchair users, caregivers and communities to increase levels of participation. However for this strategy to be effective fundamental challenges related to low numbers of CBR workers and lack of resources and recognition need to be addressed.

However these complex situations require engagement from multiple stakeholders to ensure comprehensive and long lasting change to ensure people's right to mobility are realised (UNCRPD Article 20). Collaborative advocacy efforts and implementation of national policy and standards are required to increase availability of appropriate wheelchairs through wheelchair services and to strengthen efforts to remove barriers to participation (UNCRPD Article 9 and 19). In particular greater understanding of the significant challenges for children using wheelchairs and their caregivers is required to develop relevant comprehensive strategies to meet their holistic needs.

5.2 Limitations

Due to the restricted time frame, human and financial resources in this study (in partial fulfilment of degree purposes), the following limitations could not be controlled:

The methodology using one focus group discussion with each group was not ideal and a second focus group discussion with each group would have provided richer information and enabled deeper exploration. In order to partially address this limitation, a summary of each discussion was sent to the relevant focal person for validation and expansion, and the focal persons' responses were included as an additional data source.

The data was analysed manually by myself, the researcher, due to financial constraints. The use of qualitative data analysis software may have provided a more rigorous analysis.

Communication systems (access to email, cell phones and network availability in Uganda) affected sampling, preparations and logistics and also verification. The impact on the study was countered by triangulating the use of various methods and additional time allocated to the different processes. Much is lost in translation, and the use of translators for the focus groups in Luganda, Konja and Luo supplemented by English, which was a second, third or fourth language for the participants is recognised as a limitation.

5.3 Implications

This study demonstrates the need for specific focus on enhancing the role of CBR workers in supporting PWD in accessing and using wheelchairs. In less-resourced settings with complex barriers to accessing services and participation their role is crucial however unless this is acknowledged and training and closer collaborations with wheelchair services their benefit will not be realised. Efforts to improve wheelchair provision are likely to be enhanced by increased awareness of complex barriers to utilisation of services and products and by developing responsive strategies such as greater collaborations with CBR workers.

5.4 Recommendations

Practical implementation of research findings can be challenging so the following recommendations are grouped for the benefit of different stakeholders.

Government action

- The National Wheelchair Coordinating Committee of the MOH Uganda could be further empowered to promote standards in the Uganda Code of practice of wheelchair provision. Key to this is being ‘gate keeper’ to ensure products donated, imported and locally produced are appropriate for the context and advocating for national budget allocation to increase availability.
- NWCC and MGLSD could ensure a comprehensive strategy for establishing, decentralising and strengthening wheelchair services, ensuring available repair services and increasing joint advocacy efforts. The WHO wheelchair training packages could be used but should be combined with on-going mentoring and monitoring.
- The contribution of CBR workers in facilitating equitable access to wheelchair services and responding to the holistic needs of wheelchairs users and their caregivers, should be recognised and enhanced by the following
 - increased presence in local communities
 - access to financial resources to support their activities
 - method to prove their role and skills
 - supporting opportunities for peer support
- To enhance utilisation of available services the MOH and MGLSD should consider providing financial resources to transport users to services or service providers to users.

International stakeholders

- Training is required to enhance and strengthen the referral and support function that CBR workers can play. The WHO could consider increasing the range of wheelchair service training resources to include modules for CBR workers and other community level cadres. This could include definition and understanding of appropriate wheelchairs, basic information on wheelchair types and features, purpose and function of a wheelchair service, skills to use and care for a wheelchair and environmental adaptations for the home.

Local stakeholders enhancing provision and use of wheelchairs

- To strengthen efforts to improve wheelchair provision in an area the wheelchair service and community-based organisations would benefit from increasing awareness to PWD and other relevant stakeholders to the availability. This should aim to mobilise community support and clarify ambiguous situations related to historical approaches to wheelchair provision.
- Specific knowledge and skills related to wheelchairs and new approaches to wheelchair provision can enhance the support CBR workers can provide to wheelchair services and wheelchair users. Wheelchair services would benefit from working with community-based organisations to transfer information, agree roles and increase collaboration.
- Identifying and building role models and parent support groups is recommended to enhance support available to wheelchair users and to increase advocacy efforts to enable increased levels of participation.
- Wheelchair users require training and on-going mentoring to enhance use and care of their wheelchairs. Wheelchair services, CBR workers and other relevant stakeholders could discuss improved strategies to achieve this.

Further research

- Further exploration is required to understand the situation of disabled children who use wheelchairs in less resourced settings in order to develop strategies to ensure benefit of a wheelchair is achieved by the child and family.

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Appendix A

Participant information and consent form

TITLE OF THE RESEARCH PROJECT: Exploring CBR workers' perceptions of their role in wheelchair provision in three areas of Uganda

REFERENCE NUMBER: S14/10/210

PRINCIPAL INVESTIGATOR: Nicky Seymour

ADDRESS: 8 Country Club Road, Constantia, Cape Town, South Africa.

CONTACT NUMBER:

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the Focal Person any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you or your organisation negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree initially to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University, South Africa and permission has been gained from Uganda National Council for Science and Technology. It will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study is being carried out in three areas in Uganda: Kasese, Gulu and the central region. One focus group will be carried out with up to six people in each area. During the focus groups we will discuss wheelchair service provision in your area.

The research is being carried out because in many parts of Uganda and the world organisations are trying to work out how to ensure people who need wheelchairs can access them and continue to use them to achieve their rights. The World Health Organisation has

recommended that wheelchair services and community organisations work together to ensure this. A wheelchair service has been started in (Name of hospital) which covers the same area as your organisation. You have therefore had the opportunity to observe the impact of this service and to see where on-going challenges exist.

In the focus group we will discuss this together to try to identify the main challenges in your area and to understand the reasons for them. We will then talk about what you and other community workers could do to improve or change the situation. At the end of the group we will talk about what needs to happen after the Focus group in order to share the ideas with others and to plan next steps in your area.

The results from the three focus groups will be presented in a research paper once the information has been analysed. It is hoped that we will be able to learn from the experiences of everyone in the groups and influence the planning of wheelchair service provision in other areas of Uganda or countries in the future.

What is the process that you can expect?

The focus group will be approximately 2 hours long and will take place in March in an area in (name of area). If you agree to be involved you will need to be available for the focus group at the time and place communicated to you. The focus group will include five or six people from your organisation as well as two researchers (from Motivation Africa) who will facilitate the group. You will sit in a circle and talk about your experiences of wheelchair service provision, guided by some general questions.

After the group you may be contacted to confirm some information for the researcher.

At the end of the group suggestions for next steps for you and your peers will be discussed. This will no longer be part of the research project.

Why have you been invited to participate?

The focus group will have the best results if the people in the group have had experience with those who need or use wheelchairs in your area and are comfortable to talk about it. The researcher would also like people who can explain what they have seen and can have realistic ideas on how to change things.

You need to be confident with talking in a group situation and able to explain your views. We feel you have the right experience and qualities that are needed to ensure that this is a meaningful process.

What will your responsibilities be?

- Arrive on the correct day and time for the group.
- Complete a short questionnaire
- Plan to stay for the whole duration of the group unless you choose to withdraw.
- Participate in and contribute to the group.
- Work together with the researcher and other participants to understand the situation and think how to change it.

Will you benefit from taking part in this research?

It is hoped that by being part of the group you will benefit by increasing your understanding of what people needing and using wheelchairs in your communities are going through. You will also work together with others to think about what can be done. You may be able to make some changes immediately after the group which might help you make more impact with your work.

As a group you may have some ideas which can be further discussed with your manager.

You can also be happy that the information you provide may help to inform plans for developing other wheelchair services in the future and may impact people in other communities who use wheelchairs.

If you do not agree to take part, what will happen?

You have a right to not be involved. There will be no negative impact for you or your organisation. You also have the right to withdraw at any time even if you first agreed to participate.

Will everybody know what you have said?

Other people in the group will hear everything you say. The researcher will also make a recording of the whole group so the information can be analysed. Your name will not be used in any reports. Feedback to your organisation after the group will be agreed with everyone in the group and so will also be confidential if you choose.

Will photographs be taken?

Photographs and video will be used to help the researcher review and analyse the discussions. *You have a right to decline this.* Photographs and video will also be used to present the research. *You have the right to decline this.*

If you agree to take part in the study, but decline to be photographed the researcher will agree with you before the group where to sit to ensure you are not included in any photographs. Every photograph will be thoroughly checked to ensure before being used to ensure you are not in it.

Will you be paid to take part in this study and are there any costs involved? No, you will not be paid to take part in the study but your transport and refreshment costs will be covered. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- You will receive a copy of this information and consent form for your own records.
- You can contact the researcher, Nikola Seymour at +27845715030 or Seymour@motivationafrica.org.za or the research assistant, Patience Mtuti at mtuti@motivationafrica.org.za if you have any further queries or encounter any problems.
- You can contact the Stellenbosch University Health Research Ethics Committee at ++27 21-938 9207 (Email: ethics@sun.ac.za if you have any concerns or complaints that have not been adequately addressed by the researcher.

Declaration by participant

By signing below, I agree to take part in a research study entitled *Exploring community workers perceptions of wheelchair service provision in Uganda and the role they can play within this.*

I declare that:

- I have read or had read to me this information and consent form and it is written in a language which I understand.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been forced to take part.

- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the plan, as agreed to.

<i>Read the question and tick yes if you agree and no not.</i>	Yes	No
I agree that <i>video recording</i> can be used by the <i>researcher only to analyse</i> the focus group		
I agree that <i>video recording</i> can be used to <i>publess resourced settingsly present</i> the research		
I agree that photographs can be used by the <i>researcher only to analyse</i> the focus group		
I agree that photographs can be used to <i>publess resourced settingsly present</i> the research		
I agree that a voice recording can be used by the <i>researcher only to analyse</i> the focus group		
I agree that a voice recording can be used to <i>publess resourced settingsly present</i> the research		

Signed at (*place*) on (*date*) 2014.

Signature of participant

Signature of witness

Declaration by focal person

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*) on (*date*) 2014.

Signature of investigator

Signature of witness

Appendix B

Reference and identification

Pre-focus group questionnaire

1. Name
2. Gender: Male Female
3. Contact number
4. Period of time working with (name of organisation)?
.....
5. How many adults and/or children who need or use a wheeled mobility device are in the area you work in?
Tick as appropriate: 0 -10 11 -20 20 and over
6. What activities do you currently carry out with people who need or use wheeled mobility device?
.....
.....
.....
7. Have you received any training on wheeled mobility devices? Yes No
When was the training?
How long was it?
Who delivered the training?
8. Have you received any other training for your job as a CBR worker?
.....
.....
.....
9. Do you or any of your family have a disability?

You	Yes	No
Family member	Yes	No
10. Do you or any of your family need or use a wheeled mobility device?

You	Yes	No
Family member	Yes	No

Appendix C

Example focus group schedule

Agenda	Method	Notes
Approx..30 mins - Introduction	Introductions Explanation of the research, the process for the focus group, confidentiality, recording instruments. All consent forms signed, questionnaires completed	Focus on developing a rapport between participants and researcher. Agree group language and role of translators 'Wheeled mobility device' (WMD) = wheelchairs, supportive seating, tricycles 'People' = adults and children. Confidentiality for people in the group as well as users/peers not present. A written summary will be used to ensure the same explanation is provided to all groups.
Approx. 20 mins - Question 1:	What challenges exist for people who need or use WMD in the areas you work? Each person to introduce a real life story to illustrate the challenges	This will include three structured, open questions. Each question was followed up with prompts to elicit responses from participants and to probe. Points captured in flip chart
Approx. 30 mins - Question 2:	Why do you think these challenges exist?	Questions were not answered in a linear progression. Points raised in Question 2 were explored with explanations and points relevant to 3 and 4.
Approx. 30 mins - Question 3:	What can CBR workers do about this and what is needed to do this?	Emphasise was placed on the role of CBR workers to encourage realistic and relevant solutions.
Approx. 10 mins- Summary, next steps and close	Decide as a group what to do with the information from the FGD. Explain the next step for the research	Ask the group to appoint a person to be available for the verification interview (this does not have to be the focal person)

Appendix D Extract from Focus group discussion database

Area	Gender	Disability	Time with org in yrs	Training received related to CBR role	WC users worked with	Current activities with wc users	Trainign received on wc	When	Duration	Who
2	M	No	6	CBR Training	11 to 20	Hospital referrals, Guiding to start school, Teaching ADLs	No			
2	M	No	8	CBR Training	20 over		No			
2	F	No	6	(other 2 trainings for my job	20 over	Referrals to hosp and rehab, Training (tolieting, being healthy, use of wc) Doing passive exercises. Sensitization	No			
2	M		4	CBR training	20 over	Maintainance training , Advising clients to report when wc is not functioning	Yes	2014	1 day	Physio with Motivation Africa
2	M	Yes	9	CBR Training	0 to 10	Referrals , Assessment of mobility device, ADLs and giving exercises	Yes	2014	2 hours	Physio with Motivation Africa
2	F	No	1	no	0 to 10	Supervising	Yes	2014	12 hours	Physio
2	M	No	1		0 to 10	WC technician, training user, counseling user and Parents	Yes	2014	1 day	Physio - WC service
2	F	No	1	At university	0 to 10	Training user and carer on how to use & push	Yes	2014		Kyambogo university

Appendix E**Consolidated findings table**

	Area 1	Area 2	Area 3
	Challenges		
1 Self Care	<ul style="list-style-type: none"> Common disabilities in Children are CP and Downs syndrome, a cause can be malaria. The parents don't realise it is a problem early enough and therefore they are not diagnosed early enough leading to worsening of the condition. Community belief systems in witchcraft prevent parent seeking help early enough. Disabled children are neglected and abandoned Health care and medications are not always accessed when needed. This can be due to small support systems ie a sick mother can't take a child to the hospital Health issues due to unsanitary areas and access issues and type of wheelchair Changing eating habits due to lack of toilets Lack of privacy for disabled women, abuse and then neglect. Pregnant disabled women get treated harshly 	<ul style="list-style-type: none"> Some products and fittings are not appropriate and the children are still not in a better situation. (Some children's head and necks are not supported in the wheelchairs) 	<ul style="list-style-type: none"> Parents neglect and abandon disabled children People are uncomfortable to go to the hospital because of the way they are treated. They feel they are 'despised'. (esp expectant women) In school children with disabilities have challenges with managing themselves such as preventing sores and informing others when they have sores. There was some opinion that it was more difficult for girls to share than boys. Children are shy and school staffs don't understand.
2 Mobility	<ul style="list-style-type: none"> Not accessing a wheelchair even if it is available and needed: Parents don't know about services, can't access them or choose not to due to stigma ie sense that a wc means no hope, (common – Pg5) Children don't always get to use the wheelchairs they have been given. Children level of activities and types of needs change impacting the way the chair is used and affecting durability The wheelchairs don't always last as long as needed Not easy for people using wheelchairs to get where you need to or want to go 	<ul style="list-style-type: none"> At times those in need choose not to access the wheelchairs available: Parents lack understanding of wheelchairs and are aware of an afraid of barriers to use. Sometimes parents refuse a wheelchair as they think it is too complex or it won't fit into their house. Parents would prefer modified wheelchairs to suit their needs. The need for wheelchairs is high but supply is not always constant or accessible. – Providers may be too far away, or too costly to access, wheelchair services because provision takes a long time and service staff numbers are low so supply is slow – Difficult to move products from one place to another – so not used at home for example during holidays – child therefore doesn't get to play 	<ul style="list-style-type: none"> Not easy to access appropriate wheelchairs when needed and available: don't hear about the availability; they are too afraid to go to the hospital, the hospital is too far away, products have a price which they did not have before, appropriate service takes time and too few services and trained providers (overstretched) Adults say wcs have greatly improved their mobility – (problems repairs) Wheelchairs don't last as long as they should ie people don't maintain, parts are stolen, repairs and spares are costly, products are stored outside

3 Interpersonal relations	<ul style="list-style-type: none"> Dependant on others for help, this is not always available, and people get tired of helping 	<ul style="list-style-type: none"> Users are dependent on others to help for many daily activities. Sometimes children cannot move out of their wheelchairs as no-one to help + other children don't play with them. It can be too time consuming for someone to assist, people also get tired of helping over time as the novelty wears off 	<ul style="list-style-type: none"> Confless resourced settingsting need for support: need it but concerns re abuse Children require a lot of mentorship to develop self-esteem and see their value.
4 Community	<ul style="list-style-type: none"> Participation in school and school related activities is different from other children such as not being able to go home for lunch and sometimes not being able to go to school as the parent has to prioritise work. Reasons: parents see it is a visible sign; it may be too difficult or tiresome or because of environmental inaccessibility. 	<ul style="list-style-type: none"> Parents are afraid to show they have a CWD (child with disability). They may wish for the child not to survive. Attitudes are negative and fearful due to lack of knowledge of families and communities on the causes and (whats the point). Belief systems are deeply rooted. Disabilities are believed to be contagious The wheelchairs that have been provided are not always used for optimum benefit (ie either not used when needed, or used incorrectly) as people may not understand, remember instructions, be too busy, environment, impact of seasons, lack of assistance and for other reasons. This is the case even if they have received training as even if they want to do it right they don't consistently remember everything. Some parents have a wc for their child and still lock them indoors during the day and only use the chair when the CBR worker comes down the street? This is not identified or prevented unless there is follow-up. In this case children's disability may not improve and the 'community' may never get to see that a child received a wheelchair – so there is no impact'. 	<ul style="list-style-type: none"> People can't participate in activities they choose due to barriers with using their wheelchair. Only use in a confined space, sometimes don't go to school, at times leave wc at home or when going to hospital. Problem is roads and paths, access issues, difficulty with transport

	Reasons		
attitude	<ul style="list-style-type: none"> Community attitudes are negative: affected by traditional beliefs of witchcraft and seeing person as a burden The attitudes and influence of the community is very strong.. People are labelled and branded. Lack of knowledge (PWD, family and community) about disability in general, the benefits of a wheelchair and where to access support (ie wc services) This results in support systems being small and community not being inclusive e.g. transport and health services; see support of PWD to be 'a waste'. 	<ul style="list-style-type: none"> Negative attitudes & belief systems Lack of understanding and knowledge in the community and with service providers e.g. Lack of awareness on building standards and correct people are not being consulted Parents lack understanding of child's needs and children rights, and don't always understand the benefits of a WC, or how to use the WC properly. Leads to ++ concerns for a family: fear to destroy , fear to be imprisoned 	<ul style="list-style-type: none"> Lack of knowledge on and negative attitude towards disability in the community and with parents – this is however changing due to sensitization and new causes e.g. RTAs (medical model, charity model) People are uncomfortable to go to the hospital because of the way they are treated. They feel they are 'despised'. Lack of trust between different stakeholders: PWD don't always trust CBR workers, CBR + PWD find difficult to go into hospitals
environment	<ul style="list-style-type: none"> Inaccessible environments (homes and community) Distances are great Transport and road infrastructure is inaccessible and /or unsafe 	<ul style="list-style-type: none"> Environment barriers e.g. mountainous area, inaccessible buildings and facilities e.g. toilets and homes, large distances for PWD, families and CBR. Takes time to get anywhere. 	<ul style="list-style-type: none"> Inaccessible environments and distances: built and natural; grass thatch houses
Service systems & Poless resourced settings	<ul style="list-style-type: none"> Poless resourced settings are ineffective and national body (NWCC) is not funded and therefore also ineffective 	<ul style="list-style-type: none"> Lack of leadership and poless resourced settings makers awareness of need and actual prevalence. Resources are needed to raise awareness (e.g. leaders: politicians, religious leaders, community leaders expect facilitation) Too few centralised WC service providers or locations for spares and repairs Lack of follow-up / any one in community who can help 	<ul style="list-style-type: none"> Mixed messages on the right to assistive devices. Should people pay or should the government provide and if there is a cost what is it for. Low resources of services, schools, community – disability perceived as being expensive Lack of information reaching remote places Overstretched wheelchair services: few trained staff with many other responsibilities beyond WC service provision

Products	<ul style="list-style-type: none"> Not all wheelchairs are appropriate or issued through a service (i.e. still distribution style) Insufficient appropriate products available: especially children. Lack of funding from govt for local workshops to produce local products, too few trained personnel Products are difficult to maintain and spares are difficult to access 	<ul style="list-style-type: none"> Wheelchairs are not lasting as required <ul style="list-style-type: none"> they are not used and end up rusting, parents easily forget care & maintenance instructions, no sense of ownership, lack of understanding of the use, no repairs made, misused, wcs are sold, given away too few places to go for repairs . Hospit is too far 	<ul style="list-style-type: none"> Not all wheelchairs are appropriate or issued through a service (i.e. still distribution style). Some product quality is not good, some design is not appropriate, some are not provided appropriately Lack of information on how to use the wheelchairs correctly or optimally Lack of repair facilities
Poverty	<ul style="list-style-type: none"> Poverty of PWD and families 	<ul style="list-style-type: none"> Poverty affects families lack time for disabled child. Small houses and far from the service Affects education levels <ul style="list-style-type: none"> a. they are not used and end up rusting, b. parents easily forget care & maintenance instructions, c. no sense of ownership, d. lack of understanding of the use, e. no repairs made, f. misused, g. wcs are sold h. given to other people <p>pressures on families Women must look after family, also work?</p>	<ul style="list-style-type: none"> Poverty of families
Personal factors	<ul style="list-style-type: none"> People have to make a lot of hard decisions because of barriers ie accept a wc that is not appropriate because of lack of funds; not use the wc because the building is inaccessible; not send a child to school because it is hard to push and border border. Parents have to take a lot of responsibility especially single mothers who are also the breadwinner and with other children – tired and don't want to inconvenience others. There is also a sense of self-pity and they quickly lose momentum. People can be very disappointed when they overcome one barrier such as they get a wheelchair and are confronted with another such as an inaccessible house. 	<ul style="list-style-type: none"> Actual prevalence in entire area is unknown. Small pockets in areas with CBR might be known but there are big gaps and many people hidden Mixed emotions of the families ie too busy, want to take ownership, fear of not knowing how to use product properly, not wanting to destroy it, grateful for the product and only want to use on special occasions some leave the service without getting a wheelchair. The impact on clients and families is on emotional level: 'feel they have wasted time, Demoralised, stigmatized, segregated, inferiority complex, disrespect of human rights' 	<ul style="list-style-type: none"> Raised expectations due to history of being let down Life can be difficult for parents: as they have to work hard ie father carrying the child and wheelchair to get to school, traveling long distances to access community services. Fear for children esp girls, very protective over girls. Fear of sexual abuse. Level of empowerment varies from community to community depending on level of exposure, Education, Economic status, Urban VS Rural. Generally those with higher education level, have reliable income and those in Urban setting are more empowered compared to those with low education/ low income and from Rural settings.

	Role		
Empowerment and community awareness: inclusion	<ul style="list-style-type: none"> - Sensitising and supporting parents on disability and the needs of their children. They need constant reminding to attend to their children, to follow advice, to access services available to them. To support them in making the right decisions and to help them understand the consequences of decisions. This is also needed to prevent community attitudes from influencing them. This is through one to one home visits - Sensitizations can target specific groups such as parents on health issues and disability or businesses on accessibility and village health workers, leadership such as local authorities, religious and school authorities - Access to school is multi-pronged in other words the CBR worker engages teachers as well as other pupils about disability and inclusion. Accessibility training , access audit Develop a model school - Parent support groups can be formed <ul style="list-style-type: none"> o used for transferring information. o make more use of these groups by forming wheelchair committees. Groups can be connected with other community poverty reduction and income generation programmes - Identify and build strong role models ie people using wcs and parents. <ul style="list-style-type: none"> o can help other people using wheelchairs o can help sensitization in the communities o can represent at council meetings. <p>People need to be identified, and built up to develop the knowledge on how to play this role. Exposure will help to develop passion which is an essential requirement.</p> 	<ul style="list-style-type: none"> • Work directly with the family through home visits to help understanding of the disability, learning about the wheelchair, motivate to participate. This can take many visits to the family and a lot of talking to convince them to treat their child differently and take advantage of opportunities such as school and a wheelchair. • Sensitize and train broader family, close community and broader community as well as other service providers to help person using a wheelchair. This also helps to spread the word to other (cascade effect) • Target local, religious and cultural leaders. Share information at community meetings to inform about disability and wc service availability. The message will cascadebut facilitation is needed normally • Use Parent support groups to help transfer messages to other community members • Influence community members by entering communities in groups of CBR workers including disabled people. This gives more credibility to CBR workers and provides support. Ensuring a PWD is part of the group makes significant impact. Empowering PWD • Be a role model by interacting with people with disabilities in front of the community, playing with children, eating with people with epilepsy – helps to dispel beliefs and encourages other to do the same. Makes parents and children feel very good about themselves 	<ul style="list-style-type: none"> • Attend local council meetings to <ul style="list-style-type: none"> • share information on service availability, • lobby for funds, • raise awareness of disability and need for inclusion • Sensitise: Parents, neighbours and community through community meetings (arranged through request to local council meetings – at village level • Form and support parent groups. • Empower role models to represent PWD and attend local council meetings • Collect data of people needing and using wheelchairs. • Connecting different services and areas of community – information transfer

Support of the wheelchair service	<ul style="list-style-type: none"> ○ Identification and referral ○ Help people use wheelchairs as optimally as possible 	<p>Wheelchair services</p> <ul style="list-style-type: none"> • Mobilise people for outreach services ie identification and Screening. Identify a group of community members who need to be assessed – see how to cost share on transport • Attend the service with clients to support the client, • learn and help with wheelchair assembly and user training and learn • Carry out home visits: find out the difficulties, make adaptations such as toilet + bath, encourage activity and participation, motivate, help them see what is possible • Help to ensure health with high risk issues related to impairment such as pressure sores and nutrition • Empowerment through connecting people with income generating activities • Assist families to maintain and do basic repairs of products • Identify people who were provided a wheelchair which needs to be reviewed by the service and re-refer to the service • Collate and share numbers in order to understand prevalence of those needing wheelchairs compared to those who have received an appropriate one • Help to understand the costs of enabling wheelchair users to access the services they need, in order to help fundraising and lobbying for funds. Try to raise funds for CBR and PWD 	<p>Service models and access to the service</p> <ul style="list-style-type: none"> • helping services reach people in communities through outreach or Facilitating access to the wheelchair service: • identifying, screening and referring; • helping clients get to the wheelchair services; • advising and informing parents on the benefit & availability of wheelchairs (not raising expectations) • how the service works (ie cost and process); <p>Supporting clients when at the service through the process</p> <p>Following clients up and supporting in the community: through home visits</p> <ul style="list-style-type: none"> • to help use of the product, • remind to care, • how to store. • Train more family and even neighbours Assist with doing small repairs, and providing ideas for and supporting local repair services • Provide advice and support to improve accessibility in the home, school and community areas
	Some children need access to a second wheelchair		

	Need		
	<ul style="list-style-type: none"> - Programmes with a comprehensive approach to children and adults using wcs: provision of a wc, accessibility, income generation, sensitization of community and family. - Training: <ul style="list-style-type: none"> o what is an appropriate wheelchair o how does a wc function, o maintaining, o how it feels to use a wheelchair o Safety issues. o Accessibility and adaptations of the home. <p>This training has been attended by the CBR workers attending this meeting however not the CBR volunteers. This training should be available to parents and CBR volunteers</p> - Resources to assist sensitizations - Connections with local services e.g. district health teams - Information sharing platform to ensure CBR volunteers are aware of services available Research to be shared with MOH and MOG to raise awareness 	<ul style="list-style-type: none"> • Facilitation for outreach, general CBR activities for CBR worker to attend the service centre to learn, to train others. To facil group/team work • Training on wheelchair use, repair and maintenance, accessibility, measurement and adjusting products at follow-up; Tools needed • Refresher CBR training + more CBR workers • Local fundraising skills and simple budgeting • Communication mechanism with the wheelchair service- plan, negotiate • Meetings of CBR workers (39) • 	<ul style="list-style-type: none"> • Empowered CBR spread in district i.e. one per county. • Connected with each other • Same level of baseline knowledge • Facilitated to do their work i.e. home visits • Updated knowledge on poless resourced settingsies • Refresher CBR training • Updated ability to identify different impairments early • Form of identification to facilitate legitimate movement into communities and hospitals • Ideally there would be improved access to wheelchair services and repair services by increasing the number of these services • Training from wc service • How to access a wc • Repair and maintenance • Adaptations • Central person to connect with the wheelchair service to have updates on product range and availability • Resources • Stationary • Pictures of different types of wheelchairs for informing clients
	- Need 2 chairs	Other things needed to accompany lists above but beyond the scope of CBR workers <ul style="list-style-type: none"> • WC services need to follow-up • Wheelchairs services and repair services need to be decentralised 	
CBR		CBR <ul style="list-style-type: none"> • Too Few CBR workers and not connected or known to each other • No facilitation for CBR worker to support PWD or do related activities and hard to raise community 	CBR <ul style="list-style-type: none"> • Too few and not in all communities, afraid to let people down, varying skills due to diff level training, different exposure and interest. • Varying opinions on if and how CBR should be

	<p>funds for PWD. CBR feeling they need to support costs</p> <ul style="list-style-type: none">• CBR workers become despondent with attempting different ways to raise money for their work and failing• CBR training is expensive. CBR workers feel they can train others but find it difficult as they lack resources. Results in people seeing the knowledge as inaccessible knowledge/ specialist skills (reinforces medical model)• CBR workers are not aware of different types of wheelchairs and don't have the skills and knowledge to help those in the communities using wheelchairs ie repairs• CBR workers can become disempowered, due to lack of knowledge and trust on CBR workers, difficulty to make an impact	<p>paid. Some no longer working because of no pay. Want contribution to be acknowledged ie payed through local govt structures and some recog by parents and DPOs</p> <ul style="list-style-type: none">• different understanding of poless resourced settingsy and rights e.g. related to right to a free device and contribution towards a wheelchair• Lack of confidence on structure of CBR in the community ie role and position of CDO. Could be due to diff levels of training• Lack of agreement on role and responsibility of CBR workers vs CDO (ie training others)• Ad hoc delivery of services e.g. home visits were carried out and then stopped, attending community meetings is not consistent
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Appendix F

Example of data analysis strategy

