AN EXPLORATION AND DESCRIPTION OF RURAL REHABILITATION SERVICE MODEL IN THE MBHASHE MUNICIPALITY, AMATHOLE DISTRICT IN THE EASTERN CAPE PROVINCE OF SOUTH AFRICA: A PILOT STUDY

(Presented in an article format for the African Journal of Disability).

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DECLARATION

I, Nozipiwo Joyce Gysman declare that the work contained in this research assignment is entirely my own, original work (except where acknowledgement indicates otherwise), and it has not been previously submitted for any other degree at Stellenbosch University or at another University.

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ABSTRACT

Background

People with disabilities are still disadvantaged in accessing health and rehabilitation services, especially those who reside in rural areas, despite the available policies. Rehabilitation is one of the components of Primary Health Care (PHC) but it remains excluded and poorly understood in PHC programmes. Despite available policies to address rehabilitation for people with disabilities (PWDs), PWDs still have difficulty accessing the rehabilitation services. Rehabilitation remains:

- excluded and poorly understood in PHC programmes,
- fragmented and uncoordinated with services inaccessible to some parts of society especially in the rural context compared to urban counterparts,
- dominated by the medical model and institutionalization of services, and
- questionable in terms of relevance of services as there is less involvement, guidance and support from communities where these rehabilitation services are being provided.

Aim of the study

To explore and describe rehabilitation services rendered in a rural setting of Mbashe municipality in the Eastern Cape Province in South Africa.

Study objectives

To describe the rehabilitation and health services in the selected area; to identify the key role players for rehabilitation services in this area (both community-based and institution-based); to describe the rehabilitation pathways available within the health facilities and the community; to explore the challenges experienced by all role players delivering rehabilitation services in the study area; to determine the perceptions of people with disabilities with regards to the current model of rehabilitation in the study area; and, to make recommendations for addressing the challenges with regard to rehabilitation services in the study area and the existing rehabilitation model.

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Method

A qualitative exploratory and descriptive study design was implemented to describe the rural rehabilitation service model in the Mbashe Municipality in the Amathole District in the Eastern Cape Province of South Africa. Four areas out of nine (Gusi, Hobeni, Nkanya and Xhora) were conveniently selected in the study setting. In-depth interviews were conducted with Health Professionals from the District hospital (Madwaleni). Semi-structured interviews were conducted with the community representatives inclusive of, the Clinic Nurse Practitioner (one from each of the clinics in four selected areas); The Chief/Chieftain (one from each area in four selected areas); and a person with a disability, a representative of persons with disabilities. Focus group discussions (a group from each area) were conducted with persons with disabilities their families and their communities.

Instruments used for developing interviewing schedules for data collection were based on Kaplan's Framework of Organisational Capacity, (1999) and the Wheel of Opportunities (Lorenzo & Sait, 2000). These instruments were used interchangeable to address the objectives of the study. Qualitative methods of data analyses were applied whereby segments of data were broken down into manageable categories which were later grouped and subjected to content analysis to identify emerging themes.

Findings

Themes that emerged from interviews conducted with health professionals, communities and focus group discussions with persons with disabilities revealed that the current model of rehabilitation was institution-based. Participants in rehabilitation services, though aware of available health and rehabilitation services, experienced their main challenge in gaining access to these services. One of the main challenges was related to transport to gain access to health and rehabilitation services. Home visits were not part of the rehabilitation services and this limited rehabilitation professionals in understanding about home and cultural situations of their patients. Rehabilitation goals were not fully met with one of the highest goals of rehabilitation

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– which is community participation – was not met by persons with disabilities in their rehabilitation process.

Conclusion

The study findings indicated a need for the development of a rehabilitation model that will be accessible and will provide an opportunity for participation as well as integration of persons with disabilities with their families as well as their communities. Community-based rehabilitation was seen as a suitable rehabilitation service model for this rural community.

Key words: Disability; Accessibility; Rehabilitation; Community integration and participation

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Agtergrond

Persone met gestremdhede, veral die wat in landelike areas woonagtig is, ondervind steeds probleme ten opsigte van toegang tot gesondheidsorg, ten spyte van beskikbare beleid. Rehabilitasie is een van die komponente van primêre gesondheidsorg (PGS). Dit word egter uitgesluit en swak verstaan in PGS programme. Ten spyte daarvan dat beleidsdokumente wat fokus op die insluiting van persone met gestremdhede beskikbaar is sukkel persone met gestremdhede steeds om toegang tot rehabilitasiedienste te verkry. Rehabilitasie is steeds:

- Uitgesluit van en swak verstaan in PGS programme;
- Gefragmenteered en ongekoordineerd, met dienste wat ontoeganklik is vir sommige groepe, meer spesifiek so in landelike areas as in stedelike gebiede;
- Oorheers deur die mediese model en institusionalisering van dienste;
- Die relevansie van rehabilitasiedienste kan bevraagteken word omdat betrokkenheid, leiding en ondersteuning vanuit die gemeenskappe waar die dienste aangebied word beperk is.

Doel van die studie

Om rehabilitasie dienslewering in die landelike Mbashe munisipaliteit in die Oos-Kaap Provinsie te ondersoek en beskryf.

Studie doelstellings

Om rehabilitasie en gesondheidsorg in die studie area te beskryf; om die sleutel rolspelers vir rehabilitasiedienste (gemeenskapsgebaseerd sowel as in hospitale) in die area te identifiseer; om die rehabilitasie roetes wat in die gemeenskap en gesondheidsorg fasiliteite beskikbaar is te beskryf; om die uitdagings wat alle rolspelers tydens die lewering van rehabilitasiedienste ervaar te ondersoek; om vas te stel wat persone met gestremdhede se persepsies van die huidige model van rehabilitasie in die studie area is; om aanbevelings te maak wat die uitdagings met betrekking tot rehabilitasiedienste en die bestaande rehabilitasiemodel in die studie area aanspreek.

Metodologie

`n Kwalitatiewe, eksploratiewe, beskrywende studie was gedoen om die rehabilitasiediens model in die Mbashe Munisipaliteit in die Amathole distrik in die Oos-Kaap Provinsie van Suid Afrika te ondersoek. Vier van die nege areas (Gusi, Hobeni,

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Nkanya and Xhora) in die groter studie area was geselekteer deur `n gerieflikheids steekproef. In diepte onderhoude was gevoer met gesondheidswerkers van die distrik hospitaal (Madwaleni). Semi gestruktureerde onderhoude was met gemeenskapsverteenwoordigers, insluitende vier geregistreerde verpleegkundiges, een van elkeen van die vier klinieke in elk van die geselekteerde areas; die vier hoofde van die areas; `n persoon met `n gestremdheid, en `n verteenwoordiger van persone met gestremdhede gevoer. Fokus groep besprekings, een per area, was gedoen met persone met gestremdhede, hulle families en hulle gemeenskappe.

Die instrumente wat gebruik was tydens die ontwikkeling van onderhouds skedules was gebaseer op "Kaplan`s Framework of Organisational Capacity, (1999)" en die "Wheel of Opportunities" (Lorenzo & Sait 2000). Beide instrumente was gebruik om die studie doelstellings te bereik.

Bevindinge

Temas wat na vore gekom het uit die onderhoude met gesondheidswerkers, gemeenskappe en in die fokus groep besprekings met persone met gestremdhede het onthul dat die huidige model van rehabilitasie in institusies gebaseerd was; deelnemers was bewus van die beskikbare gesondheids- en rehabilitasiedienste, maar het probleme ondervind om toegang tot die dienste te verkry. Een van die grootste uitdagings was `n gebrek aan vervoer. Tuisbesoeke het nie deel uitgemaak van die rehabilitasiediens nie en dit het daartoe gelei dat rehabilitasie diensverskaffers `n beperkte begrip gehad het van die kulturele situasie van hulle pasiënte. Rehabilitasie doelstellings was nie ten volle bereik nie. Een van die belangrikste doelstellings van rehabilitasie, gemeenskaps integrasie, was nie bereik deur persone met gestremdhede tydens the rehabilitasie proses nie.

Samevatting

Die bevindinge van die studie dui daarop dat dit nodig is om `n rehabilitasie model te ontwikkel wat toeganklik is en die geleentheid sal bied vir deelname en integrasie van persone met gestremdhede in hulle families en gemeenskappe. Gemeenskapsgebaseerde rehabilitasie was gesien as `n geskikte rehabilitasiediens model vir hierdie landelike gemeenskap.

Sleutelwoorde: Gestremdheid; Toeganklikheid; Rehabilitasie; Gemeenskapsintegrasie en deelname.

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Introduction:

Rehabilitation is broadly described as a goal-orientated and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level within their environment, and thus providing people with the tools to lead healthy and productive lives (UN, 2006; National Rehabilitation Policy (NRP), 2000). It can involve measures intended to compensate for loss of function or functional limitation (e.g. use of technical aids) and other measures intended to facilitate social adjustment or re-adjustment. However, as Sherry (2015) argues, its greatest contribution lies in addressing activity limitations and overcoming participation restrictions through intervention, at both individual and environmental levels. The highest goal of rehabilitation is to attain full community integration by the individual (NRP, 2000).

Health professionals commonly known/understood to deliver rehabilitation services are Physiotherapists, Occupational therapists, Speech therapists, Audiologists as well as Orthotists and Prosthetists. There are other professionals that also play a role in the rehabilitation of an individual to reach their goals such as doctors, nurses, dieticians and family members. Rehabilitation services are offered in health facilities such as hospitals (secondary and tertiary hospitals), hospital outpatient departments, rehabilitation centres that commonly have both inpatient and outpatient services, and community health centres and clinics.

Lately, new policies are being discussed e.g. National Health Insurance (NHI) which is being piloted in Provinces such as the Eastern Cape while others are under review (Reengineering PHC) (Baleta, 2012, Philpott, McLaren, Laryea-Adjei, Gelders, 2001-2011). According to the Situation Analysis (2001-2011) of Children with Disabilities in South Africa, the Re-engineering of PHC and the National Health Insurance promises to bring the provision of health services at ward level and in schools, thereby providing potentially significant opportunities for prevention and early detection of disabilities (Philpott, McLaren, Laryea-Adjei, Gelders, 2001-2011).

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The Eastern Cape Province is the second largest Province in South Africa and the greater part of the Province is rural. It is worth noting that almost half of the South African population lives in rural areas (Kok & Collison, 2006) which continue to show the highest poverty levels and poorest health indicators – including those for rehabilitation – in the country (Massyn, Peer, English, Padarath, Barron, Day, 2015; Gaed & Eager, 2013). Despite the availability of policies such as the NRP (DOH, 2000), UNCRPD (UN, 2011) and the WHO Community Based Rehabilitation (CBR) Guidelines (WHO, 2010) aimed at addressing rehabilitation, PWDs are still disadvantaged in accessing rehabilitation services (Sherry, 2015). Furthermore, Sherry (2015) adds that rehabilitation remains poorly understood and seriously constrained in both under-resourced and well-resourced provinces in South Africa. There is a need to establish how the above policy reforms are being translated at ground level through ensuring availability and access to rehabilitation services to ensure that the needs of PWDs are met. This study, therefore, aimed to explore and describe rehabilitation services in a rural setting of Mbashe municipality in the Eastern Cape Province in South Africa with the goal of recommending a rural rehabilitation service model.

Rural health systems consistently suffer difficulties in attracting and retaining rehabilitation staff. These health systems also experience difficulties in providing professional support for the staff that is committed to work in rural areas. Due to the absence of professional support it is a challenge to ensure good practise and governance that can provide coordinated, quality service at all levels of health service delivery which can overcome logistical constraints (Versteeg, Toit, & Couper, 2013). While these issues also affect urban services, rural districts are more seriously impacted, due to a historical lack of investment on building the infrastructure, inappropriate budgeting procedures and local political and socio-economic factors (Gaede & Versteeg 2011; Edgar et al 2015). Rural underdevelopment and poverty, particularly in the former homeland areas as is the situation in the EC, contribute to poorer social determinants of health, and a higher burden of disease (Sherry, 2016:6)

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According to the PHC strategy that drives the public health services for the country, PHC services should be accessible, available, affordable and equitable. With this PHC framework, rehabilitation is one pillar of PHC alongside prevention, promotion and curative interventions (NDOH, 2010). The key to PHC including rehabilitation services, is for individuals to access health services closer to where they live (NDOH, 2010). The majority of PWDs struggle to gain access to health and rehabilitation services in rural areas. Some of the major problems experienced by PWDs at a primary level of care are lack of services at this level. As a result, PWDs are subjected to travelling long distances to gain access to rehabilitation services. This poses a challenge to rural communities that are blighted by poverty and poor geographical infrastructure as a legacy of the apartheid system, as transport to health facilities is costly and remains a scarce resource (Mji, Braathen, Vergunst, Scheffler, Kritzinger, Mannan, Schneider, Swartz, & Visagie 2017; Ned, Cloete, & Mji 2017). Hence this study thus aims to explore and describe rehabilitation services in a rural setting of Amathole District in the Eastern Cape Province in South Africa with the goal of recommending a rural rehabilitation service model.

The problem statement

The core principles of both comprehensive PHC and Community-Based Rehabilitation are still reflecting as challenges when looking at rehabilitation services in South Africa. Despite available policies to address rehabilitation for people with disabilities (PWDs) (NRP 2000, UNCRPD 2006, WHO 2010), a large proportion of persons with disabilities are still disadvantaged in accessing health and rehabilitation services especially in rural areas. Although rehabilitation is one of the components of PHC, it remains;

1) excluded and poorly understood in PHC programmes,
2) fragmented and uncoordinated with services inaccessible to some parts of society especially the rural context compared to urban counterparts,
3) dominated by the medical model and institutionalization of services, and

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4) questionable in terms of relevance of services as there is less involvement, guidance and support from communities where these rehabilitation services are being provided.

Considering these issues, it is unclear how contextual and cultural aspects of the community and people that access rehabilitation services are considered. It is unclear how the highest goal of rehabilitation, which is community integration, is being facilitated as the rehabilitation services are predominantly institution based. Additionally, since the passing of the Framework and Strategy for Disability and Rehabilitation (FSDR) in South Africa (2015–20) and the mandate to translate this framework to provincial implementation plans, it is unclear how the planning is happening and how links are being made with what is currently happening in communities to avoid reproducing the failure of the NRP, which was largely unimplemented (Mji, Rhoda, Statham & Joseph 2017)

Motivation

As a rehabilitation health professional who has worked in the Eastern Cape Province, I have been part of the rehabilitation health professionals who have experienced working with insufficient materials, poor infrastructural and human resources. Though the highest goal of rehabilitation is full community integration of the person with disabilities, it has been my observation that there is no link between the health institutions and communities that deliver services for an effective rehabilitation service delivery model. Though our mandate is improving quality of life for the individuals, their families and communities, our efforts are often undermined by the existence of fractured services, working in profession-specific silos and lack of community-based services (Ned, Cloete & Mji, 2017). Additionally, rehabilitation services are uncoordinated and not integrated within the health services delivery model (Sherry, 2015). As a result, there are no clear referral pathways to create a seamless service delivery mechanism from institutions to the communities (Mlenzana & Mji 2010; Ned & Lorenzo, 2016; Ned, Cloete & Mji, 2017).

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It appears that the present focus for rehabilitation is still institution-based and dominated by the medical model without clear and relevant models for rural rehabilitation and no attempt or effort to study the lives of rural people, their culture, function, with the goal of enhancing their functionality as this will have an impact on their quality of life. I tend to see disability as a Human Rights and a development issue and there are policy and political imperatives to support this notion. Despite this, there is evidence that persons with disability within the SA context, especially those residing in the rural areas, are heavily marginalized and lack community-based rehabilitation services that could improve their lives and lead to community participation (Jelsma, Maart, Eide, Toni, & Loeb, 2007). Firstly, the lack of manpower to deliver rehabilitation services has influenced my realisation that making use of already existing resources, including people with disabilities themselves, their families, their communities and prescribed health professionals, could be beneficial to the development of a rehabilitation service delivery model for rural rehabilitation.

Secondly, although an attempt has been made to bring young graduates, some of whom are from urban areas and had also studied in those areas, to rural areas where there is scarcity of rehabilitation services, the type of service delivery model is still a medical institution-based model. Such a model does not take cognizance of the cultural beliefs of the people it intends to serve, nor the active participatory role they should be playing to inform the relevance of services. There is an ongoing battle for dominance of cultural practices from both the health professionals and the rehabilitation clients (Baleta, 2012). Culture is what we learn from parents, families, and communities (Coleridge, 2006). As a result, the cultural beliefs of the people with disabilities and their communities may differ from those of the health professionals. This tends to prevent health professionals from educating communities about disability and health matters in general, especially the area of disability prevention and health promotion - using examples of available local resources at community level. There also appears to be an unwillingness from the rehabilitation health

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professionals to learn and understand the daily lives and cultural beliefs of rural clients (Baleta, 2012).

These young practitioners need support in the form of experienced rehabilitation professionals and resources such as equipment to strengthen their undergraduate training in addressing disability issues. In an article by Ned, Cloete and Mji (2017) which presented a case of an experience of a community service rehabilitation health professional; Ned sharing her experiences during her community service period in 2012. She revealed that practising rehabilitation in under-resourced contexts with poor allocation of resources is challenging and constrains any possibility to facilitate the end goal of rehabilitation, which as earlier mentioned, is community integration.

Though these young graduates are perceived as enjoying working in the rural environments, they do not, unfortunately, get enough support to assist them to cope with the challenges of rural rehabilitation (Ned, Cloete and Mji 2017). Nor do they learn about the culture of the rehabilitation patients they manage that require integration in communities with that specific culture (Coleridge, 2006; Baleta, 2012). The more experienced rehabilitation health professionals that understand rural life are scarce in rural areas and are most of the time working for urban clinical environments, while others are in managerial positions (Sherry, 2016; Ned, Cloete and Mji 2017). Unfortunately, even health professionals in these rural rehabilitation placements, such as the nurses and doctors, that are available for these young graduates, it is not clear how much they themselves understand about the rehabilitation of PWDs and the role they could play in supporting the young graduates (Ned, Cloete and Mji 2017).

The young graduates end up being supervised by nurses and doctors who do not have the concept of rehabilitation at primary healthcare level (Ned, Cloete and Mji 2017). This lack of rehabilitation knowledge by health professionals deprives the rehabilitation health professionals of the opportunity to do the outreach to the communities in rendering the rehabilitation services. Their scope of practice is thus

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limited as they appear to be stuck in hospitals and clinics (Sherry 2015). There appears to be a general lack of understanding from these supervisors that the highest goal of rehabilitation is community integration – hence there is a need to support the young rehabilitation graduates to enter the communities they work for, and learn about the cultural practises of the communities, including the activities they perform. This is to ensure that their rehabilitation programme is in line with these activities and to use these activities during rehabilitation as a yardstick for their clients' improvement and participation.

For the young graduate, it becomes ultimately a matter of finishing the community service contract and period with no extension of their service for the benefit of the communities which, for the first time, have started experiencing rehabilitation services (Ned, Cloete and Mji 2017). It appears that there is a general need to understand the challenges of the existing rehabilitation services in rural areas in the Eastern Cape Province of South Africa.

Critical research questions that the study has attempted to answer

The overarching question for this is study is:

What is the nature of rehabilitation services provided in a rural setting of Mbashe municipality in the Eastern Cape Province? Subsidiary research questions are as follow:

- What rehabilitation services are available in the study setting?
- Who are the key role players in these rendered services?
- What rehabilitation resources are available?
- What challenges do both the rehabilitation service providers and users experience?
- How can the rehabilitation services be contextually relevant to the community needs?

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Aim of the study

To explore and describe rehabilitation services rendered in a rural setting of Mbashe municipality in the Eastern Cape Province in South Africa.

Objectives of the study

- Describe the rehabilitation and health services in the selected area.
- Identify the key role players for rehabilitation services in this area (both community-based and institution based).
- Describe the rehabilitation pathways available within the health facilities and the community.
- Explore the challenges experienced by all role players delivering rehabilitation services in the study area.
- To determine the perceptions of people with disabilities regarding the current model of rehabilitation in the study area.
- To make recommendations for addressing the challenges with regard to rehabilitation services in the study area.

The significance of the study

It is envisaged that the critical outcomes of the study will bring about the understanding of the existing rehabilitation service delivery model in a selected rural area of the Eastern Cape Province of South Africa and recommend aspects that could address challenges with regard to rehabilitation services in the study area. The study will also bring about recommendations on how to develop pathways to address how best to utilize the available resources to render a better rehabilitation service in a rural area. It will show how to put the role players (health professionals) and the people receiving treatment/therapy together; create solutions to the challenges of the current model of rural rehabilitation; and highlight the need to empower nurses and doctors on disability and rehabilitation; in order to assist and provide support for the inexperienced, newly qualified therapists who are working in rural areas without support.

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Literature Review

This section will cover 1) Disability incidence and prevalence; 2) An overview on disability including medical, social, ICF models and latest thinking around disability including African rural views towards persons with disabilities (PWDs); 3) Rehabilitation service models, including aspects on culture and rehabilitation; 4) Access, barriers to rehabilitation especially CBR; 5) Policies driving disability and rehabilitation; 6) Rural rehabilitation models of best practise; 7) A brief overview of literature underpinning tools used in the study; 8) The rehabilitation pathways; and, 9) A Summary of the Literature review.

Disability incidence and prevalence in South Africa

Stats South Africa states that the statistics on disability prevalence are paramount in assessing development challenges and other life circumstances faced by people with disabilities. However, it is known that calculating prevalence has been a complex task as it is influenced by many factors used, such as methodology, sampling, and differing definitions of disability, amongst other issues (Sherry, 2015). This complexity is also evident in South Africa. For instance, the 2011 census indicates a disability prevalence of 5, 2% (Stats SA, 2011). According to the 2011 Census Disability Monograph Executive summary, the Eastern Cape Province has the third highest disability prevalence (Eastern Cape 9.6%; Northwest 10%; Free State 11 %). The Province with the lowest disability prevalence in 2011 was Gauteng.

More recently, the Washington Group on Disability Statistics introduced a set of six questions based on the ICF model of disability, which captures the interaction of impairment and environment in producing actual levels of functioning (including mobility, vision and hearing, communication, cognition and self-care). This tool is being widely implemented in international and regional data collection, including the South African Census 2011, which profiled people with disabilities in South Africa in relation to the arrangement of demographic characteristics, including age, gender, geographical location and racial group (Statistics South Africa, 2014a). The report

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found an overall disability prevalence of 7, 5%. It excluded children under five and people with psychosocial and some neurological disorders, hence its outcome cannot be taken as conclusive. The exclusion of mental health, neuropsychiatric and substance use (MNS) disorders from this census confirms the tendency of South African Policy makers to interpret disability as a physical, biomedical phenomenon.

Another estimate of disability prevalence in South Africa is drawn from the World Report on Disability (World Health Organisation, 2011) which compiled estimates from two sources, namely the World Health Survey (2002-4) and the Global Burden of Disease Survey (2004 update). From this report, the combined estimated prevalence of disability in South Africa is 24, 2%, significantly higher than the global estimate of 15, 3 to 15, 6% (WHO, 2011). Similar to the Washington group on disability statistics, this figure also does not address the MNS disorders and includes only adults aged 18 years and older. The wide variation between this figure and that yielded by the 2011 Census indicates the above-mentioned uncertainties and complexities of measurement methodologies. As a result, there is still considerable work to be done in producing comparable, accurate and comprehensive data on disability prevalence in South Africa (Samman & Rodriguez-Takeuchi, 2013; Schneider, Dasappa, Khan, & Khan, 2009; WHO, 2011).

While precise figures are unknown, it can be assumed that the number of people living with significant functional impairment is increasing in South Africa. The quadruple burden of disease (includes the infectious diseases – specifically HIV and TB; maternal and child mortality; violence and trauma; and non-communicable diseases of lifestyle) creates a formidable shadow of chronic illness and impairment, alongside successes in prolonging lives (Sherry, 2015). The transition of HIV/AIDS from a terminal to a chronic illness, through the successful rollout of Highly Active Antiretroviral Therapy, has particular implications for disability in a population with one of the highest rates of infection in the world (Hanass-Hancock , Regondi & Naidoo , 2013). The global rise of mental illness, which has strong links to the local burden of disease,

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is another leading cause of disability and mortality following HIV and TB in the country. (Burns, 2011; Lund, 2014; Lund, De Silva, Plagerson, Cooper, 2011; Sherry, 2015).

The burden of diseases, however, speaks only to the impairment level of disability and overlooks some of the diseases contributing to the burden, some of which are poverty related. There are also many studies showcasing that people experiencing the burden of disease also experience activity limitation and participation restrictions. When one unpacks this, people with disability experience activity limitation and participation restriction whereby it is the societal factors (environment and poverty) that actually disable people. The South African context offers further challenges in environmental terms, particularly for the large proportion of the population still living in poverty. While impairments dwell predominantly in the health domain, disabling environments span education, public space, basic services, livelihoods and social structures, among others (Sherry 2016). Health services themselves may constitute disabling environments, both through their non-inclusive design, and through the medicalising conception of disability predominating within them (Vergunst, Swatz, Mji, Kritzinger and Braathen, 2017). Existing measures of disability prevalence in South Africa fail to take account of the wide variation in living environments of its citizens, and are therefore likely to miss the extent to which disability compounds other vulnerabilities in disadvantaged communities like Madwaleni rural area (Vergunst, Swatz, Mji, Kritzinger and Braathen, 2017)).

<u>Dominant models and frames used in rehabilitation</u>

This section elaborates on disability and culture including the various models that are used to try and gain an understanding regarding the concept of disability and rehabilitation.

Disability: WHO defines disability as any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being (for example, difficulty in speaking, hearing or walking) (NRP, 2000). Disability is

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understood to be a multidimensional experience, which changes over time and context (WHO, 2011). It may arise from a long-term impairment but may also be the result of short-term or episodic conditions, rendering it a dimension of the universal human experience, rather than the characteristic of a defined group (WHO, 2001). At the same time, disability over the lifespan is understood to produce cumulative vulnerabilities and compounded disadvantage, which affects not only the individual but also her/his household and community (Duncan & Watson, 2009).

According to the White Paper on the Rights of Persons with Disabilities, which based its interpretation from the UNCRPD, disability is a complex and evolving concept and its current definition reflects a more progressive view of disability than was the case in the past (White Paper on the Rights of People with Disabilities, 2015). The White paper also states that, there is no single definition of Disability that has achieved international consensus (White Paper on the Rights of People with Disabilities, 2015). The rights-based definitions share common elements inclusive of the presence of impairment; internal and external limitations; barriers which hinder full and equal participation; a focus on the abilities of the person with disabilities; loss of or lack of access to opportunities due to environmental barriers; and/or negative perceptions and attitudes of society; and lastly, that disability can be permanent, temporal or episodic (Sherry, 2016).

There are various models and frameworks that are used to try and gain an understanding regarding the whole concept of disability. All these definitions have been coined outside the African and rural context and working with people from this paradigm may begin to assist in understanding how disability is defined within this context. The three commonly used models and frameworks are the medical model; the social model; and, the ICF.

The medical model of disability

This model views disability directly as a problem of the person that experiences the disease, trauma or health condition. It further sees disability as mainly requiring

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medical care provided in the form of individual treatment by professionals. The emphasis of the medical model is on the diagnosis, and the diagnosis tends to categorize individuals according to their impairments. The challenge with this model is that it is mainly an institution-based model and ignores the social aspects of an individual which are critical for community integration (Vergunst, Swatz, Mji, Kritzinger and Braathen, 2017).

Social model

While the social model views disability as a result of the limitations in accessibility of the environment where the person lives or works, it further views disability mainly as a socially created problem, and tends to see disability not as an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment (Vergunst, Swatz, Hem, Eide, Mannan, Maclachlan. Mji & Schneider, 2017).

In an article by Ned, Mji, Krige, Muller, Duvenge, Runowicz and Joubert (2015) it is affirmed that the physical and social environmental factors play a vital role in disabling and enabling individuals.

The social environment is relevant in the sense that, health professionals and other members of the community may have poor understanding of disabilities which may cause challenges for both health professionals and the community with regard to interaction with people with disabilities. A large proportion of people with disabilities is within the communities they live rather than in institutions or health facilities. The challenge with the social model is that it tends not to highlight the medical condition and problems that are a result of the impairment and the need for medical intervention which is when most of these services are institution based (Ned, Mji, Krige, Muller, Duvenge et al., 2015)

The International Classification of functioning, disability and health (ICF)

A recent classification of disability is WHO's International Classification of Functioning, Disability and Health (WHO, 2001). This Model defines impairment as

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the physical, mental or cognitive limitations that an individual may have, such as the inability to walk or speak; an impairment is also an anomaly of body structure or function; anatomical, physiological or psychological (WHO, 2001). It also takes into consideration the environmental barriers that are usually placed at societal level and personal factors that can also either be facilitators or hindrances in rehabilitation. The development of the ICF by the WHO has been particularly influential in bringing together the concerns of the health system (specifically preventing, reducing and remediating impairment) and those of the disability movement and human rights (WHO 2001; Jelsma 2009). Significantly the ICF has also shifted the perspective on disability as a long-term or permanent condition, to a universal aspect of the health/ illness experience, across the lifespan (WHO, 2011). The UNCRPD draws from the ICF model but acknowledges the contested and evolving nature of disability as a concept. It defines disability as resulting from the interaction between persons with impairments, and attitudinal and environmental factors that hinder their full and effective participation in society on an equal basis with others (United Nations, 2006). Depending on the context, these three models of interpreting disability could be interchangeably used during the rehabilitation process.

Disability and culture

This study has alluded in the earlier section that, although an attempt has been made to bring young graduates to rural areas where there is scarcity of rehabilitation services, the type of service delivery model is still a medical institution-based model that does not take cognizance of the cultural beliefs of the people that they serve (insert reference). There is an ongoing battle for dominance of cultural practices from both the health professionals and the rehabilitation clients (Coleridge, 1993). According to Coleridge, to view culture as uniform in any country will inevitably lead to serious misunderstandings because it ignores the specific and immediate texture of people's lives. It is the culture of the community that needs to be studied, not simply the generalised culture of the country (Coleridge, 1993)

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Peter Coleridge states that Disability is defined by culture, he further mentions that the tendency to categorise all people with different impairments as 'disabled' is a fairly recent phenomenon emanating from western societies. Many traditional societies do not have an exact equivalent in their own language for the word 'disabled', and they can seldom match the three-tier concepts in English of 'impairment', 'handicap' and 'disability espoused by WHO AND DISABILITY theorists. However the traditional societies usually do have words for specific impairments such as deaf, blind, and lame. Furthermore, what is counted as a disability, that is, that which prevents someone from fulfilling the roles normally expected of them, differs from one culture to another. In other words, the way societies think about disabled people is determined by a variety of cultural variables, including the nature of impairment. It is therefore essential for planners of community disability programmes inclusive of rehabilitation practitioners to know and understand how different impairments are viewed within the target community in order to plan effective interventions, especially since many disability programmes place changing attitudes among their main objectives.

Cultures are not cast in stone, they have a present, a past and a future. It is almost impossible to say what is indigenous to a particular society because every country has been subjected to a continual process of cultural evolution and transformation throughout its history and this process will continue indefinitely. Cultures are not intact and sealed for ever by reference to an original, more or less mythical, state, they are being continuously influenced and changed by contacts of all kinds between various people (Coleridge, 1993). This is the situation in the study setting of the rural area in Amathole District, where the culture is still valued by this community and where inhabitants are expected to abide by the cultural values.

Cultures do not reflect a consensus but are to a large extent, manifestations and often manipulations of power between different agents within a culture. In a particular culture, not everybody is a strong supporter of the cultural practise, especially when

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it cuts across their own interest. Disability is understood as a complex experience, embedded in the physical, socio-economic and cultural realities of the rural South African context (Coleridge, 1993). When the researcher grew up in the 1960's, all children, including children with disabilities, would attend the same school. Then in the 1970's education and health policies were introduced that created special schools, for example, schools for the physically disabled; schools for children with mental health problems and other types of disability. These policies somehow discriminated against children with disabilities. Most recently, the department of Education has introduced the inclusive education policy, where all children may go to the same school including those with disabilities. Policy implementation should ensure the smooth integration of children with disabilities into mainstream schooling – this might include assisting teachers in understanding cultural nuisances that might undermine the integration of disabled children in mainstream schools. Article 30 of the UNCRPD places specific obligations on the state to take measures that will promote, protect and uphold the cultural rights of persons with disabilities, including the rights of deaf persons to deaf culture and the right to enjoy access to participation in cultural life in accessible formats. (White Paper on Rights of People with Disabilities, 2015)

Rehabilitation

Rehabilitation is a goal-orientated and time-limited process aimed at enabling impaired persons to reach an optimum mental, physical and/or social functional level, thus providing them with the tools to change their own lives. It can involve measures intended to compensate for loss of function or functional limitation (e.g. use of technical aids) and other measures intended to facilitate social adjustment or re-adjustment. The highest goal of rehabilitation is for the individual to attain full community integration.

Though there are recent definitions to rehabilitation (Who Disability World, 2011) the researcher intend to present this comprehensive operational definition of

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rehabilitation by Hellander (1992): rehabilitation includes broad issues about rehabilitation including measures aimed at reducing the impact of disability for an individual, enabling the achievement of independence, social integration, a better quality of life and self-actualisation. He continues to argue that rehabilitation not only includes the training of disabled people but also interventions at a society level (elimination of physical and attitudinal barriers), equalization of opportunities, adaptations of the environment and promotion and protection of human rights. Equalization of opportunities includes the physical environment, housing, and transportation, social and health services, educational and work opportunities, cultural and social life, including sport and recreational facilities.

In the past many regulations and laws prevented disabled children from integrated schools, and adolescents and adults were barred from vocational training and employment. There was reluctance of society to integrate disabled people into public life. Authorities sought special solutions in terms of separate facilities for schooling, living, and sheltered workshops for employment. The World programme of action concerning Disabled Persons was adopted by the UN in 1982 and emphasized equalization of opportunities as major point. Recent policies and constitutional reforms and democratisation have made governments more responsive and receptive to proposals that promote human rights for persons with disabilities

Institution-based rehabilitation

Inpatient/institution-based rehabilitation is designed for patients who require intensive interdisciplinary rehabilitation services. These inpatient programmes are designed to improve function and promote each patient's highest degree of independence. Inpatient rehabilitation care is also known as hospital-level, or acute, rehabilitation care. This sophisticated level of care is not available in other settings, such as nursing homes, skilled nursing facilities, assisted living centres or extended care centres.

At an inpatient rehabilitation facility (IRF), clinical teams coordinate medical

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treatment, specialized services, rehabilitation treatments, and patient-assistance services, all while providing the emotional support and encouragement that patients need to make great strides in recovery. Patients must be able to participate in a minimum of three hours of therapy per day (Stark, 2018). In the public service healthcare situation, patients who are inpatients or admitted in hospitals will get an opportunity to access the rehabilitation services available in the hospital. The effectiveness of the inpatient rehabilitation services also depends on the availability of rehabilitation health professionals and equipment needed for the rehabilitation of the patient.

Outpatient based rehabilitation

Outpatient based rehabilitation is the rehabilitation for patients who are not admitted in health facility. The outpatients access rehabilitation from their homes. As a therapist myself, outpatients would access rehabilitation services on an appointment basis that is, they may attend rehabilitation once, twice or three times a week during office hours. The outpatient rehabilitation is a convenient option of accessing rehabilitation services for those patients who live closer to the health facility and for whom the rehabilitation services are conveniently accessible. A convenient situation which is mostly not practical in a rural environment. Outpatients usually have a minimum contact session and supervision with their therapist for rehabilitation compared to the period of rehabilitation as inpatient. This also depends on the severity of the physical activity required and the extent of impairment that requires rehabilitation or contact with the therapist.

Outreach programmes

The outreach programme means taking the rehabilitation service from a health facility closer to the communities. It may be from the hospital to a clinic or community health centre closer to the communities that need the rehabilitation service. In some rural areas the clinic or community health centre may be far from the people who need the service and the rehabilitation service may take place under a tree, in a church building

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or school as long as the place is accessible to the people who need the rehabilitation service. The outreach programmes also are scheduled on an appointment basis with times and dates during which the rehabilitation health professionals will be available. In the Buffalo City Local Service Area (LSA) in 2004 the LSA rehabilitation coordinator together with the therapists from the Empilweni community health centre would join the mobile clinics to the rural areas around the East London area when conducting their outreach programmes.

Community-Based Rehabilitation (CBR)

Community-based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities which is implemented through the combined effort of people with disabilities, their families and communities and the appropriate health education, vocational and social services (WHO, 2010). CBR is an approach to delivering services to the populace and not a service itself. Its principles are applicable at all levels of service. CBR provides and delivers effective rehabilitation services as it takes an inclusive development approach to working with persons with disabilities (Ned et al., 2015). It is also a multi-sectoral strategy for social inclusion, poverty alleviation and inclusive development championed by the World Health organisation and others as the gold standard for action on disability. CBR encompasses action across five domains or sectors namely, education, health, livelihoods, social life and empowerment. It is envisaged as a complex, locally set of specific processes carried out by range of agencies and actors with the full participation of people with disabilities and their families. (Sherry, 2016).

Disability as a social, developmental and human rights issue shifts the focus of intervention from individualised biomedical treatment to a combination of personal and societal responses (Sherry, 2016). Community-based rehabilitation (CBR) has been championed by the WHO as a rights-based, intersectoral approach aimed at social inclusion and the removal of barriers to people's full participation as citizens in

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society. The WHO, 2010 CBR framework includes rehabilitation as a specific activity within healthcare. In this sense rehabilitation refers to a set of measures which enable people with disabilities to achieve and maintain optimal functioning in their environments (WHO, 2001). This includes services provided across a range of contexts (from home and community to hospital), and through a range of providers, including rehabilitation professionals such as occupational therapists, physiotherapists, speech pathologists, audiologists and orthotists and prosthetists. In South Africa, the health sector is the primary provider of rehabilitation services, via public, private and non-governmental organisations

National and international policies related to disability and rehabilitation.

In South Africa, since 1994 new human rights and health related policies and White papers have been developed to improve the service delivery model for rehabilitation services and assist in improving the lives of PWDs.

The government of South Africa committed itself to bringing health services closer to the people by adopting the Primary Health Care (PHC) approach of which rehabilitation is an important component (White Paper SA, 2015). The National Rehabilitation Policy (2000) states clearly that services should be restructured and strengthened in order to improve access to these services for those who did not have it before. This policy also emphasises that there is a need to find solutions to the many problems associated with rehabilitation. Rehabilitation health professionals and managers have come to realise that part of the solution is to involve the clients in decision-making so that they can own the process and be empowered at the same time. One of the objectives of this study is to determine the perceptions of people with disabilities with regard to the current model of rehabilitation in the study area so that they can be empowered.

An ethos will thus develop in society that will ensure quality of care at all times, with respect to human dignity and the acknowledgement of a person's right to self-determination. This study has involved people with disabilities themselves, their

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families and the communities they live in. The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities proposes that rehabilitation services should be available in the local community with the involvement of persons with disabilities and their families (Sherry, 2016).

All the citizens of a country benefit from rehabilitation services as rehabilitation aims at restoring functionality or maintain the individual's optimal functionality in their environment as much as possible and strengthen the abilities further to compensate for the reduced level of function in some parts of the body (UNCRPD, 2007). Relatives of the affected person also benefit from rehabilitation, as it has a positive outcome in producing functional families that contribute to the communities towards a better quality of life for themselves and their communities. The goal of the National rehabilitation policy is to improve accessibility to all rehabilitation services in order to facilitate the realisation of every citizen's constitutional right to have access to health care services (NRP, 2000). Policies and White papers such as:

- The South African Constitution, Chapter 2 of the Bill of Rights, Section 28 (1b) (S.A., 1996)
- Re-engineering of Primary Health, (NDOH, 2010)
- National Rehabilitation Policy (NRP, 2000)
- Integrated National Disability Strategy (White Paper S.A., 2015)
- United Nations Conversion on the Rights of Persons with Disabilities (UNCRPD, 2007).
- Framework and Strategy for Disability and Rehabilitation, (NDOH, 2015)

All these policies and white papers are meant to improve access to health and rehabilitation services and improve the lives of people with disabilities. Unfortunately, people with disabilities or impairments in a rural setting/area encounter multiple barriers to mobility, activities of daily living, and social participation. Long distances, difficult terrains, lack of accessible transport and often lack of access to piped water, sanitation and electricity, make minor impairments to be far more significant (Duncan & Watson, 2009). Such barriers will also impact on

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access to healthcare. All these factors give reason to believe that rural people with disabilities are an especially vulnerable population and raising questions regarding implementation of these policies.

Lately, new policy imperatives have been implemented such as the National Health Insurance policy (NHI) (Baleta, 2012). According to the Situation Analysis (Stats SA, 2001-2011) of Children with Disabilities in South Africa, the Re-engineering of PHC and the National Health Insurance promises to bring the provision of health agents at ward level (lowest level of municipal administration) and in schools, thus providing potential significant opportunities for prevention and early detection of disabilities (Philpott, McLaren , Laryea-Adjei, & Gelders, 2012)

The Primary Health Care Package of South Africa confirms that Primary healthcare is at the heart of the plans to transform the health services in South Africa. An integrated package of essential primary healthcare services available to the entire population will provide the solid foundations of a single, unified health system. It will be the driving force in promoting equity in healthcare (Primary Health Care Package, 2013). The Primary Health Care Package also acts as guidance for provincial and district health authorities to provide these services.

Rehabilitation services are an integral part of the services provided at the primary level. This constitutes a reorientation of rehabilitation from mainly institution-based services to community oriented and community-based services. Communities, and particularly people with disabilities, should be involved in designing, implementing and monitoring services for people with disabilities. This prevents a disability service from being seen narrowly as a therapy service provided only by a certain category of staff. All health personnel in co-operation with all other sectors and the communities/people themselves are responsible for making society inclusive of all people, including people with disabilities. (Primary Health Care Package, 2013).

PHC shares with CBR the principles of empowered community engagement, appropriateness to local needs, a holistic vision of health and an inter-sectoral vision

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of action informed by human rights and social justice. (Sherry, 2016). As mentioned earlier, within CBR health is one of the five key domains of action and includes, prevention, promotion, curative services, rehabilitation services and the access to assistive devices (WHO, 2010). PHC offers an excellent fit to deliver these within CBR framework. Unfortunately, in South Africa ongoing developments in PHC have largely neglected to consider disability in their design and delivery, excluding many people with disabilities from the healthcare they need (Moodley & Ross, 2015).

The National Health Insurance (NHI) Policy is defined as a health financing system that is designed to pool funds to provide universal access to quality, affordable personal health service for all South Africans based on their health needs, irrespective of their socio-economic status. NHI will be implemented through the creation of a single fund that is publicly financed and publicly administered. The health services covered by NHI will be provided free at the point of care. The NHI is a policy shift that will contribute towards poverty reduction and addressing the inequalities inherited from the past, as the funding will be linked to an individual 's ability to pay and benefits from health services will be in line with an individual's need for health care. There is a need to establish the extent to which these policy reforms have improved the rehabilitation services in the country and benefited the lives of disabled people and children. (NHI Version 40, 2015).

The National Health Insurance promise to bring the provision of health agents at ward level (lowest level of municipal administration) and in schools thus providing potential significant opportunities for prevention and early detection of disabilities (Philpott, McLaren, Laryea-Adjei, Gelders, 2012).

Universal access is one of the features of the NHI which means that all South Africans will have access to needed promotive, preventive, curative, rehabilitative and palliative health services that are of sufficient quality and are affordable without exposing them to financial hardships. This feature further states that South Africans will have the right to access quality health services on the basis of need and not

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socioeconomic status.

Brief overview of Literature underpinning instruments that were used for the study

This study, through the use of the wheel of opportunities and Kaplan's Framework for organizational capacity will try to explore and describe rehabilitation services rendered in a rural setting of Mbashe municipality in the Eastern Cape Province. The use of these instruments will be presented in the methodology to describe how tools for data collection were developed.

The instruments are:

1). Wheel of Opportunities.

The Wheel of Opportunities was informed by the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (WHO, 1993). It was developed by Lorenzo and Sait (2000) as a participatory evaluation tool, designed specifically to inform upon the positioning of persons with disabilities in relation to their participation of service delivery programs aimed at persons with disabilities. The 22 rules provide preconditions for equal participation, target areas for equal participation, implementation measures, the monitoring mechanism and also cover all aspects of life of the disabled persons.

This instrument consists of spokes whereby each spoke will represent an opportunity for a basic human right that is expected to be available and accessible for persons with disabilities. This instrument allows the direct participation of people with disabilities themselves.

Below is Figure 1. Representing the Wheel of Opportunities:

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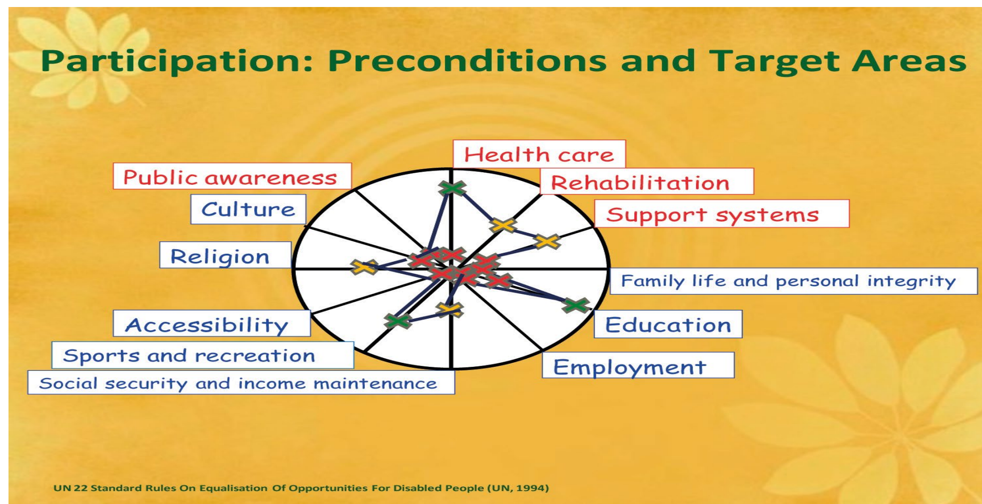

Figure 1: **Participation: Pre-condition and Target areas, Wheel of opportunities for participation (Lorenzo & Sait 2000.) This instrument will be used to develop a tool for data generation for the focus group for people with disabilities.**

This tool was used first to explore from persons with disabilities the nature of health rehabilitation services that they received from the rehabilitation services in the study area. Secondly it assisted to explore the extent of participation in their communities by hearing from persons with disabilities where they placed their level of participation on the different spokes of the wheel, thereby giving an indication of their level of community integration.

A previous rehabilitation-related study using the wheel of opportunities was done by Ned-Matiwane, (2013) to explore the capacity of family and service providers to facilitate the participation of disabled youth in accessing opportunities in skills development and employment in Cofimvaba.

The following are the opportunities represented by each spoke of the wheel of opportunities. Each opportunity is a basic human right that should be available and accessible for PWD.

The following twelve (12) items are the opportunities represented by each spoke of the wheel of opportunities:

1.1 Health

According to Sherry, 2016 health is the capability set which represents to a person or

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community the combination of beings and doings they most value and have reason to value, given their available resources and opportunities. Health is complex multi-dimensional and personally defined. It includes both 'elementary' functioning, such as the ability to be free from disease and pain and complex functioning, such as the ability to fulfil valued social roles (Arina & Navved, 2009).

1.2 Rehabilitation

Rehabilitation is a broad issue which includes measures aimed at reducing the impact of disability for individuals, enabling them to achieve independence, social integration, a better quality of life and self-actualisation. Rehabilitation not only includes the training of disabled people but also interventions at a society level (elimination of physical and attitudinal barriers), equalization of opportunities, adaptations of the environment and promotion and protection of human rights. (NRP, 2000, WHO Disability report, 2011)

1.3 Support systems

A support system is a multipronged initiative from family, friends, community and public service providers to support persons in need, in this context it is what persons with a disability need to be able to cope with everyday activities in spite of their limitations. (Sherry, 2016).

1.4 Family life and personal integrity:

Family is what all people need to feel complete with a sense of worth, belonging and being loved or cared for (Gaede & Versteeg, 2011).

1.5 Employment

Employment is a relationship between two parties, usually based on a contract where work is **paid** for, where one party, which may be a corporation, for profit, not-for-profit organization, co-operative or other entity is the employer and the other is the **employee**. The stability of the economy rests on the ability to maintain a **low** unemployment rate and provide a safe, secure workplace. **Working**, whether paid or

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unpaid, is **good** for our health and wellbeing. It contributes to our happiness, helps us to build confidence and self-esteem, and rewards us financially (Kok & Collinson, 2006).

1.6 Education:

Education is a gradual process which brings positive changes in the human life and behaviour. It also means helping people to learn how to do things and encouraging them to think about what they learn. Through education, the knowledge of society, country, and of the world is passed on from generation to generation. It is not only by going to school that people learn but from communities, environment, and families. It is a lifelong learning process.

1.7 Social security and income maintenance:

Social security is a government initiative in the form of funding for communities and persons who have retired or are have a disability, as well as those who have been disadvantaged/displaced by natural disasters or violence. The maintenance and management of the funding is important and includes budgeting and constructive use of the money/funding (Jelsma et al, 2008).

1.8 Culture:

Culture is the characteristic and knowledge acquired by a particular group of people, encompassing, language, religion, cuisine, social habits, music and arts. Culture is a way of life for groups of people, that is, the way people do things. This further means that culture is learnt from others and not something that a person is born with (Coleridge, 2006).

1.9 Sport and recreation:

Sport is a form of recreation where individuals participate in recreational activities other than work for enjoyment. It is an important requirement for the body, mind and soul for stimulation. Sport also brings people together when participating as a team. It subjects people to an opportunity for sharing, tolerance, and behaviour

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modification. However, people with disabilities have limitations that restrict them from participation in sport, but they can fully participate (Lincoln & Guba, 1985).

1.10 Accessibility:

Access to services and environment is always a challenge for people with disabilities because of their physical and/or mental and sensory limitations.

Accessibility defines the users' ability to use products/services but not the extent to which they can attain goals (https://wwwinteraction)

A 2011 W.H.O report revealed that about 15% of the world's population had some disability. When designing, the number and type of potential accessibility issues users will have should be considered. Barriers include visual (e.g., colour blindness), motor/mobility (e.g., wheelchair-user concerns), auditory (hearing difficulties), seizures (especially photosensitive epilepsy) and learning (e.g., dyslexia). Also design to maximize ease of use when users (of any ability) encounter your creation in stressful/mobile situations. By designing to reach all ability levels, one will produce output virtually anyone can use and enjoy (or find helpful/calming), whatever the context. Designing for accessibility thus help all users as it accommodates all types of disabilities.

1.11 Religion:

Religion is the set of beliefs, feelings, dogmas and practices that define the relations between human beings and the sacred or divine. A given religion is defined by specific elements of a community of believers: dogmas, sacred books, rites, worship, sacraments, moral prescription, interdicts, and organization. The majority of religions have developed from a revelation-based on the exemplary history of a nation, of a prophet or a wise man who taught an ideal of life (atheism.free.fr/Religion/what-is-religion-1htm). Religion is also a very sensitive issue where people have different religious beliefs, as religion has different meanings for different people.

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1.12 Public awareness:

The environment where people have been raised plays a vital role regarding the understanding and knowledge of the available public resources and safety about social, scientific or political issues (for example, the Disabled People's Organisations). Organisations for people with disabilities are platforms for PWD, their families and communities to have an opportunity to integrate and participate in the rehabilitation of people with disabilities themselves. In the methodology with focus groups with PWD, it will reveal the extent of awareness of PWD, their families and communities have about the available resources in their communities. (Ref www.endvawnow.org/en/article/248-public-awarness.html

These opportunities will be used as a guide to generate themes in the focus groups with people with disabilities.

2. Kaplan's Framework of an Organisational Capacity.

Kaplan derived criteria consisting of a number of elements that must be present for any organization to be effective (Kaplan, 1999). According to Kaplan: organisational capacity theory identifies six features of organisational life and these are:

- The conceptual framework reflects the organization's understanding of the world.
- The organizational attitude incorporates the confidence to act in and on the world in a way that the organization believes to be effective and to have an impact, while accepting responsibility for social and physical conditions 'out there'.
- The organizational vision and strategy provides a sense of purpose and flows out of the understanding and responsibility of the organizational attitude.
- Organizational structures and procedures are defined and differentiated to reflect and support vision and strategy.
- Individual skills, abilities and competencies are relevant to the task at hand.
- Material resources should be sufficient and appropriate.

These elements are arranged in a hierarchy of importance with the top three elements

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being transitory and invisible but determining the capacity of an organization and its seen effectiveness; the lower three elements being visible and tangible and more easily measurable. Kaplan maintains that the elements outlined need to be present and coherent for an organization to have capacity and to be effective (Kaplan, 1999).

Below in Figure 2 are the 6 elements of Kaplan's framework as explained above:

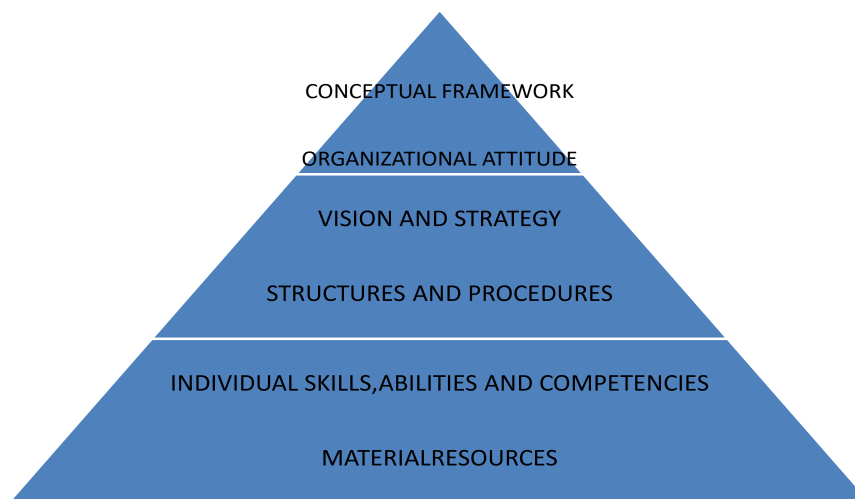

Figure 2: Kaplan's conceptual framework of an organizational capacity (Kaplan, 1999)

This study used Kaplan's Framework for organizational capacity as an instrument to describe the rehabilitation services offered in the research site. The rehabilitation services offered in the study were taken as an organization and this instrument by Kaplan was used to explore whether the rehabilitation services in Madwaleni have the capacity to deliver comprehensive rehabilitation services for PWDs residing in the study area and using these services.

Previous rehabilitation related studies using Kaplan's Framework were done by de Wet, (2012) exploring organisational capacity of rehabilitation services in Gugulethu Day Centre, and Liebenberg (2012) exploring organisational capacity of rehabilitation services within the Overberg region of the Western Cape. Gcaza, Lorenzo and Mji (2008) used Kaplan's Framework for organizational capacity to evaluate the partnership between Disabled Children's Action Group (DICAG), South Africa and

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Norsk Forbund for Utviklingshemmede (NFU), Norway during the period 1997–2004.

The Rehabilitation pathways

This study also adopted and used a table of the rehabilitation pathway that was developed by South Australian Department of Health structure of Rehabilitation Pathways in their Stroke Unit (2010 pg. 5 of 9) (see appendix 5). The rehabilitation pathway is a journey involved during the process of the rehabilitation (treatment) of patient. This journey is a process towards independence or full recovery if possible. The table will show the current rehabilitation pathways in the study area from the secondary hospital to the community. It will also show the stages with evidence of guidelines and functionality of the individual from a very acute stage up to the stage of community integration by the patient at home.

Summary of Literature Review

This chapter has explained the concept of rehabilitation and disability and has highlighted the fact that disability is a Human Rights issue that requires attention from the authorities and government. The national and international policies related to rehabilitation and disability described above are a guide towards the implementation of rehabilitation services for all the citizens of South Africa whether residing in urban or rural settings. Although attempts are made to bring more rehabilitation health professionals to rural areas in the Eastern Cape Province of South Africa, the service delivery model is still a medical model. The reviewed literature highlighted the need to establish how these policy reforms have translated at ground level to improve access to the rehabilitation services in the study area, especially within Primary Health Care and ensure that the needs of PWDs are met. The current rehabilitation model is not a holistic approach for rehabilitation services in a rural setting. Community-based rehabilitation (CBR) has been championed by the WHO as a rights-based, intersectoral approach aimed at social inclusion and the removal of barriers to people's full participation as citizens in society. The description of the South African health system appears to be divided along socio-economic lines, where

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in urban areas health and rehabilitation services are available and accessible versus the rural areas where these services are not easily accessible or are unavailable, and mostly, rural areas are poverty-stricken. The NHI feature of universal access further states that South Africans will have the right to access quality health services on the basis of need and not socioeconomic status. The instruments (Wheel of Opportunities; Kaplan's Conceptual Frame Work of an Organisational Capacity) used in the research study were used to reveal the current model of rehabilitation in the research rural area and highlight the extent of the implementation/ non implementation of the policies as discussed above.

Methodology

Study Design

This is a descriptive, exploratory, qualitative pilot study that explored the challenges of rural rehabilitation services experienced in a specific context. Descriptive, exploratory studies are essential when breaking new ground because they afford space for reflection about events and facilitate the probability of yielding new insight and an understanding of the area in the research process (Katzenellebogen, Joubert, Abdool-Karim, 1997). The qualitative research paradigm also involves the collection of a variety of empirical materials. According to Denzin and Lincoln (1998) it allows the researcher to deploy a wide range of interconnected interpretive practices, hoping always to get a better understanding of the subject matter being researched.

In this study, the knowledge about rehabilitation services from both the rehabilitation professionals and the clients has been explored and an attempt has been made to present the interpretation of rehabilitation services in the study area through the eyes of these individuals. The challenge with descriptive studies is related to the people who are being investigated – that they should be well represented (Sherry, 2016).

In this research study I gained an understanding of the experiences of participants within their natural environments, whereby I explored the phenomena in their

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context. Madwaleni area is a rural area situated in Kwa Bomvana a typical example of a rural area in South Africa. Below is a brief description of the study setting:

A Brief Description of the Study Setting:

This study is based in Mbashe, a municipality of Amathole District in Xhora (Elliotdale) in the Eastern Cape Province. Amathole District comprises four municipalities with a population of 1,678,942 of which Mbashe is one these municipalities. The census results for 2001 revealed that the highest proportion of people with disabilities (23.7%) live in the Eastern Cape Province (Statistics South Africa Census, 2011). The people who reside in the study setting are called AmaBomvane. Today many of AmaBomvane families live below the poverty line, and migratory practices have eroded the stability and backbone of the family unit and eliminated the socio-economic development level of their area (Jansen, 1973).

Madwaleni (a secondary) hospital and nine clinics render the health and rehabilitation services in the area (see attached map below). Rehabilitation professionals are based at this secondary hospital and from time-to-time visit the nine clinics surrounding the hospital as needed. Each clinic renders services to approximately six to eight clusters of villages. For this study, the researcher focused on the secondary hospital that renders rehabilitation services and the four conveniently selected clinics namely: Nkanya, Vukukhanye, Xhora and Hobeni. Below in Figure 1 is the map of part of Elliotdale, showing Madwaleni Hospital, the nine surrounding clinics, the villages, Mbhashe and Xhora River and part of the Indian Ocean. These four selected clinics give services to village wards of: Nkanya, Gusi, Xhora and Hobeni. Each village ward has an elected chief and a Councillor residing over the ward and clusters of villages linked to each ward.

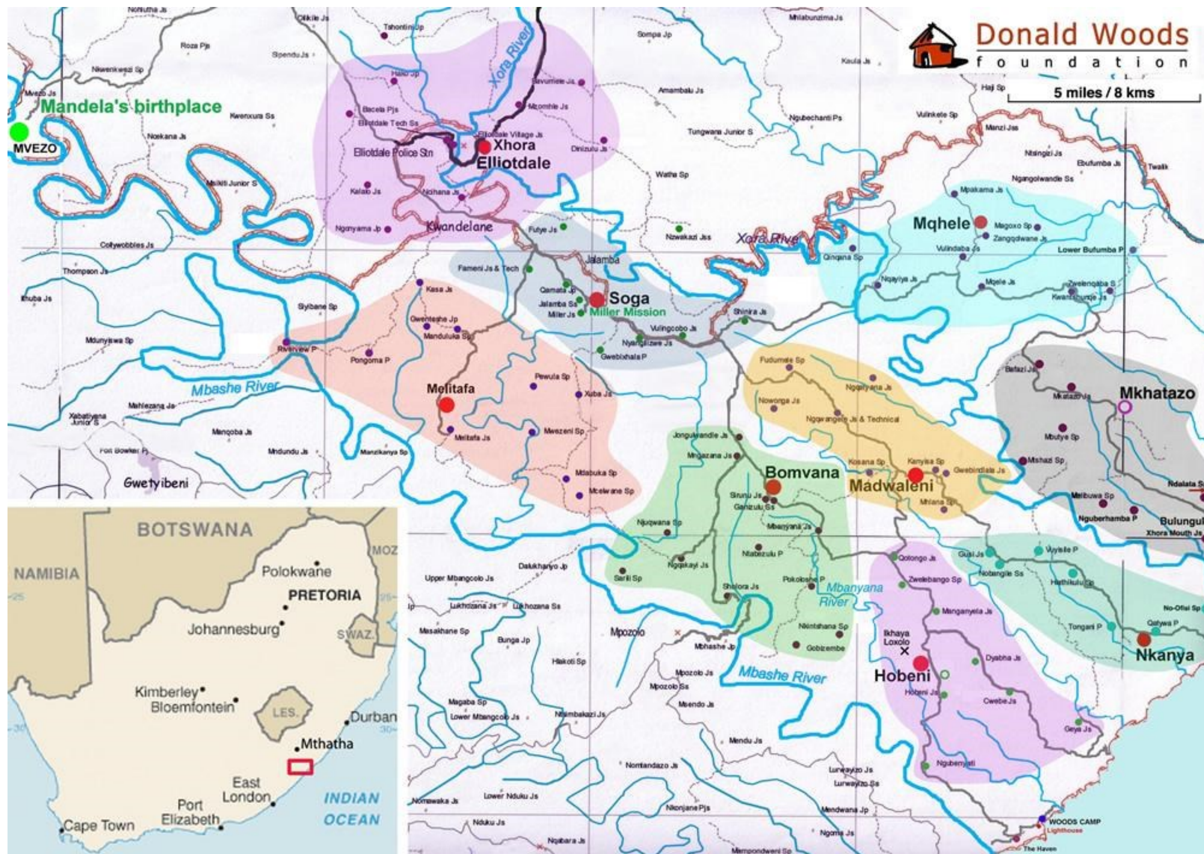

Figure 3: Map of part of Elliotdale, showing Madwaleni Hospital, the nine surrounding clinics, the villages, Mbhashe and Xhora rivers and part of the Indian Ocean (Donald Wood Foundation, 2006)

Study Population:

The study population comprised of:

- All rehabilitation health professionals, clinic nurse managers, doctors and administrative managers working at the secondary hospital in Madwaleni area, as it is the only secondary hospital in this area.
- All clinics that service Mbhashe Local Service Area and all clinical nurse practitioners in these nine clinics (there is one clinical nurse practitioner in each clinic). All Chiefs and Councillors attached to Mbhashe Local Service Area.
- All PWDs that reside in the cluster villages linked to the nine clinics that service the people from Mbhashe area.
- All family members and care givers of persons with disability in the Mbashe local service area.

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Study Sample:

The decision on who to include in the study sample was done during community entry whereby, the study samples in the study were selected purposefully to ensure that suitable participants who can answer the research question to get rich data were included. Below is the presentation of sampling strategy and the study sample for each group:

Study sample from the Secondary hospital: Health and Rehabilitation professionals

A visit to the secondary hospital to consult with all the rehabilitation health professionals, the nurse managers and doctors from clinical sections (medicine, orthopaedics, surgery, obstetrics & gynaecology) including the outpatient's departments was done. The aim of the study and the tools to be used was explained indicating their role in terms of participation. Their availability and time frames were negotiated with the health professionals and at some instances the health professionals could not be available due to patient loads.

The sample for the health professionals working at the secondary hospital, consisted of one nurse manager who represented all the nurses from the secondary hospital. The clinical manager represented all the doctors in the hospital as she was managing all the clinical sections of the hospital inclusive of orthopaedics, surgery, internal medicine, Obstetrics & Gynaecology; Rehabilitation manager, including the Chief Executive Officer of the secondary hospital, were selected to represent the sample from the secondary hospital. Below in table 1 is the presentation of the study sample of health professionals working at the secondary hospital:

Table 1. Study sample: Health professionals from secondary Hospital

Participant no	Title	Profession	Gender	Number of years
1	Chief Executive Officer	Professional Nurse	Male	More than 10yrs
2	Manager:	Professional Nurse	Female	More than

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	Nursing services	(represented all nurses in the hospital as there was one nurse in each clinical department and ward)		10yrs
3	Manager: Rehabilitation Services	Occupational Therapist	Female	3yrs
4	Clinical Manager	Doctor (represented all the doctors in the hospital as she was managing all the clinical sections of the hospital inclusive of orthopaedics, surgery, internal medicine, obstetrics &gynaecology)	Female	More than 5yrs

Source: Study sample from the community: Clinical Nurse Practitioner; the Chief; a representative of PWD

The four clinics out of the nine have been strategically and conveniently selected according to their location. Vukukhanye clinic, is embedded within the Madwaleni hospital; Hobeni clinic is approximately 30km from Madwaleni hospital; Xhora is approximately 40km from Hobeni and is on the main road to a referral hospital which is Mthatha Academic hospital, and Nkanya is the furthest from the secondary hospital approximately 45km away, with challenges of the Xhora river – which some of the communities have to cross and is usually overflowing during the summer season. Clinical nurse practitioners were drawn (one) from each of these four clinics. All clinical nurse practitioners have been in the clinic for more than three years. As mentioned above, each clinic has six to eight clusters of villages serviced by that clinic with a residing Chief and Chieftains and a councillor for each cluster of villages. The Chiefs were from the four conveniently selected areas within the villages of: Nkanya, Xhora, Hobeni and Gusi. Also, the representatives for persons with disabilities were from each of these four areas.

<u>The sampling process that was implemented</u>

Clinical nurse practitioners (one for each clinic: Nkanya, Xhora, Hobeni & Vukukhanye). The clusters of villages that are linked to the clinics each have a

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Chief/Chieftains, a Councillor and representatives of the people with disabilities. The councillors and the Chiefs were from the four conveniently selected areas within the villages of: Nkanya, Xhora, Hobeni and Gusi linked to each clinic of the four (4) conveniently selected clinics). The Chiefs and Chieftains - one from each area), there were two Chieftains from the Xhora area as the area was divided into two sections by the authorities and councillors, representatives of people with disabilities for each area. All the study representatives from the community were eager to participate. Below in table 2 is the sample of participants from the community:

Table 2. Study sample from the Communities of Nkanya, Xhora, Hobeni and Gusi

Title	Gender	How many
Chief	Male	3
Chieftains	Female	1
Nurse Practitioner	Female	3
Nurse Practitioner	Male	1
Representative of Persons with Disabilities	Male	4 (inclusive of 2 persons with paraplegia; 1 person with right hemiparesis from stroke, and 1 person with clubfoot.

Participants: Persons with disabilities

The researcher asked both the chiefs and clinical nurse practitioners to identify key informants who are people with disabilities in their area. The key informants were told that it is important for the study to have a good representation of all types of impairments, as a result, all types of impairments were represented. For example, physical disability; mental illness; blind; deaf and persons with epilepsy. It was also explained to them that, those with severe disabilities and/or are unable to speak for themselves, including disabled children, their parents, family members, or representatives may speak on their behalf. At the beginning of the research study, when the researcher struggled to get the required number of participants for each group, the researcher utilized snowball sampling method whereby the researcher enquired from the already available PWDs if they knew another person with the

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required type of impairment for inclusion into the group (Rubie & Babbie, 1993).

People with disabilities in each area were inclusive of those who were currently receiving rehabilitation; defaulters; discharged clients. Three clients in Xhora who required rehabilitation were discovered and referred to Xhora clinic; two clients in Nkanya area were referred to Nkanya clinic. People with disabilities who were residents of that particular village participated. Children with disabilities who are under the age of 18 years and those who are severely disabled and could not speak for themselves were represented by parents, caregivers and some by community members who are their neighbours. All the people with disabilities were willing to participate.

The researcher aimed to have approximately six to eight PWDs of mixed types of disabilities for each cluster of villages serviced by each clinic. The researcher ended up with ten PWDs for each village as the villagers who are disabled were bought along by their families, the families wanting to express their needs, their frustrations, perceptions and suggestions. This rendered four groups of ten PWDs – each group coming from each village cluster and the families of PWD.

Below in table 3 are participants who were people with disabilities, family members of people with disabilities and carers of people with disabilities.

Table 3. Participants: People with Disabilities (the four areas: Nkanya, Xhora, Hobeni and Gusi have been combined together)

Participant	Adult/ child	Type of disability	Gender	Number of participants per disability
	Children	Cerebral palsy(CP)	Female& Male	7 (3males and 4females)
	Adults	Paraplegia	Male	3
	Children	Paraplegia	Male &female	5
	Adult	Mental illness	Male &Female	5 (2 females & 3 males)
	Children	Mental illness	Male&Female	5(3 males & 2females)
	Adult	Epilepsy with mental illness	Male	1
	Child	Epilepsy with mental illness	Female	2

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	Adult	Post CVA with Hemiparesis	Male	5
	Adult	Rheumatoid Arthritis	Female	2
	Adult	Head injury	Male	3
	Adult	Mental illness	Female	2
Parents	Adult	Not applicable		5
Caregivers	Adult	Not applicable		20 consist of: Five caregivers of CP children with six neighbours accompanying. One caregiver of mentally ill adult. One caregiver of the epileptic with mental illness. Three caregivers of post head injured persons. Four caregivers for the persons with mental illness
Community members	Adult	Not applicable		23: Most of these community members were passing by and were called by the Chief's advisors to come and join other villagers.

The 4 tables for participants for each group of people with disabilities are attached as Appendix 6 (Hobeni, Nkanya, Xhora, Vukukhanye/Gusi)

Data Collection

Development of tools for data generation

The two (2) instruments that were mainly used to collect data had already been mentioned in the literature review (Wheel of Opportunities and Kaplan's Framework of Organisational Capacity) were used to develop tools for data gathering for the study. In addition, the research kept a field journal to record all required changes to the research process. The first instrument used was Kaplan's framework for developing the in-depth interviewing guideline (attached as appendix 2) to describe rehabilitation services in Madwaleni (used for the sample of health professionals in the secondary hospital & community-Nurse Practitioner; Chiefs and representative of PWD) and the second instrument was the Wheel of Opportunities (designed by Lorenzo & Sait, 2000)) which is based on the UN standard rules on equalisation of opportunities for people with disabilities, was used to develop the guideline for

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conducting focus group discussions (used for the sample of people with disabilities) (attached as Appendix 4).

Kaplan's Framework on organisational capacity

All six elements (as mentioned in the literature review) that Kaplan outlined were used as a guide in developing an interviewing guide (tool) to describe the rehabilitation services in the research site. The structures at Mbhashe Local service area that render health and rehabilitation services were regarded as a rehabilitation organisational structure and these were:

a. the secondary hospital
b. the four conveniently selected clinics and the village clusters linked to each clinic.

The interview schedule that was used to describe the status of rehabilitation services in this area from the sample of all rehabilitation health professionals based at the secondary hospital, nurse managers, doctors from each clinical department (including out patients department) and administration managers as well as Clinical nurse practitioners and Chiefs, Chieftains and councillors linked to each clinic of the four (4) conveniently selected clinics was developed from Kaplan's framework (1999).

The six organizational features of Kaplan's Framework have been operationalized in the interview schedule questions focusing on the understanding of rehabilitation by health professionals covering the following:

- The various roles and responsibilities with regard to rehabilitation of people with disabilities (PWDs).
- How are the rehabilitation services organized and contribute to the community integration and participation of the disabled persons?
- Whether the organizational structure for rehabilitation offers adequate resources to render a comprehensive programme.
- How does the organisations in the area that render rehabilitation services promote or hinder the development of rehabilitation services in the research.
- How do expectations of people with disabilities and their families affect the process of rehabilitation?

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- What lessons have been learnt from the partnership with rehabilitation health professionals with PWDs their families and communities?

The Wheel of Opportunities

The Wheel of Opportunities developed by Lorenzo and Sait (2000) as a participatory evaluation tool that identifies the UN 22 Standard Rules for the Equalization of Opportunities (see appendix 4) was used during focus group discussions with persons with disabilities.

The 12 spokes of the wheel of opportunities were used during the focus group discussion with people with disabilities in the four study areas. The two spokes focusing on health and rehabilitation were used to explore health and rehabilitation-related aspects while the other nine focusing on participation were used to explore how persons with disability see their level of participation – the access spoke was used to hear from participants about their access to equal opportunities (Sait & Lorenzo, 2000). The Wheel of Opportunities for participation was drawn on a flip chart (see figure 1 under literature review) and participants were asked to make a cross on each spoke to indicate the level of participation in each opportunity. On a continuum, low participation would be marked closer to the centre of the wheel, average participation around the centre of the spoke, and high participation closer to the outer edge of the wheel. A discussion was then held about the barriers and facilitators of each opportunity, and how low and average markers could be changed to high participation. Facilitators of accessibility to the components that lead to participation in their community were identified through the Wheel of Opportunities for participation.

Process of data collection:

The overall data collection period took three months. This study drew on multiple methods of information inclusive of in-depth interviews, semi-structured interviews, focus group discussions (FGDs), record reviews, and a journal.

Process of data collection using an interview schedule developed from information

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from Kaplan:

a) **The Rehabilitation health professionals, the clinical manager (doctor), the nurse manager. (In-depth interviews)**

The in-depth interviews were conducted in the Chief Executive Officer's (CEO) boardroom in Madwaleni hospital as recommended by the CEO. The in-depth interviews were conducted in English as the clinical manager and rehabilitation service manager's first language was English; the nurse manager and the CEO could speak both English and isiXhosa.

The interviewing guide (see appendix 2) developed from Kaplan was used to facilitate the interview. For the purpose of this study open ended questions were asked related to their perceptions of rehabilitation services of Madwaleni hospital and the current model of rehabilitation linked to the six elements of Kaplan that describes organisational structure. The open-ended questions that were asked by the researcher at the beginning of the interview guided the researcher to further questions. The health professionals were advised by the researcher to be honest when giving their perspective of the rehabilitation services/hospital so that if there is a feeling of dissatisfaction, it may be expressed with recommendations if possible. A tablet and a tape recorder were used to record the interviews, the reasons for the recordings were explained to the health professionals and were accepted. The clinical manager was the only doctor that could be part of the in-depth interview due to the shortage of doctors. There were only two doctors at the hospital, the other doctor was consulting patients in the outpatient's department. The clinical manager had to leave just before the end of the interview to attend to an emergency labour case. The interview session took an hour excluding the time consumed for the signing of the consent forms (attached as appendix 7).

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b) The Chief, Nurse Practitioner, representative of the people with disabilities (Semi-structured interviews) from the four areas: Nkanya, Xhora, Hobeni and Gusi and related clinics: Nkanya, Xhora, Hobeni and Vukukhanye

O'Donoghue confirms that a semi-structured interview means a face-to-face encounter between the researcher and participant's perspectives on their lives, experiences or situations as expressed in their own words. Semi-structured interviews allow greater depth than with other methods of data collection (O'Donoghue, 2007)

The semi-structured interviews with the Chiefs, the nurse Practitioner and a representative of PWD were conducted in isiXhosa as the participants and the researcher's first language is isiXhosa. The interviews took place in the clinic for Hobeni as advised by the Chief due to the shortage of nurses in the clinic but in the other three cluster villages the interviews were held in the Chief's homestead. In Hobeni clinic a consulting room was identified by the nurse Practitioner where the interview was held. The researcher, the Chief, the nurse Practitioner and the representative of PWD were all seated around the table. The representative of PWD was sitting on his wheelchair as he was a person with paraplegia (post-spinal-cord injury in the mines) but others on chairs. The interview session started with a short prayer by the representative of PWD as requested by the Chief. The data collection was done by the researcher.

People with disabilities (Focus group discussion)

A focus group is a group interview that brings about a group discussion. Corring, (1995) states that, focus group interviews work because they tap into human tendencies and are helpful when insights, perceptions and explanations are important. Focus groups also generate interactive data that results in enhanced disclosure, access to the participant's own language and concepts (Holloway & Wheeler, 1996). The researcher had an opportunity to explore the meaning and understanding that people with disabilities had of the current model of rehabilitation.

There were ten people with disabilities in each FGDs of the four (4) focus groups, one

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for each cluster of villages attached to each of the four clinics (see table 3 and appendix 6). Other participants were twenty (20) caregivers inclusive of five (5) parents of children with cerebral palsy as shown in table 3 and twenty-three (23) community members who were passing by and called by the chief's assistants to come and participate. The researcher conducted focus groups with the people with disabilities in a central place in the Chief's homestead (as it is the point entry in the rural villages and respected by villagers) where the majority of villagers sat on the grass (the Chief provided benches for those who were unable to sit on the grass). The focus groups took place in the morning session where for each group, the exact time to start the group was negotiated with people with disabilities and their families. They did not keep to the exact time as they first had to take care of other household chores before coming to the focus groups.

The focus groups for each cluster village started and ended with a short prayer as advised by one of the key informants from Nkanya cluster village. The short prayers were led by one of the elder men or women as recommended by the Chief of that particular area (Hobeni, Nkanya, Xhorha, Gusi/Vukukhanye)

The researcher personally conducted the collection of data and did not use a research assistant. The participants were informed by the researcher that the discussions would be recorded as the researcher had to listen to their responses at a later stage. A tablet was used to record the focus group discussion and it was shown to the participants as well as how it functions. The focus group guide used, was generated from the Wheel of Opportunities which was drawn on a flip chart. This focus group guide provided people with disabilities the opportunity to provide their perspective about experiences with their disabilities and the current model of rehabilitation. It was explained to the participants that there were no wrong or right answers, and that they needed to express themselves freely and comfortably when responding to the guiding questions of the tool. This explanation was important so that the researcher could formulate their own perceptions for each opportunity on the wheel (attached as

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Appendix 4)

The aim and purpose of the study was explained to them. They were reassured that confidentiality would be maintained at all times. PWDs were allowed to tell their stories uninterrupted on the activities/therapy/interaction that took place or currently taking place with rehabilitation services. The language of communication during focus groups was in isiXhosa, the researcher's and participants' first language.

The process of signing the consent forms was outlined from the beginning to accommodate the people with disabilities and community representatives. Forms were written in their mother tongue and for those who could not read the consent form, it was read to them. It was explained that they are not obliged to participate in the study, and they were made aware that if they changed their minds about participating they were able to do so and no action will be taken against them. The focus groups took an hour for each area and each focus group ended with a prayer by one of the elders.

Table 4: Summary Data Collection Methods

Instrument used to develop tool	Method	Group
Kaplan's Framework of an Organisational Structure	In-depth interview	Health professionals in the Secondary hospital.
	Semi-Structured Interview	Chief/Chieftain; Nurse Practitioner; Representative of persons with Disabilities
Wheel of Opportunities	Focus Group discussions	People with Disabilities

c) Record reviews:

The researcher viewed rehabilitation health professionals' records of clients that attend rehabilitation services with regard to number of patients seen monthly, type of conditions, frequency of attending rehabilitation services and those discharged from rehabilitation services. The files reviewed were selected amongst those files of the patients that were expected to return for follow up for continued rehabilitation as indicated by the rehabilitation manager. These files were a concern for the

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rehabilitation manager as some were last seen six to twelve months before the record reviews by the researcher, some not seen as often as preferred by the rehabilitation health professionals. The records that were reviewed in the rehabilitation department were those of adult and paediatric patients with the following conditions: Neurological conditions (Cerebral Palsy, Stroke, head injuries,); Physical conditions (Fractures, tendon injuries post repair); Medical conditions that would cause physical impairments (diabetes–amputations); Psychiatric conditions.

Below in table 5 is the information on the record reviews:

Table 5: Record reviews in the Rehabilitation Department in Madwaleni Hospitals. (Female = F; Male = M)

Record no.	Sex	Age	Impairment	Frequency of attending rehabilitation	Progress at time of reviewing the record
1	F	5years	Cerebral Palsy – spastic quadriplegia	Once monthly- home visits (which had stopped 6 months before the record reviews by the researcher	Could sit on a CP chair provided by the therapists. (Rehabilitation had stopped 6 months before the record reviews by the researcher).
2	M	15 months	Cerebral Palsy with flaccidity	Once monthly at Xhora Clinic during the outreach from Madwaleni hospital	Could sit supported in a CP chair provided by therapists
3	F	11yrs	Learning difficulty	Therapy had stopped 12months before record reviews,	The girl was attending a school close to her home, still in Grd1.
4	M	18months	Developmental delay	Once monthly	Pull to sitting from lying with assistance, provided with a chair for support
5	M	3months	Club foot	Once fortnightly at the clinic to adjust the splint.	Eversion of the foot was improving with support of the splint
6	F	62years	Stroke with right hemiparesis	Had an intense three weeks rehabilitation when she was admitted at the hospital (Siyaphila ward). Then discharged home, could not	Could turn herself in bed, pull to sit in bed with assistance and transfer to a chair, pull stand with assistance and walk with the aid of a quad-pod with support on the hemiplegic side

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				attend rehabilitation	
7	M		Lower limb Amputee above knee	Received rehabilitation for two weeks then discharged home	Provided with a loan wheelchair while waiting for the amputee wheelchair.
8	F		Rheumatoid Arthritis	Attending rehabilitation daily as she was still admitted at Siyaphila ward	She was Provided with resting splits to relieve pain as she was still in acute stage. She could manage basic activities of daily leaving, washing, dressing with assistance, feeding with adaptive spoons
9	M		Hand tendon injury post repair (in Mthatha then transferred back to Madwaleni)	Daily rehabilitation, was due for discharge in a week.	Recovering with active-passive flexion and extension of fingers.
10	M		Brain injury	Receiving daily stimulation	Disorientated in bed had difficulty to sit up.
11	M	19yrs (epileptic)	Burns	Could come for rehabilitation once a month.	Developing contractures of the shoulder and keloids around the shoulder joint
12	F	32yrs	Depression	Daily rehabilitation, admitted	Stable, participating in creative and re-creative activities with other clients.
13	M		Spinal cord injury	Daily admitted in Siyaphila ward for 2weeks.	Could manage transferring himself from the bed, chair to the wheelchair with assistance.

Summary of information that emerged from record reviews:

From the record reviews it emerged that, the patients had a set treatment program and were receiving rehabilitation in the rehabilitation department of the hospital on a regular basis. The progress made by patients was also recorded. The patients were discharged with a home treatment programme and a follow-up date for the therapists to monitor progress and review the treatment where necessary. Thirteen records were reviewed as shown on table 5.

Journal

The journal was used to capture the researcher's reflection on critical incidences

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observed related to the interactions with the participants and in the field. As well as the researcher growing in understanding of the current model of rehabilitation in the rural setting she identified barriers to implementation of the available policies to address rehabilitation for people with disabilities (PWDs). The researcher kept a reflective journal after each meeting with the participants from the four selected areas as a reminder of all the observations in the different four areas. Methodologically the journals contributed in documenting the fact that the Chiefs increased the number of participants by inviting more participants to the focus groups, so that more people could benefit, than the researcher had planned for. The researcher observed this indigenous characteristic of Traditional leaders and how to work with leadership in a rural setting.

Feedback workshops

After transcribing the information interviews and focus group discussion, the researcher went back to the participants, that is, people with disabilities, the rehabilitation health professionals, the doctors, nurse practitioners from the clinics, Chiefs/Chieftains, the Councillors and the representatives of the people with disabilities, and conducted workshops to confirm through consultative dialogues if what is documented by the researcher is a true reflection of the information they have given.

Data Analysis

Data Management

Data from the in-depth interviews for health professionals from the hospital were in English. The semi-structured interviews in the community, including the Chiefs, Councillors, Nurse Practitioners from the four clinics and persons with disabilities from the four communities and data from the focus group discussions was transcribed and translated into English as the focus groups were done in isiXhosa. The transcriber was the researcher herself for confidentiality. The data was kept under lock and key and only the researcher had access to data. The transcription was checked by the

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researcher to ensure that the information on the transcripts is the same as that on the audio-CD.

Content Analysis

All transcribed data were analysed by the researcher using content analysis. Content analysis is a research tool used to determine the presence of certain words or concepts within the data collected to assist the researcher to start making inferences about the information that is emerging in the data. The researcher firstly familiarised herself with the data to understand the overall meaning of the information (Barbie & Mouton, 2001). Secondly, the data was broken down into manageable categories which were later grouped and subjected to inductive analysis to identify emerging themes. These themes were presented with supporting statements drawn into narratives from process of coding and categorizing of data and direct quotes from the participants. In Holloway and Wheeler (1996), content analysis is referred to as the process of identifying, coding and categorizing the primary patterns within the data. For the data from the focus group discussions, elements of the spokes were used deductively as emerging themes, and the same process that was applied to the data for the in-depth and semi-structured interviews was used to break down data into manageable categories which were later deductively grouped to fit in and support the themes that were developed from the wheel of opportunities.

Further on, the analysed data was confirmed through consultative dialogues that the researcher held with participants to deduce whether they agreed on the analysed data and themes that emerged as well as supporting statements. Although themes were presented individually, the reader should bear in mind that there are interconnections as one theme influences and relates to the other themes.

Trustworthiness and rigour

The researcher established trustworthiness and rigour by using: Credibility, triangulation, confirmability and transferability:

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Credibility

In the semi-structured interviews, the participants were the clinical nurse Practitioner (provider of health services); the representative of PWD (recipient of health services including rehabilitation services); the Chief (a community leader). In the in-depth interviews, the participants were all health professionals who render health and rehabilitant services in the study area with the ability to provide credible information on their challenges and experiences with rendering the services, as well as the focus groups where the participants were people with disabilities themselves with their families and communities actively participating to provide credible information on their perceptions. The researcher continued to gather data until saturation was reached.

Triangulation

In the study the researcher made use of a combination of various sources for data collection i.e. focus group, recorded interviews, and journaling, so that the case could be illuminated from all sides. Four person/participant sources were used to collect the data namely: the rehabilitation health professional from the secondary hospital, nurse practitioners from each clinic, community representatives (Chiefs, Chieftains& Councillors) and people with disabilities. The greater the triangulation in research, the greater the confidence a researcher will have in his findings (Denzin, Lincoln, 1998). The rationale for this is that no single method alone can adequately treat all problems of discovery and testing. It was quite invigorating for me to hear people with disabilities in the focus groups expressing their views on how they perceived the current model of rehabilitation.

Confirmability

After the data collection phase, it was very exciting to share the experiences with the supervisor as the supervisor also shared her own experiences that were motivational, good or bad.

The analysed data were given to a researcher skilled in qualitative data analysis to

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check if there was agreement with themes. Pseudonames and anonymization of data was ensured and no real names of the participants were used in all data collection steps. The summaries of transcriptions were given to participants (health professionals) to verify if information was correct. This process ensured that my findings were an accurate interpretation of the experience and ideas of the participants rather than the preferences of the researcher. (Babbie & Mouton 2001)

Transferability

Extensive field notes were taken on the environment where the study took place, observation notes and on observations that may contradict my original theoretical ideas. A thorough description of processes and data is provided to allow judgements about transferability to be made by the reader. Purposive sampling was used to select participants to ensure information rich participants will be selected.

The supervisor was initially engaged in discussions regarding the data to give insights on the structure in which to logically present the data. The draft research report containing the analyses and conclusions was submitted to two supervisors for their critical evaluation for peer evaluation and to ensure the accuracy of findings.

Ethics

Ethical Scientific Relevance of the study

All the people with disabilities in this country have a right to access rehabilitation services. Rehabilitation Health Professionals also have a responsibility to investigate whether people with disabilities do have access to rehabilitation services irrespective of residing in a rural or urban environment, as they are advocates for people with disabilities (S.A., 1996). Rehabilitation is the key towards full community integration for people with disabilities.

Suitability of the investigator

I am a Rehabilitation Health Professional who had been directly involved in the rehabilitation of people with disabilities, who is currently the manager for

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rehabilitation and Disability services in the Province, responsible for the coordination rehabilitation and Disability services in the Eastern Cape Province. All the information gained will be used by the investigator to make recommendations that will improve the rehabilitation service delivery model in rural areas of the Eastern Cape Province.

Protecting the interests of the participants.

The research participants are people with disabilities who are recipients of the rehabilitation service and the therapists who render rehabilitation services to these people, the community representative including the families, neighbours and community-based representatives. It was explained to the participants that the aim of the study was to assist them and the government by gathering all the relevant information for better service delivery. The people with disabilities and the community-based representatives were also informed that there will be no compensation or extra grants given to them for participation, as the aim of the study was to assist in improving the quality of service delivery that they currently receive. When the researcher detected that persons with disabilities were not receiving the services they needed or were being mistreated at home or in the healthcare service, the cases were referred to the local social workers both in the hospital and the district services.

The in-depth interviews for the rehabilitation health professional took place at their hospitals and traveling expenses were not necessary. The people with disabilities, their families and the community-based representatives were interviewed at the Chief's homestead as it was a respected and private place, where the participants felt more comfortable. The real names of the participants were not used, and pseudonames were used to maintain anonymity and confidentiality.

Permission to conduct study from Stellenbosch University

Researcher obtained ethics approval to conduct the study from Stellenbosch University Health Research committee on 14 November 2016 ethics approval number

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S15/03/062. Once this was received application was forwarded to the Provincial Health Department which the study received on: 14 December 2016.

Conclusion of Methodology

This chapter provides a justification for a descriptive, exploratory, qualitative study which explored the challenges of rural rehabilitation services experienced in a specific context as an appropriate design for this study. It is a descriptive exploratory study that has used Kaplan's Framework and Wheel of Opportunities to gain an understanding from participants regarding rehabilitation services in the study area. Focus groups, semi-structured interviews and in-depth interviews were used as data generation methods. The data was analysed both inductively and deductively. The next section will present the findings of the study.

Presentation of Findings

This chapter present findings that emerged from the interviews (in-depth and semi-structured) and focus groups with rehabilitation service providers, persons with disabilities and their families, and community members in Madwaleni-Xhora. These analysed findings will be organised aligned with the objectives of the study which were;

- To describe the rehabilitation and health services in the selected area.
- To identify the key role players for rehabilitation services in this area (both community-based and institution based).
- To describe the rehabilitation pathways available within the health facilities and the community.
- To explore the challenges experienced by all role players delivering rehabilitation services in the study area.
- To determine the perceptions of people with disabilities with regards to the current model of rehabilitation in the study area.
- To make recommendations for addressing the challenges with regards to rehabilitation services in the study area.

1. **Describing the rehabilitation and health services in Madwaleni.**

This section describes rehabilitation and health services as provided in two available

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levels of care namely secondary hospital (also known as district hospital) and Clinics (primary healthcare level).

Rehabilitation and health services at the Secondary hospital

The Madwaleni hospital is a referral hospital for the nine clinics of Xhora area. The hospital consists of inpatient department with different wards viz, Medical; Surgical; Orthopaedics; Gynaecology and Obstetrics with female and male sections for each ward as well as Paediatrics. In the outpatient department, patients are consulted by doctors and nurses. The majority of doctors are from other countries and do not speak the local language. In the different outpatient departments, patients are seen by doctors and then referred to the rehabilitation department for further management. The rehabilitation department consists of Physiotherapy services; Occupational Therapy services but did not have the speech and audiology services at the time of data collection. The staffing comprised three occupational therapists and three physiotherapists.

The rehabilitation health professionals have developed an inpatient rehabilitation ward named Siyaphila ward. During in-depth interviews the rehabilitation manager (RM) in Madwaleni hospital explained:

> *This ward gives the inpatients an opportunity to receive intense rehabilitation whilst in hospital and also to be taught the rehabilitation home programme before they are discharged from the hospital. However, this inpatient rehabilitation programme is a limited period of time of two to three weeks and not all patients can be kept due to insufficient space and staff shortage***. (RM)**

The rehabilitation department consists of the Physiotherapy section, the Occupational Therapy section and the Speech Therapy section. There is a treatment area for each section, however, when the need arises, the patients are treated in the same area by all three rehabilitation health professionals or two rehabilitation health professionals may treat in the same area. The physiotherapy section has two treatment rooms, a

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gymnasium and a paediatric section. A section of the gymnasium is used as an office space shared by the three physiotherapists. The occupational therapy department has two treatment rooms, one room used for training the patients on Activities of Daily Living (ADL) (self-care activities) and a kitchen. The second room is a paediatric treatment area which is user-friendly for children. The occupational therapists share the open plan gymnasium with the physiotherapists. The patients' records are kept in the same records room where there are shelves for occupational therapy and shelves for physiotherapy records.

In the rehabilitation department the patients (referred from the outpatient clinics of the secondary hospital; or from the wards as inpatients) are registered, interviewed, assessed and then put on a treatment programme to come to the hospital for rehabilitation. There is an interdisciplinary practise in the rehabilitation department as some patients may require services from all the rehabilitation team members in the rehabilitation department, for example a stroke patient.

Rehabilitation Services Records: The rehabilitation health professionals in Madwaleni hospital keep patient records in the form of a file for each patient. These records revealed that they see both adult and paediatric patients. Paediatric conditions inclusive of cerebral palsy; learning disabilities; developmental delay; burns; club foot; premature babies. Adult conditions inclusive of psychiatry (depression, Schizophrenia, anxiety); head injuries; stroke; amputees; spinal-cord injuries; rheumatoid arthritis; osteo-arthritis; hand injuries; burns. The rehabilitation health professionals treat approximately one hundred patients per month. The rehabilitation health professional (RHP) during in-depth interviews from the secondary hospital confirmed:

> *On discharge, the follow up treatment sessions in the community is done by referring the patients to the nearest clinics. The rehabilitation health professionals then further consult the patients in the clinics, if the patients manage to access the clinics, if not, the rehabilitation discontinues and the*

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> *patient will not receive any further rehabilitation from home as there is no community based rehabilitation, no home visits, by the rehabilitation therapists.* ***(RHP)***

The only health workers that visit the homes are the community-based health workers from the clinics and the professional nurses from the Donald Woods Foundation. The Donald Woods foundation was set up in 2003 as a living memorial to the life of campaigning journalist, Donald Woods. This Foundation works to empower local people. A new head office was officially opened in May 2014 at Hobeni, one of the areas where data for the study was collected.

The rehabilitation health professionals also clarified:

> *We refer our patients to a nearest clinic and the patients will be seen at the clinic on the days of the outreach clinics by the rehabilitation health professionals.* ***(RHP)***

The patients from Vukukhanye clinic are the only patients who are seen at Madwaleni hospital as this clinic is embedded in the premises of Madwaleni Hospital.

Rehabilitation and health services at the clinics

The clinics are mainly run by nurse practitioners. These practitioners consult with the patients at the clinic and prescribe medication for the patients. When complications that are beyond the clinic's scope of practise arise, the nurse practitioner refers the patient to the secondary hospital which is Madwaleni hospital. The nurse practitioner **(NPH)** from Hobeni confirmed during semi-structured interviews:

> *There are other categories of nurses that work with me at the clinic namely two enrolled assistant nurses; three assistant nurses.* ***(NPH)***

The nurse Practitioners alluded to seeing persons with disabilities at these clinics as well, but access remains an issue. For instance, one nurse practitioner from Hobeni clinic stated:

> *People with disabilities do come to the clinic for consultation for medical*

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ailments sometimes but they do not comply with the clinic visits as scheduled. ***(NPH)***

Another nurse practitioner in Xhora **(NPX)** clinic explained:

People with disabilities experience difficulty in accessing the services at the clinic as well as their families do not manage to bring them to the clinic due to the poor infrastructure of the roads and transport that is not accessible for people with disabilities. ***(NPX)***

There are health practitioners doing community work in the form of home visits, as a way of bringing services closer to the people, however this is also limited as alluded to below by a nurse from Hobeni clinic:

There are community health workers in the community, but they can only monitor the treatment given at the time, and patients need further examination by professionals for the review of treatment. **(NPH)**

The Chief from Hobeni **(CH)** added:

Though the clinics offer health and rehabilitation services there are also the Khaya Loxolo and DWF, they do not offer any formal rehabilitation services but use both the clinics and the Secondary hospital to respond to the health and rehabilitation needs of persons with disabilities. ***(CH)***

This clearly indicates that the rehabilitation and health services in the clinic are still institution based and are not easily accessible to PWD. There is a vital need for these services to be brought closer to the people thereby improving access to these services.

2. Identifying the key role players for rehabilitation services in this area (both institution based and community based).

The key role players for rehabilitation services in this area are Rehabilitation Health Professionals (Physiotherapists; Occupational Therapists) who are based in the secondary hospital and from time-to-time visit the clinics as confirmed by the manager for rehabilitation services (**MRS)** stating:

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> *Visits to the clinics are done to render rehabilitation services, the total number of rehabilitation health professionals is six comprising of two permanent physiotherapists and one community service physiotherapist, one permanent occupational therapist and two community service occupational therapists. There are no speech therapists* and *no audiologists, this creates a gap in this area of rehabilitation.* ***(MRS)***

The nurse practitioner who is the first consultant at the primary health care level, that is the clinic, is a key role player at this level of facility. The staff compliment of the clinic comprises one or two professional nurses, two staff nurses and one or two assistant nurses. However, the Xhora Clinic is bigger (community health centre) than the other clinics and comprises of Eighteen (18) Professional nurses; four (4) Enrolled nurses and nine (9) enrolled nursing assistants. This means that there is a higher staff complement compared to other clinics.

The nurse practitioner from Hobeni **(NPH)** stated:

> *Most of the patients with disabilities who access health services from the clinic are known by us nurses in the clinic.* ***(NPH)*** *She also shared a wish:*

Home visits by the nurses for the patients with disabilities would make life easier for the patients with disabilities. She further mentioned:

> *They sometimes default their treatment for other ailments as they struggle to get to the clinic due to the bad infrastructure of the roads and the terrain from their homes to the clinics.* ***(NPH)***

The Chiefs; councillors and community development workers (CDW): In the communities for each village the point of entry are the community leaders. These community leaders know the villagers, including people with disabilities. As mentioned earlier, six to eight clusters of villages are serviced by each clinic, the interaction of the villagers with people with disabilities differs from each cluster village. The villagers also know each other very well. The researcher was informed by

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the villagers (who became the key informants) about the households with family members who were disabled. The Chiefs have also been identified as one of the key role players for rehabilitation.

The Chiefs also knew all the households of the village, the family members of the household including people with disabilities. This displayed a responsible leadership role by these indigenous leaders. Also, during the semi-structured interview session with one of the Chiefs, Nurse practitioner and representative of PWDs in Hobeni, the Chief **(CH)** was concerned and said:

> *The toilets that are provided by the municipality are not accessibility for PWDs in the village as well as the roads and transport.* ***(CH)***

He also stated:

> *There is a lack of support by Government for the NGO/DPO in the village called Ikhaya Loxolo. (adding) The Ikhaya Loxolo is a home for the children with disabilities as their parents and or caregivers struggled to look after these children. There are also no outreach services from the clinics to the Khaya Loxolo NGO both health and rehabilitation.* ***(CH)***

People with disabilities

The villagers who are patients are initially seen at the local clinics situated within that cluster of villages, for the purpose of this study they are seen in each one of the four conveniently selected clinics depending on the catchment area of that particular clinic.

The Nurse Practitioners stated (Hobeni, Nkanya, Xhora and Vukukhanye):

> *I see the patients at the clinic and then refer to the next level of care which is the secondary hospital. In the secondary hospital the patients are seen by the consulting doctor at the outpatient's department and then referred to other departments including the rehabilitation department for further management.* ***(NPH, NPN, NPX, NPV)***

The family members and other people from the community who brought the people

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with disabilities to the Chief's Homestead for the focus groups. The families and communities presented a lot of caring for their families and neighbours. They advocated for those who could not speak for themselves. The aunt of a child with cerebral palsy was interviewed as the child had difficulty with speech and could not express herself.

3. Describing the rehabilitation pathways within the health facilities and the community:

The Rehabilitation pathways within the health facilities.

This structure of Table 6, Table 7 and Table 8 was adopted from The South Australian Department of Health structure of Rehabilitation Pathways in their Stroke Unit (2010 page 5 of 9). (See appendix 5) and has been populated with the Rehabilitation Pathways in Madwaleni Hospital, the clinic and the community.

Table 6: Rehabilitation Pathways in Madwaleni Hospital

Outpatient department	Person with disability (PWD) is seen by the medical practitioner, receives acute treatment/ admitted and referred for rehabilitation. Some patients are sent directly to outpatient rehabilitation without being admitted to the hospital.
In the ward	PWD is seen by the rehabilitation health professional first time in the hospital ward and if requiring longer rehabilitation is sent to the rehabilitation department of the hospital and admitted at that level.
Within the rehabilitation department	PWD is assessed by the rehabilitation health professional and the rehabilitation treatment program will begin. PWD will be taken back to the ward. There are wards called 'Siyaphila' that are dedicated for patients who must receive rehabilitation for both male and female patients. The rehabilitation program will continue on a daily basis until the PWD is discharged from the hospital.
	PWD is provided with a treatment/exercise program to take home. The caregiver or family member (if available) is shown how to manage the PWD at home. PWD will be given an appointment to go to the nearest clinic for further rehabilitation. May be seen once a month/week/fortnight depending on the availability of the rehabilitation health professionals. When the condition of the patient needs a higher or specialised level of care, the patient will be referred to Nelson Mandela Academic Hospital or Bedford Hospital for the specialised treatment for example: Orthopaedics, hand surgery, burns, psychiatry and other specialised conditions.

Table 7: Rehabilitation pathway in the clinic

In the	PWD is seen at first by the nurse practitioner and then sent to the treatment room of the

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clinic	visiting rehabilitation health professional from the Secondary hospital.
	The rehabilitation health professional will continue with the program and may provide some assistive devices when applicable.
	PWD will go back home, when necessary the patient will be referred back to the Secondary hospital.

Table 8: The Rehabilitation pathway at the community

At home	PWD will sit/lie in bed/continue with activities or exercise program depending on his/her level of functional ability, family support, community support including the community leaders.
Community	Support groups in the villages where the support groups are established by the community leaders who are PWD themselves. The Khaya loxolo NGO in Hobeni village that keeps and look after children with chronic disabilities. The chronic conditions like, High Blood Pressure, Diabetes, HIv will be picked up by the Donald Woods Foundation's community health workers. Community Health workers are deployed from the clinics and the Donald woods Foundation.

The support groups are not established in all the villages where the research took place – Hobeni is the only village with a support group for people with disabilities. These are the current rehabilitation pathways in the study area at the hospital, clinic and the community.

The challenges experienced by all role players delivering rehabilitation services in the study area.

The role players delivering rehabilitation in this study are all the health professionals in the secondary hospital, the nurse practitioner from the clinics, the Chiefs as they most often take care of PWD (in their homesteads) who do not have families of their own and the representative of PWD who is a person with disabilities himself, but coordinates community projects for people with disabilities in the village cluster. Themes emerged from the tools developed from Kaplan's framework of an organisational capacity (1999**)** from both in-depth and semi-structured interviews. The views of the role players delivering rehabilitation in Madwaleni are presented in italics.

Themes that emerged from the in-depth interviews with the Health Professionals

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from the secondary hospital, inclusive of the rehabilitation health professional manager based at the secondary hospital, nurse manager, and chief executive officer, doctor who is the clinical manager in Madwaleni Hospital were:

- Understanding and interpretation of operationalization of rehabilitation services;
- Challenges Experienced by Rehabilitation Health Team in delivering rehabilitation;
- Absence of Community Based Rehabilitation in Madwaleni;
- Cultural differences as a concern of the rehabilitation health professionals and other health professionals;
- The absence of a proper referral system in place undermine comprehensive rehabilitation for mental health patients
- Lack of communication with the existing community-based NGOs
- Challenge of insufficient resources;
- Recommendation by the rehabilitation and health professionals in the hospital and clinic.

Below is the presentation of the above themes supported by statements that emerged from the categorization of data from participants and some direct quotes from participants:

a) Understanding and interpretation of operationalization of rehabilitation services.

This theme explains how rehabilitation is operationalised and practised by rehabilitation professionals at Madwaleni. This theme also reveals the dedication by rehabilitation health professionals on their responsibility of rehabilitating their patients and strengthening rehabilitation internally within the hospital. The rehabilitation health professionals seem to understand the need for stronger rehabilitation health systems with the secondary hospital. Since rehabilitation at Madwaleni seems to be institution-based there appears to be a need to create a space for patients that are discharged from the secondary hospital to have a longer period to receive rehabilitation. This would improve the rehabilitation discharge outcomes and ensure when patients are discharged from rehabilitation services are be able to participate at least in activities of daily living (ADL ward run by OTs). They also

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understood the possibility of not seeing the patient again once discharged. This statement is further supported by the statement below:

The rehabilitation manager explained:

> *We have a dedicated rehabilitation ward in the hospital named "Siyaphila" where we keep patients with impairments that need intense rehabilitation for one to two weeks and then discharge them to their homes.* ***(RM)***

The theme further expands on challenges experienced during the implementation of rehabilitation services due to heavy workloads and the distances patients had to travel and costs that linked to these appointments. Earlier in this study the levels of poverty in this area have already been highlighted. She further stated:

> *We give a follow up appointment to come to the hospital after a month. She further elaborated:* ***(RM).*** *Rehabilitation should continue daily but the patients cannot afford to come daily for rehabilitation services.*

The rehabilitation health professional highlighted the importance of teamwork in the rehabilitation of patients as supported by the statement below:

> *We work as a team in the rehabilitation department, with other team members who are doctors, nurses and the admin staff as well, as they are the officers who first register the outpatients when they come to Madwaleni hospital. (RM)*

This information from the interview made it clear that within the hospital, rehabilitation services are rendered in a team approach system but the service is limited to the hospital - an indication of an existing challenge of an institution-based rehabilitation service and a gap in the rehabilitation services in the study area. This raises questions with regard to the highest goal of rehabilitation which is community integration and support for the rehabilitation patients to reach this goal.

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b) Challenges Experienced by Rehabilitation Health Team in delivering rehabilitation:

This theme addresses the different challenges experienced by rehabilitation professionals in the management of patients, especially the area of home visits which they saw as limiting their scope of practise. They seem to understand the short period of time they are able to keep patients in the hospital. It came strongly from the rehabilitation health professionals:

> *Our inability to see our patients after discharge from hospital as often as we wish limits our scope of practise as the persons with disabilities are in the communities where they live and only hospitalised for a short period of time.* **(RM)**

They would like to start home visits, but their hands seemed tied in this regard as the model that is used by Madwaleni hospital is institution based. Since the building of the clinics, it continues to see itself as a secondary referral hospital with the clinics playing the role of primary health services, and with community health workers from the clinics being the key people that visit the homes of patients. The rehabilitation manager expanded:

> *We are passionate about home visits; home visits will make rehabilitation more effective, but this is not possible now. We need to work with CBOs; NGOs; Supporters to be able to cover patients in their areas where they live***. (RM)**

They seem to have started to think about how they could solve some of the challenges of home visits they are facing by suggesting the need for collaboration with CBOs and NGOs. They seem to think this will assist to cover the patients in their area.

c) Absence of Community Based Rehabilitation in Madwaleni

In the in-depth interview with the health professionals it became clear that the rehabilitation health professionals as well as the rehabilitation team, which includes

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some of the Doctors, are passionate about the community-based rehabilitation that is currently not established in the Eastern Cape Province. Community-based rehabilitation is a strategy within community development, where people with disabilities themselves and their communities will participate in their rehabilitation including the planning. The rehabilitation manager from the Secondary hospital explained:

> *Rehabilitation in the communities where our patients live is a strategy that would make our practise as rehabilitation Health professionals more effective.* ***(RM)***

The clinical manager (Dr) further asserted:

> *Our rehabilitation health professionals who come here annually for their community service will always raise a concern about the absence of a community-based rehabilitation in this area.* ***(CM)***

This was welcomed coming from this level of management of the hospital as the process of implementing such a model including resources linked to supporting that model will need to be approved from his office. The rehabilitation manager and the clinical manager strongly mentioned:

> *Community based rehabilitation would be ideal in this rural area for its communities as it will empower the communities and the people with disabilities themselves.* ***(RM and CM)***

The area of empowerment in rehabilitation is quite critical as many of the patients with disabilities and their families after a disabling incidence struggle to see how they will manage in the near future. Even those born with impairments and disability also struggle to see how they fit in a world that has been mainly designed for able-bodied people.

The rehabilitation manager also shared:

> *There is a need for trained rehabilitation auxiliary/assistant staff to support*

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the communities with rehabilitation programmes as well as the training of nurses in rehabilitation to assist for more insight.

She (Therapist from the Secondary Hospital) further recommended:

The trainees should be members of the local communities around Madwaleni. ***(RM)***

The above statement was rewarding to the researcher, it appears that both the rehabilitation professionals and the other health teams through qualitative enquiry are creating solutions for themselves (Rubie & Babbie, 1993)

d) Cultural differences as a concern of the rehabilitation health professionals and other health professionals:

This theme revealed that therapists have a role to play in the education of their patients and their families about their health conditions instead of associating the lack of knowledge with cultural differences. They would also learn from their patients understanding and interpretation of their conditions from the patients' point of view and understanding. It appears that there are cultural related tensions, as each seems to have a different interpretation of health and illness. This theme highlights that they also need empowerment with regard to the ideology and knowledge of the people in the rural communities.

The rehabilitation manager stated:

There are cultural differences between us rehabilitation health professionals and our patients and their families, they perceive mental illness as witchcraft, and we perceive it as a psychiatric condition. ***(RM)***

The therapist further expressed:

This sometimes creates tensions between the health professionals and the patients and families. ***(RM)***

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d) The absence of a proper referral system in place undermine comprehensive rehabilitation for patients with mental illness

The nurse manager, the CEO and the clinical manager raised a concern with regards to the absence of proper referral systems for their (psychiatric) patients with mental illness. The concerns were that the patients are not down-referred back to the original hospital when discharged from the mental health hospital (a referral hospital based outside Madwaleni). She saw this as negatively impacting on the patient with mental illness. Mental health patients are lost within the health system with no clear pathway that they can follow, as supported by the statement below from the nurse manager:

> *We do not have a proper referral system, and this disadvantages our patients especially our psychiatric patients, as they are lost with no follow up.* ***(NM)***

e) Lack of communication with the existing community-based NGOs

The CEO and the nurse manager shared a concern about lack of communication with existing non-governmental organizations which are the Donald Wood Foundation and Khaya Loxolo, a home for children with disabilities. Khaya Loxolo also seemed not to have a working relationship with the hospital management or vice versa. This theme reveals that the Secondary hospital and the NGO's work in silos an indication of lack of collaboration between health authorities and NGO authorities in the study area.

> *We do not have a good working relationship with DWF as they never shared information with each other that is, the hospital and DWF although they invited the management of the DWF. (****CEO and Nurse Manager from Secondary Hospital)***

It appears that although invitations have been sent to the DWF to join the Management meetings of the secondary hospital, they seem to have not attended these meetings. This poses a problem with regard to collaboration and gaining support from these community-based NGOs. Earlier the rehabilitation manager seemed to think

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and recommend that these NGOs could assist in bridging the gap of the absence of CBR. It is not clear how this will be achieved if they do not respond to the invitations.

f) Challenge of insufficient resources to support rehabilitation services

This theme highlights that this secondary hospital in the rural area is under-resourced for both material and human resources. This impacts negatively on services that are perceived as not immediately fatal to patients. Such services are not prioritized and more often fall out of budget lists when managers start scrutinising budgets allocated to them and aligning these against their own internal budgets. Unfortunately, the rehabilitation of people with impairment and disability is hardly seen as a priority by hospital managers. This is further supported by statements below made by one of the therapists:

> *We have a challenge of insufficient resources because of budget constraints. We get wheelchairs and hearing aids, but we need more resources for our patients, for example: splinting material and pressure garment material for the burn patients. We are understaffed in all the areas of rehabilitation, for physiotherapy, occupational therapy, speech and audiology services.* ***(RM)***

It appears that these budgetary constraints have a negative impact on the provision of assistive devices for persons with disabilities as well as materials for creating splints. These types of budgetary constraints are also visible on rehabilitation personnel with complaints in the numbers that are to deliver rehabilitation services.

g) Recommendation by the rehabilitation and health professionals in the hospital and clinic.

During the in-depth interview with the health professionals, as the themes emerged when they were expressing their challenges, they also came up with some recommendations which were as follows:

- They strongly support the training of rehabilitation auxiliary/assistant staff to support the communities with rehabilitation programmes as well as the

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training of nurses in rehabilitation to assist for more insight.

The manager for rehabilitation services mentioned:

> *We would appreciate the training of rehabilitation auxiliary or technicians, nurses to be part of the support programmes in the communities. There are more nurses in our health facilities than therapist, the training may bring more insight to rehabilitation for nurses.* **MRS**

- The auxiliary trainees should be identified from the same communities where people with disabilities reside.

  The **MRS** added:

  > *The trainees should come from the same communities as the persons with disabilities.* **(MRS)**

- The development of a Provincial Mental Health Policy that would accommodate the mentally ill patients.

  The nurse manager from the Secondary hospital raised a concern:

  > *Our mentally ill patients are often lost to find as we do not have a Provincial Mental Health Policy. This policy needs urgent attention.* **(NM)**

- A referral system between Nelson Mandela Academic and Madwaleni hospitals to accommodate the follow up of the patients who are mentally ill.

  The CEO from the Secondary hospital added:

  > *There is no referral system in place for the mentally ill patients.* **(CEO)**

Themes that emerged from interviews with the Chief, the Nurse Practitioner and the representative of people with disabilities.

Four key themes emerged from the semi-structured interviews in the community, inclusive of the Chief, Councillor, the Nurse Practitioner and the representative of people with disabilities in the four sites of the study area and these were**:**

- The need for rehabilitation services for PWD (Chief from Hobeni and Nkanya)
- Rehabilitation services are not available in the villages

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- People with disabilities are accepted by the communities
- A need for attention for Adults and children with mental illness.

Below is the presentation of these four themes with supporting statements and direct quotes from participants.

h) The need for rehabilitation services for persons with disabilities (PWDs) (Chief from Hobeni and Nkanya)

The Chiefs and the nurse practitioner could see that the clinic does not have enough capacity to accommodate the rehabilitation needs of people with disabilities. Rehabilitation services for persons with disabilities are done on an ad hoc basis with rehabilitation professionals visits to the clinics. The Chiefs alluded and said:

> *There is a great need for rehabilitation services for PWD especially children, they cannot even access the schools in this area. The nurse further stated that: the therapists do not come as often as they are needed by the PWD because of shortage of therapists*. ***(CH, CN)***

Already the Chief is pointing to problems of participation in school while the nurse practitioner is pointing to the rehabilitation needs that seem not to be covered by the primary health services at the clinic. It appears that rehabilitation goals are neither reached at clinic level nor at community level, as learners with disability are not integrated at school level.

i) Rehabilitation services are not available in the villages

Earlier themes from both the rehabilitation professionals have eluded to the need for community-based rehabilitation services while other themes pointed to the need to improve communication with the community-based NGOs. This theme further endorsed these concerns by highlighting the need for rehabilitation in the villages. The nurses in the clinics do see the absence and need for rehabilitation services in the villages where people live. The clinical nurse practitioner (from Hobeni) stated:

> *It would be better if these rehabilitation services were rendered where*

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people live so that the families can learn how to continue with rehabilitation for their relatives in the absence of therapists. **(NPH)**

The clinical nurse practitioner further pointed to an important aspect i.e. that of the family learning about rehabilitation services which would lead to continuation of rehabilitation, even when the therapist is not there, and this would improve the rehabilitation discharge outcomes.

j) <u>People with disabilities are accepted by the communities</u>

This theme is an indication that the villagers do respect people with disabilities. The representative of PWD (from Hobeni) shared:

We are accommodated when there are celebration or cultural activities in village as the food and drinks (Xhosa beer) are brought to us if we are unable to access the kraal. **(PWDH)**

Though persons with disabilities were able to be respected by the people in community, what is not clear is how this is translated to participation and full integration of the disabled people, as the people with disabilities from Hobeni questioned their level of participation in village cultural events due to access problems.

k) <u>A need for attention for Adults and children with mental illness.</u>

This theme revealed that in this rural area there are older people and children who do not have families to take care of them**.** The vulnerability of older people and children are some of the struggles resulting from the apartheid laws (Sherry 2016) which syphoned the middle generation from rural areas and left older people alone with young children (Sherry 2016). Additionally, HIV and AIDs seem to have negatively impacted the middle generation in rural areas. This leaves homes with no-one strong enough to support people with other impairments such as mental health problems. All three Chiefs and the Chieftain stated:

There are people with mental illness including both children and adults

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whom we found roaming in the streets with no one take care of. ***(CH, CN, CX, CV)***

The researcher enquired about the whereabouts of these people and the Chiefs and Chieftain explained:

> *People from the villages who are mentally ill mostly end up residing at the Chief's homestead or we the Chiefs need to find a home from the communities to look after them.* ***(CH, CN, CX, CV)***

5. The perceptions of people with disabilities with regard to the current model of rehabilitation in the study area.

As indicated earlier, the Wheel of Opportunities developed by Lorenzo and Sait (2000) as a participatory evaluation tool that identifies the UN 22 Standard Rules for the Equalization of Opportunities is the tool that was used during focus group discussions with persons with disabilities to identify barriers and facilitators in the environment for the disabled person.

The different opportunities represented by each spoke of the Wheel of opportunities are a basic human right for communities including people with disabilities which should be available and accessible. Two groups of themes that emerged from the focus group of people with disabilities guided by the wheel of opportunities revealed the following:

The first three group of themes were related to health and rehabilitation. People with disability shared their impression and perceptions on the current model of rehabilitation in the study area including abilities or inabilities of PWDs and their families to participate in their rehabilitation services. Three themes emerged with regard to the current model of rehabilitation and these are:

- The meaning of Health for people with disabilities.
- The understanding of the impact of access versus no-access to health and rehabilitation.
- Barriers to access rehabilitation and health services for PWD in the study

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area

Below is the presentation of these three themes related to health and rehabilitation and direct quotes:

a) <u>The meaning of Health for people with disabilities.</u>

This theme tries to identify what health means for PWD and also reveals the different perceptions of health for this community. In the focus groups with people with disabilities it emerged that people with disabilities have different perceptions about what health is or what it means for them. When they were asked what health means for them, disabled people from Hobeni mentioned:

> *I perceive health as the ability to wake up in the morning and perform my self-care activities without assistance.* ***(PWD from Hobeni****).*

While those from Xhora shared how they perceive health:

> *I perceive health as the absence of pain, if a person does not experience pain then the person is healthy even though the person has a disability.* ***(PWD from Xhora)***

Disabled people from Nkanya felt that the ability for a person to be healthy is influenced by observing and performing the ancestral rituals appropriately where a person is guided by the elders. **(PWD from Nkanya).**

In these three contributions, participation seem to be featuring quite strongly. Disabled people also seem to be throwing a spotlight on the fact of the meaning of disability and that to be disabled is not to be sick.

b) <u>The understanding of the impact of access versus no-access to health and rehabilitation</u>**.**

This theme reveals that people with disabilities, their families and communities know where to access rehabilitation and health services, but the challenge is to access these services. Though rehabilitation is seen as beneficial by people with disabilities gaining further access to these services is difficult due to money-related issues while others

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when at home, struggle to be motivated to continue with exercises. This further confirms what has been earlier mentioned that rehabilitation services are only limited to institution-based rehabilitation. The statements below confirm this thinking.

People with disabilities from Vukukhanye said:

> *We only received rehabilitation when we were admitted in hospital and after we were discharged from the hospital we could not access rehabilitation services from the hospital because we do not have money for transport to get to the hospital.* ***(PWD from Vukukhanye)***

They further mentioned:

> *The rehabilitation that I received when I was admitted at the hospital made a difference in my ability to function but when I was at home and did not have the courage to continue with rehabilitation as advised by the therapists at the hospital my conditions deteriorated.* ***(PWD from Hobeni)***

c) Barriers to access rehabilitation and health services for PWD in the study area

This theme highlights the barriers preventing PWD from accessing the rehabilitation services as perceived by people with disabilities. These problems ranged from expensive transport, to early discharge, bad road infrastructure making it impossible to reach the hospital and clinics as well as poor socio-economic conditions.

They shared:

> *Iimoto ziyabiza kakhulu ayikho imali. Kwakungcono esibhedlele, kodwa bashesha bathi ndiye ekhaya. (I cannot afford transport to go to hospital, I was progressing at the hospital, but I was discharged quite soon).* ***(PWD from Nkanya, Hobeni, Vukukhanye, Xhorha)***

They also stated:

> *The bad road infrastructure, the inaccessible public transport makes it*

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difficult for us to reach the hospital or clinic where the rehabilitation and health services are available.

Another PWD from Hobeni added:

Siyacela Mam usithethelele pha kwa Ncedo Taxi office bangasishiyi estopini kuba sikubazekile. (Please negotiate on our behalf with the Ncedo Taxi office for the taxi drivers not to leave us on the taxi stops on the road just because we are on wheelchairs)

The caregiver of a thirteen (13) year child with Cerebral Palsy shared:

My niece acquired the cerebral palsy at birth in Johannesburg where my cousin is working in a factory. My niece received rehabilitation as a baby and could sit, roll over and eventually could pull to standing with support. ***(Caregiver from Hobeni)***

The caregiver further stated:

Her mother had a challenge of finding a care giver in Johannesburg as a result the child was brought here to the rural area in Hobeni, for the grandmother to look after her at the age of two (2) years. Since the child arrived in the rural area, she never received any form of rehabilitation as the clinic and the hospitals are very far from home. The child's developmental condition is deteriorating, and I think that the reason is the absence of rehabilitation for my niece. ***(Caregiver from Hobeni)***

On the day of the focus group the child was sitting on a wheelchair and strapped around the wheelchair for support.

The following themes from the 4th theme to the 12th theme are related to the different opportunities for participation of PWD represented by each spoke of the Wheel of Opportunities which might or might not be available for people with disabilities at community level – these are the basic human rights for communities including people with disabilities which should be available and accessible. These themes are:

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- The meaning of a support system for persons with disabilities and their communities.
- Family life and personal integrity.
- The meaning of employment.
- The meaning of education.
- The understanding of social security and income maintenance.
- The meaning of culture.
- The meaning of religion.
- The meaning of sport and recreation.
- Public awareness,

Below is the presentation of the themes related to different opportunities for participation of PWD:

d) The meaning of a support systems for persons with disabilities and their communities:

This theme highlights the meaning of a support system for PWD and the appreciation that PWD have for the support they receive from their families. Hobeni was the only area that had a support group for PWD.

They shared:

> *Here at Hobeni we have our meetings at the Chief's homestead where we share ideas on the type of projects we would like to be involve in.* ***(PWD Hobeni)***

PWD from Vukukhanye further shared:

> *My family, my aunt and my neighbours help me. My aunt, mother and uncle help me push my wheelchair, but the roads are bad.* ***(PWD Vukukhanye)***

The community members in the study area perceive support as a gesture that should come from family, friends and neighbours but for the traditional leaders support for them is meant to come from the government. The Traditional Leaders from Hobeni and Xhora stated:

> *I do not see the support from government for people with disabilities as*

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government does not send the services to the houses of the people with disabilities, it is not easy for these people to get to the health facilities for rehabilitation services. ***(CH, CX)***

e) Family life and personal integrity:

This theme highlights that people living in the rural communities know each other; care for each other and are accommodative of each other, especially those in the same village cluster. People with disabilities from Vukukhanye shared:

I stay with my family at home. (Person with disability from Vukukhanye)

One of the caregivers shared:

I am the eldest at home and my younger brother has a disability (epileptic fits) we stay on our own but neighbours help us every day with what we need and check on us every day or invite us to come to their homes. ***(Caregiver from Nkanya)***

PWD from Nkanya, Hobeni, Xhora further mentioned:

When there are traditional events or rituals in the community we people with disabilities are accommodated by other men when we are unable to reach the kraal, they would bring the Xhosa beer to us. *(**PWD N, PWD H, PWD X)***

One of the PWD from Xhora argued*:*

Some of us PWD do not want to do anything for ourselves, we tend to be dependent on others even when we can do some chores for ourselves. ***(PWD X)***

He further mentioned:

We do not have a support group here but PWD in Hobeni do have one. We are supposed to love and value ourselves first.

It is clear from the above two themes that people with disabilities and their

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communities do have potential for development and an insight of their abilities although they are persons with disabilities.

f) The meaning of employment:

This theme highlights that PWDs in the study area perceived employment as coupled with a salary in monetary value. They shared:

> *Employment with no monetary incentive is as good as sitting at home with nothing to do*. **(From all four areas; Nkanya, Xhora, Hobeni and Vukukhanye)**

Although the majority of PWD shared the same perception as above, however one of the PWD from Hobeni shared:

> *The agricultural project that we had here at Hobeni made me feel like I was employed because we could produce vegetables to eat and sell to our communities at an affordable price. Unfortunately, that project is now inactive.* **(PWD H)**

g) The meaning of education:

This theme highlights that education means a positive change for a human life and that it is important for children to access it. Every child has a right to access education whether disabled or not, as was announced in the White Paper on Integrated National Disability Strategy (INDS). The strategy represents a paradigm shift away from perceiving disability as a health and welfare issue that identifies disabled people as ill, different from their non-disabled counterparts, and in need of care. Instead, it takes an integrated approach to addressing their broader social needs by defining disability as a development and human rights issue. A parent of a child with a disability strongly felt and shared:

> *Education is important for our children as it will help them to get jobs, we see on the television and also hear from the radios that people with disabilities do get jobs and are productive when they have skills to do the work but they must go to school first.* ***(Parent of a child with disability)***

A participant from the community shared:

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There are schools in the village but again the schools are far and the wheelchair cannot get into the classroom. (Community member from Nkanya)

A mother of a child with a disability shared:

I have to push my child to school on a wheelchair and come back to do the house chores which is a very strenuous exercise for me. ***(Parent from Vukukhanye)***

A caregiver of twins with intellectual disability said:

*My children went to school, but the teachers said they do not understand as their intellectual ability is below the others. (****caregiver from Hobeni)***

A 13year old girl with a disability shared:

My aunt had to look after others and could not push my wheelchair to school. (from Xhora)

Another Child with a disability (from Nkanya) also mentioned:

I have a wheelchair, but I cannot push myself to school the road is bad, somebody else must push me. ***(Child with disability Nkanya)***

This theme also reveals the non-participation of PWD, caregivers and communities in the education of their children.

h) <u>The understanding social security and income maintenance:</u>

This theme highlights that PWD, their families and communities know about the disability grant and they are able to access the grant. A PWD shared:

The nurse at the clinic assist us to get the disability grant. ***(PWD from Hobeni)***

The others further mentioned that:

I was assisted at Madwaleni hospital to get the disability grant. ***(A PWD***

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from Vukukhanye and Nkanya)

Another PWD added:

> *The community development workers and the councillors assist us to access the disability grant, they come to our homes to check if we have any challenges.* ***(A PWD from Xhora)***

In the four areas all participants in the focus groups gave an impression that they understand how to access the disability grant and were also receiving the assistance they need in order to access the disability grant.

i) The meaning of culture:

This theme highlights that: a) culture is an important and valuable phenomenon for people with disabilities in this rural area and b) the different cultural beliefs of communities in this rural area.

A PWD from Hobeni shared:

> *Culture is what old people practice and then tell us about the rituals that we must do and how we must do them. (**PWD Hobeni)***

A PWD from Nkanya said:

> *Culture is to respect the elders and obey their rules and you will be blessed.* ***(PWD Nkanya)***

He further stated:

> *We contact the elder men and women of the family to assist to follow the correct rituals according to our culture.*

A community member from Vukukhanye shared*:*

> *Some disabilities occur because some people don't obey the cultural rules and rituals as advised by the elders.* ***(community member Vukukhanye)***

A PWD from Xhora with a mental illness though stable, said:

> *Disability can be as result of witchcraft.* ***(PWD X)***

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This is an indication that communities in the study area have different cultural beliefs.

j) The meaning of religion:

This theme highlights the meaning of religion for people with disabilities and their communities in the study area. The PWD from Xhorha,Nkanya,Hobeni and Vukukhanye shared:

> *Religion means praying to God.* ***(PWD X N H)***

A mother of a child with disability from Nkanya shared:

> *I used to believe in witchcraft and I believed that I was bewitched hence I gave birth to a child with disability but now that I believe in God I have accepted my child and I have made peace with those that I used to believe that they bewitched me.* ***(mother of a child with disability Nkanya)***

k) The meaning of sport and recreation:

This theme highlights that the mindset of people with disabilities in the study area is that if you are in a wheelchair or have any disability you are unable to participate in sport and that, recreation is perceived as attending the cultural activities in the villages. PWD from Nkanya shared:

> *I can't play sport on a wheelchair.* ***(PWD Nkanya)***

PWD from Hobeni said:

> *We are not aware that we can participate in sport and our families are also not aware.* ***(PWD Hobeni). (***He also added: *)We participate in recreation by attending the cultural activities in our villages and we also receive the attention that other people receive. I do not see sport as form of rehabilitation as I am disabled and cannot participate in sport.*

A mother of a child with Cerebral palsy from Xhora said:

> *Sport is for children; my child cannot participate in sport as he has a disability.* ***(mother of child with cerebral palsy Xhora)***

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l) Public awareness:

This theme highlights that the PWD and their communities in the study area are aware of the public resources that are available in their communities. The environment where people have been raised plays a vital role when it comes to the understanding and knowledge of the available public resources and safety about social, scientific or political issue. PWD from Xhorha, Nkanya and Vukukhanye Shared:

> *I don't know of any DPOs or NGOs*

PWD from Hobeni shared:

> *I know Donald Woods Foundation, there were community health workers from the Foundation (oNomakhaya) and nurses who used to come to our houses whether disabled or not to assist us by monitoring our compliance with medication and clinic visits.* ***(PWD Hobeni)***

It is clear that when it comes to public awareness, the PWD and their communities from the different areas of the study area are not at the same level of awareness and the public resources are not available in all the four areas of study. As indicated earlier, Hobeni was the only area that had a non-governmental organization within the village.

The above themes have clearly indicated the limitations with regards to participation by PWD and their communities, where most barriers are as a result of government inability to provide the basic resources for communities.

Discussion of Findings

Introduction:

This chapter will discuss the findings that were presented according to the objectives of the study which are: identification of the key role players of rehabilitation in the study area; the rehabilitation pathways within the health facilities and the community; the challenges experienced by all role players delivering rehabilitation services in the study area; the perceptions of people with disabilities with regards to the current

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model of rehabilitation in the study area; and recommendations for addressing the challenges with regards to rehabilitation services in the study area. The tools that were used interchangeably in the study to highlight how rehabilitation services are rendered in Madwaleni will also be incorporated in the discussion.

1.Description of Rehabilitation and Health Services in the study area

Madwaleni hospital is a referral hospital as reflected on the findings of the study, meaning that, all the primary healthcare level facilities in the Xhora area refer patients to this hospital for further follow-up of their conditions. The hospital again has to refer back to the primary healthcare level. The interdisciplinary practise that the rehabilitation health professional had adopted had a gap because of the absence of speech therapy and audiology services.

When patients are discharged home from hospital, the rehabilitation services from the Siyaphila ward (dedicated for rehabilitation programmes) discontinue although the patients are discharged with a rehabilitation home programme. This discontinuation of rehabilitation services when patients are discharged home and the need for a community-based rehabilitation services in areas such as rural areas has already been mentioned by rehabilitation professionals such as Sherry (2015) and Ned (2017).

When they reach their homes they then do not receive the same support they received at the hospital. Also, at the clinics (down referral from the hospital) there are no rehabilitation health professionals based within communities. The availability of rehabilitation services at the clinics depends on the outreach services by the therapists from the hospital. Although these services may be available at the clinics the challenge is that PWD are unable to access the clinics. Today former homelands continue to have large backlogs in infrastructure and services, including roads, water and sanitation and electricity, and remain significantly more deprived than other parts of South Africa (Noble & Wright 2013).

As mentioned earlier in the introduction of the study, the therapists at Madwaleni are newly qualified graduates who need guidance in their practise of rehabilitation

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services in a rural setting. According to Sherry 2016, health services in rural areas experience a range of specific challenges including those common to rural and remote healthcare internationally, and locally specific issues. The former includes difficulty attracting and retaining staff, remoteness from professional support and referral services.

The therapists in Madwaleni predominantly speak English, a foreign language for the majority of the communities of Xhora, who have never been to school or attended school up to the foundation phase. This mostly poses a problem as the conversation between the therapist and the patient has to be interpreted. During this interpretation, some content is lost, and the patient may not understand or perceive what the therapist is trying to communicate. This will have a negative impact on the carryover of the home programme given to patients. Therapists are complaining of the lack of this carryover of treatment. Over and above the language issue, one of the big questions is the suitability of programmes the patients are given in relation to their home environment. Can this carryover treatment happen in their home environments? The lack of home visits will remain a big issue with regard to the suitability of the treatment programmes that therapists give to their patients to continue at home.

In Hobeni area there is a place called Ikhaya Loxolo a non-governmental organisation that cares for children with disabilities whose families are unable to look after them. This place does not offer any formal rehabilitation services. There should be a link between the secondary hospital's rehabilitation department and the Ikhaya loxolo, to monitor and empower the caregivers of Ikhaya loxolo on the rehabilitation of the children with disabilities. This indicates a gap and a lack of communication between the hospital and NGO within the same area. In South Africa the health sector is the primary provider of rehabilitation services, via public, private and non-governmental organisations (Sherry, 2016). From the above discussion it is clear that the rehabilitation services in the clinics and hospitals are institution-based and are not

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accessible for PWD.

The rural environment offers substantial physical barriers to mobility and functioning, with difficult terrain, long distances to amenities, lack of accessible transport and absence of services such as piped water and electricity. The complex socio-economic and cultural environment further adds to the likelihood that impairments will result in activity limitation and participation restriction (Duncan & Watson 2009). This impact of the environment to impairments and disability with high prevalence of disability in provinces such as the Eastern Cape, with many people living in rural areas, points to the need to strengthen rehabilitation services in rural areas.

The findings of this objective seem to point to the fact that it appears that the present focus for rehabilitation services in Madwaleni is still institution-based and dominated by the medical model with no clear and relevant models for rural rehabilitation and no attempt or effort to study the lives of rural people, their culture, function, with the goal of enhancing their functionality as this will have an impact on their quality of life.

2. **The key role players for rehabilitation in the study area (both community based and institution based).**

The key role players as identified in the chapter on findings as: The rehabilitation health professionals; nurses from the hospital; the doctors; the nurse practitioner; the Chiefs; Councillors and community development workers (CDW); people with disabilities; the family members and other people from the community. The interviews and the focus groups conducted with the role players of rehabilitation in the area revealed that there is no existing interlink and or interaction amongst the role players from the health facilities to the communities regarding rehabilitation understanding. Nor are there workshops related to assist health professionals outside the rehabilitation field on rehabilitation understanding. According to Hellander (1992), rehabilitation not only includes the training of disabled people but also intervention at societal level with elimination of physical and attitudinal barriers. Hellander further clarifies that this view of rehabilitation equalises opportunities,

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adapts the environment (for the benefit of the individuals with disabilities), promotes and protects human rights. The absence of this interlink as mentioned above seem to create gap that will not address Hellander's operational idea of rehabilitation. The good and positive aspect that beamed during the focus groups is the love, care and protection of people with disabilities by their indigenous leaders. The indigenous leaders were very visible and made suggestions of involving more people with disabilities and their families in the focus groups so that more information could be gathered by the researcher.

The Nurse Practitioner in the clinics strongly felt that the home visits by nurses from the clinic would be a positive benefit for their patients who are disabled as they are unable to access the clinics. The community health workers do visit patients in their homes to monitor the treatment, but the challenge is when the treatment has to be reviewed, which also requires an examination by a health professional. The indigenous leaders, the families and communities at large presented a lot of caring for persons with disabilities and for each other. The families, communities inclusive of the indigenous leaders as well and the most important key role players for rehabilitation – the PWD themselves – seem ready to receive empowerment and support from health professionals for the rehabilitation of those in need within their own spaces.

2. Rehabilitation pathways within the health facilities and the community

Rehabilitation is a team approach in the treatment of a person with an impairment or disability. In the secondary hospital, the researcher also found that, the health professionals work as a team and also maximally make use of available resources. Pathways are also the stages of the journey of the operations during the process of rehabilitation. The practise scenario in terms of rehabilitation pathways within the secondary hospital is well coordinated, but people with disabilities spend most of their lives in their communities and not in the hospital. There seem to be a huge gap within the pathways once the patients leave the secondary hospital. The same scenario

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applies when patients need to be seen at the clinic by the rehabilitation health professionals, if the challenges including distances, road infrastructure and socio-economic status manifest, then rehabilitation is discontinued. In the community that is, after patients have been discharged and are at home, the person with an impairment is alone or with the family whereby both need continuous education and support from the rehabilitation health professionals.

This journey is a process towards independence or full recovery if possible. Currently in Madwaleni the person in need of rehabilitation services will receive rehabilitation at the hospital and at the clinic, meaning that the rehabilitation services are institution based. As reflected in the literature review, the highest goal of rehabilitation is community integration, this integration needs to be effective in the communities inclusive of the families, the traditional leaders, other members of the community and the PWD themselves need to be empowered to participate in the rehabilitation of the individual. In this deep rural area of study, the community pathway is where the PWD becomes detached from the rehabilitation services as there is no existing structure to refer to when the PWD is discharged to go home. In an ideal situation the above pathways should be interlinked but practically the link is confined between the hospital and the clinic (institutions). As affirmed by (Mlenzana & Mji, 2010; Ned & Lorenzo, 2016; Ned, Cloete & Mji, 2017) there are no clear referral pathways to create a seamless service delivery machinery from institutions to the communities. In a nutshell there are no outreach clinics; no rehabilitation programmes; no home visits and community-based rehabilitation where you pull all the health professionals together, the communities, and people with disabilities themselves.

3. **Challenges experienced by all role players delivering rehabilitation services in the study area.**

The secondary hospital (Madwaleni) is the only hospital in a large, deep rural area and a referral hospital for all nine clinics in the area. In the operationalisation of rehabilitation services in the hospital, the rehabilitation health professionals

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established a ward within the hospital to give their patients an opportunity to receive rehabilitation before they are discharged home, this is meant to improve their rehabilitation discharge outcomes. However, this is not sufficient as the patients will eventually be discharged home and required to continue their rehabilitation. The challenges of the rehabilitation health professionals include:

a) discontinued rehabilitation services after the patients are discharged from hospital, which does not reflect the actual outcomes of the rehabilitation services they rendered. People with disabilities or impairment live with their families in their community area. They become hospitalised for a limited period then discharged home where they spend most of their time/lives. The rehabilitation health professionals strongly believe that home visits would make rehabilitation services more effective, but this is hindered by the inability to do home visit for their patients. They also felt that this limits their scope of practise. The rehabilitation team expressed their passion for their work and home visits but the lack of resources such as transport and staffing make it difficult for them to reach patients in their homes. They used to do home visits for children with cerebral palsy, but the lack of resources was a challenge. The socio-economic status of their patients exacerbates the impairment to a disability as the patients do not have money to regularly attend hospital for further rehabilitation.

b) insufficient resources because of budgetary constraints. According to the rehabilitation manager, they do receive assistive devices such as wheelchairs and hearing aids, but they need more for their patients, for example, splinting material and pressure garment material for burn patients.

c) absence of implementation of services according to the Community Based Rehabilitation(CBR) matrix includes rehabilitation as a specific activity within healthcare as well as a strategy whereby the persons with disabilities do not have an opportunity to be fully integrated in their communities and experience disadvantage of getting support for their rehabilitation. The concern about the absence of CBR in Madwaleni came strongly from all the health professionals as reflected in the themes

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that emerged from the presentation of findings and in this regard, the health professionals seem to be creating solutions for themselves.

According to Kaplan, (1999), the first three layers (Vision, Mission and Attitudes) of the hierarchy which are abstract, are essential for the development and functionality of an organisation structure such as the structure that offers rehabilitation services in Madwaleni. The health professionals in the study area seem to have a vision of wanting to see a CBR for the communities that they serve. The researcher now poses two questions: 1) What are the health professionals doing about this challenge? (mission) and, 2) Are they open minded, prepared and /or receptive towards the CBR philosophy which is about inclusion and participation of persons with disabilities and their families in the rehabilitation programmes (attitudes). The study area setting (see figure 3. under methodology) is an ideal Primary Health Care setting that needs positive attitudes of the role players that deliver rehabilitation and health services in the area to initiate the process towards the development of CBR with the assistance of the authorities of the Eastern Cape Department of Health. Central to this initiation of CBR programmes is the involvement and participation of persons with disabilities

d) cultural differences of rehabilitation health professionals and other health professionals with their patients. The health professionals generally have a role to play in this area as the patients have a different understanding and interpretation of health and illness from that of the health professionals. They would also learn from the patients their understanding of disability as a result of witchcraft. and not diseases so that they are able to empower them. This has to be a two-way process that is, health professionals should learn from their patients and patients need to be empowered about the medical conditions and how these medical conditions attack the bodies of the individuals including awareness, prevention and curation of the medical conditions. According to Mji, 2012 indigenous health knowledge informs people, especially those residing in the rural areas that there is a reason for a certain disease or illness that needs to be dealt with in a traditional manner whereby some rituals

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have to be performed.

Cultural belief systems are usually embedded and are an interpretation of how people of that context interpret health and illness, including wellness. This interpretation is linked to the response people will give when feeling ill, including having impairment and disability. The question now is, what is the cultural interpretation and meaning of impairment and disability to this community. If the highest goal of rehabilitation is community integration and participation of persons with disability within this cultural context possible – if not what needs to happen?

e) absence of a proper referral system. According to the health professionals in the secondary hospital the patients with mental illness get lost in the data base/records without a proper follow up. They then miss the opportunity of receiving psychosocial rehabilitation.

f) lack of communication with existing community-based NGO's. The health professionals unanimously voiced the need to work with the CBOs; NGOs supporters to be able to cover patients in their areas where they live. The hospital management further raised a concern that they did not have a good working relationship with the Donald Woods Foundation as they never shared information with each other that is, the hospital and DWF. Donald Woods Foundation is an NGO in the study area that renders health services in the communities whereby they visit the homes of all the communities in need of health services. The hospital manager felt that it would be important for DWF to collaborate with them so that there is transparency on the type? of services rendered by both the hospital and this NGO to avoid duplication of services.

Teamwork has been a strong point for rehabilitation health professionals to be able to render rehabilitation services in this secondary hospital despite their challenges inclusive of limited resources (equipment, transport for outreach and home visits reasonable accommodation for rehabilitation services). The challenges as expressed by the rehabilitation health professionals and the other health professionals seem to

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be requiring the attention of these health professionals themselves with the assistance of the authorities of the Provincial Department of Health. As Kaplan has eluded, the interpretation and translation of the mission, vision and attitude into action will assist the therapist in seeing how innovative strategies such as CBR could be implemented in the study area.

5.Perceptions of people with disabilities with regard to the current model of rehabilitation in the study area.

The instrument used (Wheel of Opportunities, Lorenzo & Sait) in this study to develop the tool to determine the perceptions of PWD with regards to the current model of disability in Madwaleni area, has revealed that the current model of rehabilitation has some gaps in the delivery of rehabilitation services in the study area. As reflected in the methodology and presented in the findings of this study, The Wheel of Opportunities has different spokes where each spoke represented a basic human right for PWD, whether or not available and/or accessible. Inaccessibility of rehabilitation services seems to be the highlight amongst the challenges for PWD in Madwaleni.

One of the principles underpinning rehabilitation services is equality where the National rehabilitation policy, (2000) states clearly that, all human beings are of inherently equal worth, are privy to equal rights and share the same responsibility. The policy further states that, human beings are born each a unique individual where each individual develop along different lines and each has different abilities. Even so, these differences do not make us unequal. Those who were previously treated unequally should be made to experience equality in their daily lives, by creating an environment that is conducive to acknowledgement and acceptance of differences (NRP 2000). People with disabilities in Madwaleni area perceive rehabilitation services as services that are only available in the hospital environment or setting. They confirmed in the focus groups that they could see improvement in their health and functionality when they were receiving rehabilitation services in the hospital but after being discharged from hospital they discontinued rehabilitation. The challenges they

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shared were inclusive of, socio-economic status, road infrastructure that is not conducive for people with disabilities, public transport that is not accessible for people with disabilities. The rehabilitation health professionals highlighted that patients in the hospital care including those who need rehabilitation only accept what is offered to them in terms of services/treatment without opportunities for asking? questions and according to the therapists, this is a concern that needs attention. (Education) People with disabilities in impoverished rural areas in South Africa struggle to access healthcare services despite the right to health established by the Constitution and the United Nations Convention on the Rights of people with disabilities (Sherry 2016).

According to Sherry (2016) health is the capability set which represents to a person or community the combination of beings and doings they most value and have reason to value, given their available resources and opportunities. Health is complex, multi-dimensional and personally defined. It includes both 'elementary' functioning, such as the ability to be free from disease and pain, and complex functioning, such as the ability to fulfil valued social roles (Ariana & Naveed, 2009).

In the focus groups, people with disabilities expressed the challenge of being unable to access the health services that are only available in health facilities (clinic and hospitals), due to the long distances to be travelled; poor road infrastructure; and inaccessible modes of transport. Some shared that they received some rehabilitation when they were admitted in hospitals but after they were discharged from the hospital, they did not receive any rehabilitation. They perceived the current model of rehabilitation as a service that is only available in the facilities and the urban areas. Health services in rural areas experience a range of specific challenges, including those common to rural and remote healthcare internationally, and locally specific issues. In the rural healthcare service areas, there is difficulty in attracting and retaining staff, remoteness from professional support and referral services as well as population access issues. Locally specific concerns include lack of managerial and administrative capacity, accountability and transparency in local government, deficits in key social

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determinants of health through deprivation, and socio-political dynamics (Gaede & Versteeg, 2011). Challenges with accessing adequate health and rehabilitation services may increase the likelihood that rural dwellers develop chronic illness and impairments and decrease the chance that they will be afforded the support and services they require(insert reference).

The highest goal of rehabilitation is community integration and participation of people with disabilities themselves in their rehabilitation. It has come clearly from the themes of the perceptions of persons with disabilities that there is a gap with the current model of rehabilitation. Persons with disability perceive rehabilitation as a service that is based within the institutions and, quite interestingly, they also argue that once they are not in the institutions or cannot access the institutions the rehabilitation discontinues and they understand that the discontinuation of rehabilitation leads to the deterioration of the condition and/or impairment which aggravates the extent of the disability. People with disabilities in the rural areas need empowerment.

The non-participation of caregivers, parents and communities of the study area in the education of their children is another issue for concern. Shipham and Meyer, (2002) highlighted the lack of education for disabled children in rural communities in The Winter Veldt in Gauteng. In their study they described the establishment of a community-based rehabilitation where they found 350 disabled children who needed schooling and no access to schools. In White Paper No.6, Margaret Hewitt (1999) also states that another factor that seems prevalent in successful inclusion models is the involvement of parents and families in the education of their children. Parents are viewed as valuable assets to the school community and should be encouraged to take an active role in the child's health, academic, livelihood, social and empowerment program. Parental involvement maximizes learning time, builds the student's self-esteem and focuses for individualized attention. Again, the issue of community-based rehabilitation comes as an important strategy that would be a vehicle to address the

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challenge of non-access to education for children in the rural areas amongst many other challenges as indicated in this study.

Limitations of the study

There were various limitations encountered throughout the study.

The researcher could not complete the pilot study in Amahlathi local service area as originally planned. The Chief Executive Officer of S.S Gida hospital strongly recommended that the researcher should meet with the hospital board to share the research idea, however, the postponement of these meetings consumed a lot of time as a result the researcher had to start the research in Mbhashe local service area.

In the Xhora area there are two Chieftains. As recommended by the councillor I had to meet with both and conduct the research in both areas. Unfortunately, the other Chieftain's adopted son from the community died and the Chieftain's assistants advised the researcher to discontinue.

The in-depth interviews were planned to be conducted with the nurses and doctors from the different departments of the hospital viz: Surgery; Orthopaedics; Obstetrics & Gynaecology; Medical; and Paediatrics, but due to the shortage of staff in the hospital the in-depth interviews were conducted with the Nurse Manager and the Clinical Manager (doctor). This means that the sample was smaller than planned.

Though the methodology designed for the study lends itself suitable for a description of rehabilitation services in the study area, due to the size of this methodology and that this is a research assignment, and although the researcher implemented the planned methodology, the level of depth and comprehension achieved renders this exploration a pilot study with need for a follow–up study for more in-depth enquiry.

Recommendations

According to the National Rehabilitation Policy a situational analysis that was conducted in 1997 confirmed that, rehabilitation services in South Africa are largely underdeveloped and quite inaccessible to the majority of the population, especially

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those who live in remote rural areas. The policy further states that, where services exist the focus is usually institution-based and as such the needs of the clients are not completely satisfied. Since then, when the policy was released for implementation, the Eastern Cape and other provinces did establish mechanisms to extend the coverage for rehabilitation services to the majority of the population, the poorest of the poor are the ones who struggle to access these services. The reasons for this are poverty related as well as the fact that services are concentrated at tertiary institutions and private service providers.

As indicated earlier in the literature review of this study, CBR provides and delivers effective rehabilitation services as it takes an inclusive development approach to working with persons with disabilities (Ned et al., 2015) that means inclusive of the people with disabilities themselves, their families and the communities in which they live in supported by the authorities including the government. It can be assumed that the numbers of people living with significant functional impairment/disability are increasing in South Africa, although precise figures are unknown. This strongly supports the notion that a rural rehabilitation service model inclusive of CBR is key, especially in the rural communities, as disability can be permanent, temporal or episodic (Sherry, 2016). The Eastern Cape Province is mostly rural which means the majority of the people in this province live in the rural areas.

I have observed that mental, neuropsychiatric and substance abuse (MNS) disorders have been excluded from the 2011 census, which confirms the tendency of South African Policy makers to interpret disability as a physical, biomedical phenomenon. The area of psychiatry/mental illness requires attention, and it is recommended that more research be conducted in this area in order to develop new policies and/or revise old policies to improve service delivery for mental illness/psychiatric conditions.

Rehabilitation is a team approach that requires all team members to participate, empowerment/training of nurses and doctors on rehabilitation as a concept of importance would be a strong recommendation. In the rural areas the rehabilitation

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health professionals are supervised mostly by nurses and doctors as experienced rehabilitation professionals are based more in administrative positions in the higher level of care facilities. The health professionals in the study area made some recommendations to the researcher after the presentation of their challenges as reflected in the presentation of findings. Their recommendations guided the researcher to make recommendations for this study.

The two most important objectives gained from others in the National Rehabilitation Policy for the purpose of this study were to a) improve accessibility of rehabilitation services for people suffering from conditions that can lead to disability as well as those living with disabilities; and, b) ensure participation of persons with disabilities in planning, implementation and monitoring of rehabilitation programmes. These objectives will be a guide to a suggested rehabilitation model that would bring about a rural rehabilitation model that would be accessible and effective for the benefit of PWD and their communities.

A presentation of the study and the study outcomes will be presented to the authorities of the Department of Health to share information, seek for support and resources to improve the current model of rehabilitation in the rural areas. The findings in the study area may apply in any other rural area with the same challenges.

Lastly, it is recommended that this pilot study and its methodology be used for a more in-depth future study in the study area.

Conclusion

This is a Pilot study that has used Kaplan's Framework for organizational capacity as an instrument to describe the rehabilitation services offered in the research site. As already mentioned under methodology, Kaplan derived criteria based on six elements that must be present for any organization to be effective viz, conceptual framework; organizational attitude impact; organizational vision and strategy; organizational structures and procedures; individual skills, abilities and competencies; material

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resources. This tool has assisted in revealing that the health facilities do not have sufficient capacity to render effective rehabilitation services. The wheel of opportunity is also the instrument that has been used and has focused on participation of persons with disabilities at community level. The perceptions of people with disabilities of the current model of rehabilitation are key and a very important yardstick to measure and/or evaluate the effectiveness of this model. As the slogan of people with disabilities states: "Nothing for us, about us, without us".

It has been repetitively alluded in this study that the highest goal for rehabilitation is community integration, this strongly affirms that community based rehabilitation is a priority for implementation in this rural area where this study took place. Jelsma, Maart, Toni, & Loeb, 2007 have affirmed that there is evidence that the persons with disability within the South African context especially those residing in the rural areas are heavily marginalised and lack community based rehabilitation services that could improve their lives and lead to community participation.

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APPENDIX 1

Approval Notice

Response to Modifications- (New Application)

14-Dec-2016

Gysman, Nozipiwo Joyce NJ

Ethics Reference #: S15/03/062

Title: Rehabilitation services in a rural setting of Amathole district in the Eastern Cape province: a descriptive exploratory study

.Dear MS Nozipiwo Joyce Gysman,

The **Response to Modifications -** ***(New Application)*** received on **10-Nov-2016**, was reviewed by members of **Health Research Ethics Committee 2**

via Expedited review procedures on **24-Nov-2016** and was approved.

Please note the following information about your approved research protocol:
Protocol Approval Period: **24-Nov-2016 -23-Nov-2017**

Please remember to use your **protocol number** (**S15/03/062**) on any documents or correspondence with the HREC concerning your research protocol. Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372 Institutional Review Board (IRB) Number: IRB0005239

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The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rds

APPENDIX 2

Participant Consent Form

PROJECT TITLE: Rehabilitation services in a rural setting in Amathole District in the Eastern Cape: A Pilot Study.

PRINCIPAL INVESTIGATORS: Nozipiwo Joyce Gysman

BACKGROUND

This is a study describe and explore rehabilitation services in a rural setting of Amathole District in the Eastern Cape Province.

DECLARATION:

I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT'S NAME: ……………………………………………………………..

CONTACT DETAILS: ………………………………..……………………………..

PARTICIPANT'S SIGNATURE: ……………..……………………………………..

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Date:…………………………..

Where the participant is incapable of comprehending the nature, significance and scope of the consent required or is under 18 years old, the form must be signed by a person legally competent to give consent.

NAME OF CONSENTER, PARENT or GUARDIAN:………………………………

SIGNATURE:……………………………………………………………………..

RELATION TO PARTICIPANT:…………………………………………………

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:………………………… Date:…………………..

Participant Information Sheet

Participant Information Study Title: Rehabilitation services in a rural setting in Amathole District in the Eastern Cape: A Descriptive Exploratory Study.

Name of Investigator: Nozipiwo Joyce Gysman

Name of Supervisor: Dr. Gubela Mji

This study is conducted in partial fulfilment of the M.Sc. Rehabilitation degree at the Centre for Rehabilitation Studies, Stellenbosch

1. **Research purpose and procedures**:
   This is a study describe and explore rehabilitation services in a rural setting of

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Amathole District in the Eastern Cape Province.

2. **Risks**: There are no anticipated risks specifically associated with the participation in this study.
3. **Potential benefits**: A potential benefit of participation in this research is to bring about the understanding of the existing rehabilitation service delivery model in a selected rural area of the Eastern Cape Province and be able to recommend or facilitate the process to put systems in place that may improve rehabilitation service delivery.
4. **Provisions for confidentiality:** Each participant will be assigned an identification number and no identifying information will be used in the data records. Names of specific organizations will also not be included. Hardcopy records will be stored in a locked file cabinet only accessible by the investigator
5. **Voluntary participation and the right to discontinue participation without penalty:** Participation in this study is voluntary. Refusal to participate will involve no penalty towards the individual. A participant may choose to discontinue his or her participation in the study at anytime without penalty and without having to give a reason for terminating participation in the study. Any significant new findings developed during the course of the research that may impact a participant's willingness to participate in the study will be provided to the participant.
6. **Contacts for additional information:** If the participant has any questions about the research or their rights as a research subject they may contact the explanation of whom to contact for answers to pertinent questions about the research and research subject's rights, and whom to contact in the event of a research-related injury to the subject.
7. **Termination of participation by the investigator:** The investigator has the right to terminate participation if the subject will not comply with the research protocol, if the researcher feels threatened, or if the researcher determines that it would be in the best interest of the subject and/or his/her family to cease participation.
8. **Permissions:** The investigator has obtained permission to conduct the study from Dr. Gubela Mji, Director, Centre for Rehabilitation Studies at the University of Stellenbosch. The study has also obtained permission from the Eastern Cape Department of Health.
9. **Access to transcripts:** All participants will have transcripts of their interviews made available to them and be allowed to make clarifications or delete any wording that may be perceived as identifying them.

APPENDIX 3

Interview schedule based on Kaplan for in-depth interviews with health professionals.

Guideline: 1 hour

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1. How do rehabilitation health professionals/ clinical nurse practitioners/ doctors/admin managers interpret and understand rehabilitation for PWDs.
   - How does this understanding impact on the activities and organizational development?
   - How these concepts link to advocacy and development?
   - Contextual issues – socio-economic, political (policies), cultural.
   - Disability, poverty and human rights?

2. What are the roles and responsibilities of members and staff at the different levels of the organizational structure with regard to rehabilitation of PWDs?

   - How is communication and information disseminated from National – provincial – local and vice-versa?
   - How is capacity building devolved to the local branches?
   - How effective has this been?

3. How do the activities of the organisation contribute to the rehabilitation and community integration of the disabled person?

   - What is the role of these activities in the rehabilitation and community integration of the disabled person?
   - How have the different strategies or tools have been effective e.g. day care centres, capacity building workshops, advocacy manuals?

4. How does the relationship between community-based organisations and the hospital, clinics impact on rehabilitation and community integration of PWDs?

   - Explore the nature of the relationship with Community based organisations and the hospital, clinics. How does this impact on rehabilitation and community integration of PWDs? .
   - Check the perception of the health professionals in the hospital, clinics towards the rehabilitation and community integration of PWDs?
   - How do the health professionals in the hospital manage to interact with the different racial groups and different cultural groups accessing health and rehabilitation services in the hospital?

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5. Does the organizational structure for rehabilitation offer adequate resources to render a comprehensive programme for the rehabilitation of PWDs in terms of?

- Structures and procedures
- Individual skills and abilities
- Material resources

6. How has the relationship of the organisations in the area that renders rehabilitation services (secondary hospital, clinics and disabled people's organisations) promoted or hindered the development of rehabilitation for PWDs?

- How did organisations in the area that renders rehabilitation services fulfil their promises towards PWDs?
- How have cultural factors influenced the delivery of services for PWDs Language, stereotypes and biases, images used?
- How did this impact on the delivery of rehabilitation services?
- How did the rehabilitation health professionals hinder or promote rehabilitation of PWDs?
- What changes occurred?
- What solutions/strategies that were generated?

7. How do the expectations of the PWDs, their families and community affect the process of rehabilitation of PWDs?

- How has rehabilitation health professionals managed these different expectations?
- How do the different expectations complement each other and influence outcomes?

8. What lessons have been learnt from the partnership of rehabilitation professionals with PWDs, their families and community?

- PWDs, their families and community as an indigenous unit?
- Potential to generate and contribute to indigenous knowledge systems related to solutions and strategies for the development of a rural rehabilitation model?
- Lessons about sustainabilit

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APPENDIX 4

Guide for facilitating semi-structured interviews with chiefs, chieftains, councillors, disability representatives and clinical nurse practitioners.

Who are the disabled people in your community?

What type of disabilities they have?

Where and how do they access health and rehabilitation services?

What are the barriers and facilitators to rehabilitation services?

How do you see their participation and community integration?

APPENDIX 5

Guide for facilitating FGDS with persons with disabilities using the wheel of opportunities.

The tool is used for community profiling to identify barriers and facilitators in the environment for the disabled person.

- ✓ **Health**: Are you able to access health services? If no, what prevents you from accessing the health services?
- ✓ **Rehabilitation:** For your disability did you get any form of rehabilitation? If yes, did the rehabilitation services make any difference to help you cope with your disability? If no, are you aware of rehabilitation services? Do you know where to access the rehabilitation services?
- ✓ **Support systems**: Do you get any support for your disability? If so, what kind of support? Who supports you? What kind of support do you expect to get?
- ✓ **Family life and personal integrity:** With whom do you stay at home? Does he/she assist you to perform your daily activities?
- ✓ **Employment:** Are you employed? if no, will you be able to cope if you could be offered a job? What type of work will you be able to perform?
- ✓ **Education:** Do you have schools in your village? What is your standard of education? Are you able /were you able to access school? If no, what prevented you from accessing school?
- ✓ **Social security and income maintenance**: Do you know about the disability grant? If yes, do you receive the grant? If no, do you know how to access the

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disability grant? What kind of assistance would need to able to access the grant?

- ✓ **Sport and recreation:** Do you take part in any sport activities? If yes what sport do you play? If no, what prevents you from taking part in sport activities? What do you enjoy doing when you feel like relaxing?
- ✓ **Accessibility:** Do you see your house/ village as an accessible place for you to move around?
- ✓ **Religion**: What does religion mean to you? What is your religious belief, can you tell me about it? Are you participating in religious activities in your community?
- ✓ **Culture:** What do you understand about culture? Do you see yourself as practising/obeying the correct cultural beliefs?
- ✓ **Public awareness:** Are you aware of any DPOs or offices in your area? If yes, will you tell what services are available from those offices?

APPENDIX 6

The Pathway: as adopted from South Australian Department of Health structure of Rehabilitation Pathways in their Stroke Unit (2010 page 5 of 9).

Comprehensive Stroke Unit	Person with stroke (PWS) receives acute stroke care, including rehabilitation from day one (refer to Acute Stroke Unit Protocols) until their acute phase is passed
Yes, Rehabilitation for all stroke patients.	PWS assessed in the CSU to receive rehabilitation unless he/she meet the exception rules. The default is that all PWS should receive rehabilitation unless the exceptions apply. This is based on the literature that confirms there is evidence that all can benefit from rehabilitation and there is no evidence that particular groups do NOT benefit from rehabilitation. The decision for the model of care for rehabilitation is driven by > client preference and need, i.e. ability to function in their own versus an alternate environment, as well as > expert opinion and

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	> best available evidence. The model provides flexibility and is inclusive. Decision making about where rehabilitation occurs is based on the Decision-Making Tool for Rehabilitation. This requires analysis of where the identified needs are best met for the various domains. The evidence supports that early supported discharge home is preferable if possible. The Decision-making tool becomes the Rehabilitation plan and forms the basis for all subsequent reviews.
Home	The aim for discharge (transition) is for the PWS to return home either directly from the CSU as early supported discharge OR via an inpatient unit. Access to rehabilitation either at home or as a day/out patient is available to all patients as appropriate. Home may be a residential aged care facility and if there is no access to rehabilitation or resources in aged care facility, then they may access other options as described.
Rehabilitation in the home	PWS receives (multi-disciplinary) rehabilitation in their home, with flexibility to be able to access day patient or outpatient services in a hybrid model. This option is preferred based on the evidence.
Outpatient Day patient	PWS is able to attend (day) hospital or clinic rehabilitation services as a day patient or an outpatient. Transport options are available should they be required
Inpatient Sub-acute	The PWS is assessed as requiring inpatient care using the Decision-Making tool for Rehabilitation. The PWS is transferred to a specialist rehabilitation centre where they receive care and regular assessments with the view to going home
Exceptions to receiving rehabilitation	Return to pre-morbid function: PWS has made a ‘full’ recovery in all aspects, such as functional (physical, communication etc), emotional/psychological and cognitive 2. Palliation: Death is imminent, refer to palliative care team. 3. Coma and/or unresponsive, not simply drowsy 4. Declined rehabilitation

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	All exceptions feed into monitoring/surveillance and re-entry so they can receive Page 6 of 9 rehabilitation should their circumstances change
Monitoring, Surveillance and re-entry	All PWS have ability to re-access any rehabilitation services at any time during their ongoing recovery or long-term care. Overall aim is to promote/maintain best level of function in all domains. Principles to drive processes > Focus on PWS and their supports > Available and accessible > Maintain relationship with expert team > Link with NSF registry > All information travels with PWS/family as well as maintained at the facility they attend. This includes discharge/transition summaries. This may also be held at web-based system in future. > Self-referral is available (via central number for appointment with closest facility/team) Two functions of monitoring, surveillance and re-entry 1. Monitor status/needs for change and update plan/pathway; > Improving → continue > Static – follow most appropriate path – continue or re-enter > Declining → re-enter pathway 2. Monitor secondary prevention/self-management. Two tiers of monitoring: 1. Complex - requires access to all/part of MD team 2. Simple – single discipline review (e.g. GP) Process is that review appointment is always scheduled at the completion of any stage in the pathway. The level of monitoring is also established as complex or simple at this time and the

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	appointment made with the relevant staff. The staff then utilise the Decision Making Process to evaluate across all domains and flag status/need.
Special need flags:	These flags are not exclusionary but may indicate more intensive rehabilitation or referral to specialist areas, such as psychiatry or complex medical. Some flags may be: > Pre-morbid conditions > Non-compliance > Decreased pre-morbid function > Decreased social support > Incontinence (x2) > Decreased engagement > Conversion disorders > Decreased accommodation options > Co-morbidities > Apathy

APPENDIX 7
The four tables for the four areas of data collection (Nkanya, Hobeni, Xhora, Vukukhanye/Gusi)

6.1: Nkanya

Partic ipant	**Adult/chi ld**	**Type of disability**	**Gender**	**Number of participants per disability**
	Children	Cerebral palsy(CP)	Female& Male	2 (1male and 1female)
	Adults	Paraplegia	Male	1
	Children	Paraplegia	Male &female	2
	Adult	Mental illness	Male &Female	2 (female & mals)

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	Children	Mental illness	Male	1 (male)
	Adult	Epilepsy with mental illness	-	0
	Child	Epilepsy with mental illness	-	0
	Adult	Post CVA with Hemiparesis	Male	2
	Adult	Rheumatoid Arthritis	Female	1
	Adult	Head injury	Male	1
	Adult	Mental illness	Female	1
Parents	Adult	Not applicable	Female	2
Care givers	Adult	Not applicable		5 consist of: 2 caregivers of CP children with 2 neighbours accompanying. One caregiver of mentally ill adult.
Community members	Adult	Not applicable		7: Most of these community members were passing by and were called by the Chief's advisors to come and join other villagers.

6.2 Hobeni

Participant	**Adult/child**	**Type of disability**	**Gender**	**Number of participants per disability**
	Children	Cerebral palsy(CP)	Female	1 (1female)
	Adults	Paraplegia	Male	1
	Children	Paraplegia	-	0
	Adult	Mental illness	Male	1 (male)
	Children	Mental illness	Female	2 (females)
	Adult	Epilepsy with mental illness	Male	1
	Child	Epilepsy with mental illness	-	0

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	Adult	Post CVA with Hemiparesis	Male	1
	Adult	Rheumatoid Arthritis	Female	1
	Adult	Head injury	Male	1
Parents	Adult	Not applicable	-	0
Caregivers	Adult	Not applicable		7 consist of: 1 caregiver of CP child with 5 neighbours accompanying. One caregiver of mentally ill children (twins).
Community members	Adult	Not applicable		8: Most of these community members were passing by and were called by the Chief's advisors to come and join other villagers.

6.3 Xhora

Participant	**Adult/child**	**Type of disability**	**Gender**	**Number of participants per disability**
	Children	Cerebral palsy(CP)	Female	2 (females)
	Adults	Paraplegia	-	0
	Children	Paraplegia	Male	1
	Adult	Mental illness	Male	1 (male)
	Children	Mental illness	-	0
	Adult	Epilepsy with mental illness	-	0
	Child	Epilepsy with mental illness	male	1
	Adult	Post CVA with Hemiparesis	Male	2

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	Adult	Rheumatoid Arthritis	-	0
	Adult	Head injury	Male	1
Parents	Adult	Not applicable	-	1
Care givers	Adult	Not applicable		4 consist of: 2 caregiver of CP child with 2 neighbours accompanying.
Community members	Adult	Not applicable		4: Most of these community members were passing by and were called by the Chief's advisors to come and join other villagers.

6.4: Gusi/Vukukhanye

Participant	Adult/ child	Type of disability	Gender	Number of participants per disability
	Children	Cerebral palsy(CP)	Female	2 (females)
	Adults	Paraplegia	Male	1
	Children	Paraplegia	Male	2 (males)
	Adult	Mental illness	Male	2 (males)
	Children	Mental illness	Female	1 (females)
	Adult	Epilepsy with mental illness	Male	1
	Child	Epilepsy with mental illness	-	1
	Adult	Post CVA with Hemiparesis	-	0
	Adult	Rheumatoid Arthritis	-	0
	Adult	Head injury	-	0
	Adult	Mental illness	Female	1
Parents	Adult	Not applicable	Females	2
Care	Adult	Not applicable		4 consist of: 1 caregiver

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givers				of CP child and 3 neighbours accompanying. One caregiver of mentally ill child.
Com munity member s	Adult	Not applicable		4: Most of these community members were passing by and were called by the Chief's advisors to come and join other villagers.