EXPERIENCES OF PEOPLE WITH PHYSICAL DISABILITIES WHO

PARTICIPATE IN THE COMMUNITY BASED REHABILITATION (CBR)

PROGRAMME IN OKAMATAPATI COMMUNITY, OTJOZONDJUPA REGION

A THESIS SUBMITTED IN PARTIAL FULFILMENT

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Tonderai Washington Shumba   October, 2011

DEDICATION

This thesis is dedicated to my lovely wife Chiedza and daughter Danniella.

It is also dedicated to my wonderful parents Syprian and Jane Shumba.

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My sincere gratitude is expressed to the following people and institutions

ABSTRACT

The concept of community based rehabilitation (CBR) today is that people with disabilities should have the right to a quality life. The help they need should be available to them, at a low cost. It should be offered to them and their family in a way that suits their usual way of living, whether in a village, a town or a city. There should be large transfer of knowledge and

skills about disability and rehabilitation to people with disabilities (PWDs), their families and the community.

The problem is that currently there is no evidence of the effectiveness of the Namibian CBR programme. This study aimed to explore and describe the experiences of people with physical disabilities in the CBR programme in the Okamatapati community. The objectives of the study were to explore and describe the experiences of people with physical disabilities who participate in the CBR programme in the Okamatapati community and to identify possible areas of improvement in the CBR programme in order to effectively address the needs of people with physical disabilities in Namibia.

This study utilized a research design that is qualitative, explorative, descriptive and contextual. The population in this study was all people with physical disabilities who are participating in the Okamatapati CBR programme. Purposive sampling together with a set of inclusion criteria were utilised to select the sample. Photo-voice method with follow-up group discussions was used to collect data. The photos were organised according to themes and sub-themes. Trustworthiness and ethical considerations were observed during all stages of the study.

The study revealed the following key themes: secure livelihood was viewed as an important entity to alleviate poverty; health services where health is viewed as a fundamental human right; environmental barriers where environment allows people to participate in a dignified manner with maximum independence; and HIV/AIDs and disability where CBR programme can be effective in raising the profile of disability in HIV/AIDS programmes and services.

The recommendations regarding areas of improvement could be considered to develop an action plan that would improve the quality of life of all people with disabilities.

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INTRODUCTION

"Not only do physically disabled people have experiences which are not available to the able-bodied, they are in a better position to transcend cultural mythologies about the body, because they cannot do things the able-bodied feel they must do in order to be happy, 'normal,' and sane….If disabled people were truly heard, an explosion of knowledge of the human body and psyche would take place" (Susan Wendell, n.d.).

1.1 Background and rationale

The concept of disability has evolved over a long time. Historically, the concept of disability was mainly understood in mythological or religious terms: people with disabilities were considered to be possessed by devils or spirits, for example. Disability was also often seen as a punishment for past wrong doing. Today some societies still hold these beliefs (World Health Organisation (WHO), United Nations Educational, and Cultural Organisation (UNESCO), International Labour Organisation (ILO), & International Disability Development Consortium (IDDC), 2010).

The nineteenth and twentieth centuries saw developments in science and medicine which led to a clear understanding that disability has a biological or medical basis. The medical model views disability as a problem of the individual and is primarily focused on cure and the provision of medical care by professionals. Later, in the 1960s and 1970s, the individual and medical view of disability was challenged and a range of social approaches was developed, such as the social model of disability. This social model shifted attention away from the medical aspects of disability and focused instead on the social barriers and discrimination that

people with disabilities face. Disability was redefined as a societal problem rather than an individual problem; solutions focused on removing barriers and social change, not just a medical cure (WHO, 2001). The disabled people's movement of the late 1960s in North America and Europe played a pivotal role in the change in understanding of disability. Disabled people's organizations focused on achieving full participation and equalization of opportunities for, by, and with, people with disabilities. The said organizations played a key role in developing the Convention on the Rights of Persons with Disabilities, which promotes a shift towards a human rights model of disability (United Nations (UN), 2006).

Today there are different definitions according to the different perspectives stated above. The International Classification of Functioning, Disability and Health (ICF), views disability as an umbrella term for impairments, activity limitations or participation restrictions, which result from the interaction between the person with a health condition and environmental factors, such as physical environment, attitudes, personal factors, age or gender (WHO, 2001). On the other hand, the Convention on the Rights of Persons with Disabilities, views disability as an evolving concept which results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. The Convention on the Rights of Persons with Disabilities describes people with disabilities as those who have long-term physical, mental, intellectual or sensory impairments (UN, 2006).

This study focused on physical disability as being one type of disability. Physical disability encompasses a broad range of disabilities that include visual impairment, hearing impairment, mobility impairment, traumatic head injury, and chronic illnesses. Physical

disability may be congenital, the result of injury, muscular dystrophy, amputation, or caused by a number of diseases, such as multiple sclerosis, cerebral palsy, heart disease or pulmonary disease (Goldstein, Simonds, & Sanders, 1994). People with physical disabilities experience dysfunctions, such as poor muscle control, weakness or fatigue, difficulty in walking, talking, seeing, speaking, sensing or grasping (due to pain or weakness), difficulty in reaching things, and difficulty accomplishing complex or compound manipulations (push and turn). Most people with physical disabilities have to rely on devices, such as wheelchairs, crutches, canes or artificial limbs to achieve mobility. It may be concluded that physical disability could lead to social exclusion, poverty, physical dysfunction or a combination of these debilitating conditions.

It is very difficult to estimate the exact number of people with disabilities throughout the world. However the number is increasing due to factors such as population growth, an increase in chronic health conditions, the ageing of populations, and medical advances that preserve and prolong life (WHO, 2006). More than a billion people (about 15.0% of the world's population) are estimated to live with some form of disability (WHO & World Bank, 2011). This is higher than the previous estimate of around 10.0% in the 1970s by WHO. It is estimated that there are 785 million (15.6%) people 15 years and older live with a disability (WHO, 2002-2004). Furthermore, WHO (2008) estimates a figure of around 975 million (19.4%) people. Of these estimates, 110 million people (2.2%) have very significant difficulties in functioning, and 190 million (3.8%) have severe disabilities (WHO, 2002-2004; 2008).

People with disabilities constitute the world's largest minority and an estimated 80.0% of people with disabilities live in developing countries, (UN, 2006). According to the Namibia

Population and Housing Census of March 2001 an estimated 91,516 (5.0%) of the total population of 1,830,330 are people with disabilities. Out of this population of people with disabilities, about 32,219 (or 37.6%) have physical disabilities and need orthopaedic technical services; physiotherapy; and occupational therapy services. The rural population of people with disabilities is 83.5%, with a rural to urban ratio of 5:1 (Ministry of Health and Social Services, 2006). A door-to-door disability survey, done by the Division of Rehabilitation in Okamatapapi during community based rehabilitation (CBR) training, reported that there are 66 people with disabilities in this region and 27 of them have physical disabilities (Ministry of Health and Social Services, 2010). These statistics clearly show a huge disability burden that Namibia faces, hence there is a need to address this problem.

People with physical disabilities need an improved quality of life. To achieve this, there is a huge need to use a CBR programme as a vehicle to improve their quality of life. The CBR concept was developed by the WHO at the time when primary health care (PHC) was proposed and accepted as the best way of promoting health in developing countries (Walt & Vaughan, 1981). Initially CBR was primarily a service delivery method that made optimum use of PHC and community resources. Its aim was to bring PHC and rehabilitation services closer to people with disabilities, especially in low-income countries. The early programmes focused mainly on physiotherapy, assistive devices, and medical or surgical interventions. Some also introduced education activities and livelihood opportunities through skills-training or income-generating programmes. This led to the first CBR Joint Position Paper by ILO, UNESCO and the WHO (WHO, UNESCO, ILO, & IDDC, 2010).

An increase in the global CBR programmes resulted in changes in the way CBR was conceptualized. Other UN agencies, such as the ILO, UNESCO, United Nations Development Programme (UNDP), and United Nations Children's Fund (UNICEF) became

involved, recognizing the need for a multi-sectorial approach. WHO in partnership with other UN organizations, governments and international non-governmental organizations, including professional organizations and disabled people's organizations, held an international consultation to review CBR. The report that followed highlighted the need for CBR programmes to focus on: reducing poverty given that poverty is a key determinant and outcome of disability; promoting community involvement and ownership; developing and strengthening of multi-sectorial collaboration; involving disabled people's organizations in their programmes; scaling up their programmes; and promoting evidenced-based practice (WHO, 2003).

ILO, UNESCO and WHO updated the first CBR Joint Position Paper to reflect the evolution of the CBR approach from services delivery to community development. This updated paper viewed the CBR concept as a strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services (ILO, UNESCO, & WHO, 2004). This Joint Position Paper recognizes that people with disabilities should have access to all available community services, such as community health services, social welfare and education programmes. The paper also recognizes that the CBR programme may help to improve the quality of life of people with disabilities.

In Namibia the CBR concept has evolved since 1990. Immediately after Namibia's independence in 1990, UNICEF, in collaboration with the Repatriation, Resettlement and Reconstruction Committee of the Council of Churches in Namibia, established an intergraded

area based programme (IABP) in Uukwaluudhi, in the Omusati region. The major objectives of the IABP were to empower the community to promote the rehabilitation of children with disabilities (Ministry of Health and Social Services, 2006). This children's programme was followed by a CBR pilot project in the Tsandi district, in Omusati region in 1995. In 1996, based on the findings of the Tsandi pilot project, the Okamatapati CBR programme was launched in the Otjozondjupa region. The programme included a CBR committee comprising 15 members who were either people with disabilities or family members of people with disabilities. The committee undertook to identify and refer people with disabilities, orphans, and vulnerable children, to support services, such as special schools, or to recommend them for disability grants. They also trained people with physical disabilities in their communities in basic home-based exercises they could perform with assistance from a medical rehabilitation worker who would visit them when transport was available (Ministry of Health and Social Services, 2006).

1.2 Statement of the problem

Several studies have shown the importance of evaluations of CBR programmes to monitor their effectiveness and relevance. Without evaluation, the impact of CBR cannot be confirmed and this information vacuum would negatively affect the credibility of the programme (Hartley, 2002). For this reason, it was deemed essential to explore the experiences of people with physical disabilities in Okamatapati to determine the effectiveness of the CBR programme.

Monitoring and evaluation of the Okamatapati CBR programme, to date, has focused on quantitative data. Although the Okamatapati CBR programme has been operational for more than 10 years, there are no records of qualitative assessments having been conducted. The

Okamatapati CBR programme aims to improve quality of life of people with disabilities (PWDs). Currently the CBR programme leaders do not know how the people with physical disabilities and, their carers, perceive the effects of the programme and whether there have been any changes in their quality of life. There is also limited information in the literature about the assessment of the self-perceived change in quality of life of people with disabilities participating in CBR programmes. Limited evidence is available about the efficiency and effectiveness of CBR programmes in Namibia.

In Namibia, no evaluative studies have been conducted thus far to document the experiences of people with disabilities in CBR. Therefore there is great need to explore and describe the experiences of people with physical disabilities, in the Okamatapati community, who are participating in the CBR programme.

1.3 Purpose of the study

The purpose of this study is to explore and describe the experiences of people with physical disabilities who are participants in the CBR programme in the Okamatapati community.

1.4 Objectives of the study

The objectives of the study are:

- ❖ To explore and describe the experiences of people with physical disabilities who participate in the CBR programme in Okamatapati community.
- ❖ To identify possible areas of improvement in the CBR programme in order to effectively address the needs of people with physical disabilities in Namibia.

1.5 Paradigmatic perspective

A paradigm is a framework, within which theories are built, that fundamentally influences how a person sees the world, determines perspectives, and shapes an understanding of how things are connected (Henning, Van Rensburg & Smit, 2004). Holding a particular world view influences a researcher's personal behavior, professional practice, and ultimately the position taken with regard to the research subject. Therefore paradigms influence the research question, the most relevant method, and the techniques for data collection, analysis and interpretation (Parahoo, 1997).

1.5.1 Meta-theoretical assumptions

Polit and Beck (2004, p.13) define an assumption as a "basic principle that is believed to be true without proof or verification". The meta-theoretical assumptions relevant to this study include: ontological, axiological, epistemological, and methodological assumptions. These are discussed below in terms of the concepts pertinent to this study.

1.5.1.1 Ontological assumptions

An ontological assumption enquires into the nature of reality which is "multiple and subjective, and mentally constructed by individuals" (Polit & Beck, 2004, p.15). The reality is that people with physical disabilities have different life experiences hence probably have different experiences regarding the CBR programme. Therefore professionals may, or may not, provide the expected quality of services to people with disabilities. It is, however, difficult to prove the effectiveness of the programme without exploring the experiences of people with physical disabilities who are participating in the CBR programme in Okamatapati.

1.5.1.2 Axiological assumptions

An axiological assumption addresses the role of value in an inquiry. The latter should be context bound to focus on subjective and non-quantifiable information (data) for capturing of individual aspects of phenomena in terms of individual experiences (Polit & Beck, 2004).

Exploring the experiences of people with physical disabilities who are participating in the Okamatapati CBR programme, would therefore serve as a resource to improve its effectiveness in the Okamatapati community as well as other CBR programmes across the country. It is argued that this study's value resides in an assessment of the programme; its successes and failures; and dissemination of the results to people with physical disabilities, their families, and the community, in terms of the significance of the CBR programme.

1.5.1.3 Epistemological assumptions

An epistemological assumption questions the relationship between the "enquirer and that being studied" (Polit & Beck, 2004, p. 13). The researcher is currently a CBR national program manager with the Namibian Ministry of Health and Social Services. The researcher does not have knowledge about the experiences of people with physical disabilities who are participating in the CBR programme in the Okamatapati community. To overcome this limitation the researcher used a photo-voice method to gain an in-depth understanding of experiences of people with physical disabilities who participate in the said CBR programme. The photographs that participants took and their interpretations were key to understanding their experiences of the CBR programme.

1.5.1.4 Methodological assumptions

This was a qualitative study and data were obtained through the photo-voice method. The research population was people with physical disabilities who are participating in the Okamatapati CBR programme. Methodological assumption focuses on analysis of the methods used for gaining the data (Cohen, Manion, Morrison, 2000).

A more detailed explanation of the methods used in this study is presented in Chapter Two.

1.6 Significance of the study

Since the researcher is a CBR national program manager it is anticipated that the findings of the study would add to all stakeholders using the information to improve the effectiveness of the CBR programme in the Okamatapati village and other CBR programmes in Namibia. In this way it should assist to develop good practice, and provide information which would enable the government to make informed decisions. In terms of the job description and duties of the researcher it is envisaged that the findings would lead to valuable insight and understanding of important issues about CBR programmes. The opportunity to learn from the actual lived experiences of the CBR programme's participants is invaluable.

It is envisaged that by participating in the study, participants might: become aware of elements of the CBR programme; be able to educate others about these elements; be sensitised regarding their rights to be heard; possibly gain confidence in their ability to assert ideas and engage in self advocacy; offer an opportunity to influence decisions that affect their lives and explore their own reality.

The benefits of this study in terms of the community would be: community members may gain an increased understanding and awareness of community strengths and struggles regarding the CBR programme and thus be better equipped to get involved and work toward change; community members could be armed with good information and be willing to educate and inform others about what they have learned; community members could advocate for a better CBR programme along with policies that support community members' health and well being; a sense of belonging and working together could be created and local community members could work with each other to use resources to address problems in ways that are appropriate to that area; genuine community involvement would be a respectful way of investigating community CBR issues.

1.7 Definition of central concepts

- ❖ Experience is defined as practical knowledge, skill or practice derived from direct observation of, or participation in, events or a particular activity (Merriam-Webster Online Dictionary, 2010).

- ❖ Community based rehabilitation (CBR) is a strategy for general community development that addresses the rehabilitation, equalization of opportunities, poverty reduction and social inclusion of all persons with disabilities (ILO, UNESCO, UNICEF & WHO, 2004).

- ❖ Physical disability is an inability or limitation in performing tasks, activities, and roles to levels expected within a physical and social context. Physical disabilities therefore include paralysis, weakness, contractures, amputations, tremors, spasticity and other limitations related to coordinated movement (Mann & Lane, 1995, p. 7). Physical disability encompasses a broad range of disabilities that include visual impairment,

hearing impairment, mobility impairment, traumatic head injury, and chronic illnesses (Goldstein, Simonds, & Sanders, 1994).

❖ Rehabilitation is defined as a combined and coordinated use of medical, social, educational and vocational measures to train or retrain an individual to the highest possible level of functional capacity (UNESCO, 1983).

1.8 Ethical considerations

The following ethical considerations were observed during all stages of the study:

❖ Approval to conduct the study was obtained from the University of Namibia and from the Ministry of Health and Social Services Research Unit (Annexure 1 & 2).

❖ To ensure confidentiality the labeling used in the report was totally different from that used during data collection and the organisation to prevent association. As documentary photographers, participants were told to respect the privacy of others.

❖ To protect them from harm, participants were informed of the potential risks and their freedom/right to withdraw at any stage of the study. The researcher arranged a debriefing and counseling session with the help of the Okakarara district social worker.

❖ Participation in the study was voluntary. A detailed explanation of the purpose of the study was provided to all participants; they were requested to sign a form acknowledging their informed consent. Informed consent was requested from the parent or guardian of all the participants who were less than 18 years old. The photograph subjects were requested to sign a form agreeing to be photographed and those who refused were not coerced. For children or youth under the age of 18 years, approval from a parent or guardian was sought. Participants assured the subjects that the photographs were not meant for dissemination and therefore no photographs would be shown without a subject's consent. The researcher assured the participants that the findings of the study would be used to help improve the CBR programme, and consequently their quality of life.

1.9 Summary

This chapter covers the background and rationale for the study. The research problem, the research purpose, the objectives, and the significance of the study, and the research ethics, are discussed. The research design and method are described in Chapter Two.

CHAPTER TWO

RESEARCH METHODOLOGY

When you see a man of worth, think of how you may emulate him. When you see one who is unworthy, examine yourself" (Confucius, n.d.).

2.1 Introduction

The background and rationale to the study were presented in the previous chapter. The research design and method are now discussed to help clarify the way the researcher implemented the qualitative research method in order to elicit the experiences of people with physical disabilities who are participating in the CBR programme in Okamatapati community.

2.2 Research design

Research design incorporates the sampling, the sources and the procedures for data collecting and the plans for data analysis (Fouché & Delport, 2002). Method selection remains a vitally important element of the research process. Failure to choose an appropriate method to meet the demands of a particular field of study or research aim can render a study meaningless (Robinson, 2003).

A **qualitative**, **explorative**, **descriptive** and **contextual** research design was used in this study.

2.2.1 Qualitative research design

A qualitative study draws data from the context in which events occur (Gorman & Clayton,

2005). Robinson (2003) states that individuals interpret the world in a way that their subjective experience of it influences the way in which people interact with one another. The researcher held discussions with participants to elicit their experiences with the CBR programme. To this effect, a qualitative study was relevant.

2.2.2 Exploratory research design

An exploratory research involves gathering preliminary information that will help define problems and suggest hypotheses (Kotler, Brown, & Armstrong, 2006). The overarching aim of the study being to find out more on the experiences of people with physical disabilities who are participating in CBR programme in Okamatapati community.

2.2.3 Descriptive research design

A descriptive research describes things, such as the market potential for a product (Kotler, et al., 2006). The experiences of people with physical disabilities, who are participating in the CBR programme in Okamatapati community, are described in this study.

2.2.4 Contextual research design

A contextual study includes conducting a study within its setting which includes the physical and social environment (Cresswell, 1998). Therefore in this study the data were collected through interaction with participants in their own setting, namely the Okamatapti community.

2.3 Research methods

Polit and Hungler (1997) define research methods as the steps, procedures, and strategies for gathering and analyzing the data in a research investigation. Research methods therefore include the following: study population, sampling procedures and sample, data collection, pilot testing, and data analysis.

2.3.1 Population

The research population is "the entire set of individuals about whom the reference will be made" (Pickard, 2007, p. 60). Strydom and Venter (2002) describe a population as all potential subjects who posses attribute in which the researcher is interested. They further highlight that the study population sets boundaries on the study units. The population in this study was all people with physical disabilities who are registered and participating in the CBR programme in Okamatapati. A door-to-door disability survey, done by the division of rehabilitation during CBR training in Okamatapapi, reported that there are 66 people with disabilities in Okamatapati; 27 of which are people with physical disabilities (Ministry of Health and Social Services, 2010). Table 2.1 below reflects the population and categories of people with disabilities in Okamatapati.

Table 2.1: Population and categories of people with disabilities in Okamatapati

Age range	Under 10yrs	10-20yrs	21- 40 yrs	41-60yrs	Over 60yrs
Cerebral palsy	2		1		
Adult hemiplegia			1	2	
Paraplegia			1	2	
Polio			2	1	
Others	3				
Amputation		1	3		
Arthritis					2
Clubfeet	2				
Other congenital deformities		3			
Others orthopaedic deformities	1				
Respiratory disorder	1		4		
Other medical deformities		2	5		

Intellectually challenged	4				
Strange behavior	8	4	6		
Developmental delays	2				
Speech, hearing, impairment		1			
Visual impairment		1		1	

Source: Ministry of Health and Social Services, 2010

2.3.2 Sampling and sample

Sampling is a process of selecting a representative portion of the designated population (Schneider, Elliott, LoBiondo-Wood, & Haber, 2003). For this study a non-probability sampling method (purposive sampling) was used. The inclusion criteria were: two participants from each of the three sides of the Okamatapati community; age range of 15 years to 65years; not visually impaired; not deaf and dumb; able to use a camera; able to describe his/her picture; be able to read, understand and write simple English; been involved with the CBR programme for at least one year.

A group of seven to 10 participants were suggested as an ideal size for the photo- voice method (Wang, 1999). Such a sample size is considered large enough to offer a variety of experiences and ideas, yet also allows enough time for each participant to contribute in a meaningful way. In addition groups of this size are small enough so that members are able to feel safe to share and take part in discussions (Palibroda, Krieg, Murdock & Havelock, 2009). For this study, a sample of only six (n=6) participants met the inclusion criteria as illustrated in Table 2.3. The sample size for the purpose of this study is illustrated in Table 2.2 below.

Table 2.2: Sample size

	Population Size	Sample Size	Representation of the Population
People with physical disabilities	27	6	22.2%

A profile of the participants is illustrated in Table 2.3 below:

Table 2.3: Profiles of participants

Participant	Age	Gender	Location	Years of CBR participation	Nature of Disability
1	24	Male	Central	2	Spinal cord injury: uses crutches
2	38	Male	Central	10	Stroke : uses crutches
3	34	Female	East	8	Cerebral palsy-limping of the left leg
4	40	Female	West	10	Right leg amputee: has artificial leg-prosthesis
5	29	Male	East	4	Limping of right foot
6	49	Male	West	9	Post-polio paralysis: uses wheelchair

2.3.3 Data collection method

The photo-voice method identified by Dr. Caroline Wang was utilized. Data collection involved taking photographs, participating in group meetings, recording discussions, guided dialogue, journaling, exhibition feedback and debriefing. Using community-based research activities, photo-voice is a method designed to empower members of marginalized groups to work together to identify, represent and enhance their community through a specific photographic technique (Wang & Burris, 1997). As a photo-voice participant, individuals share ideas and concerns about their experiences and their community. They also take on the role of photographer where they have the responsibility of capturing photographic evidence, assuming the role of co-researcher with responsibilities around setting research goals, data collection, data analysis and sharing research findings (Palibroda et al., 2009). A two-phased data collection was done according to a practical guide to photo-voice method (Palibroda et al., 2009). Phase 1 comprised of an orientation meeting, photo-voice process, group objectives, informed consent to participate, and photography. Phase 2 comprised of taking of photographs, collection, development, and reflection. The processes involved in the phases are described below.

Phase 1

Orientation meeting

A two day orientation meeting with the participants was done discussing the following aspects: photo-voice process; group objectives; informed consent to participate; how to use the camera; how to take photographs; subject matter and theme; special consideration and human subject.

Photo-voice process

Participants had a chance to learn more about the details of the photo-voice process. The central role of each participant and the value of what each person brings to the study were explained. Underlying issues around the use of the cameras in the community were discussed and they understood that they may not misuse this power; ethical concerns around taking photographs and the potential risks they may experience as a photographer, was emphasized during this discussion (Annexure 3).

Group objectives

Participants were informed on the objectives of the photo-voice study. They were told that the study was for academic purposes only. It was important to develop framing questions to serve as guidelines for participants in identifying potential photographic subjects that would be meaningful for them and to address the objectives of the research. The researcher provided three concise questions that targeted the objectives of the research but at the same the questions were broad enough to allow participants to explore and share their unique voice, and to state what they think needed to be known. The researcher explained the framing questions that would guide the participants in exploring their experiences with the CBR programme using the photo-voice method.

The framing questions used by the participants in this photo-voice process were:

❖ What activities best show your positive experiences with the CBR programme in your community?

❖ What new change has been brought about by the CBR programme?

❖ What do you think still needs to be addressed by the CBR programme in your community to make the environment friendly to people with physical disabilities?

Informed consent to participate

Participants were invited to participate voluntarily. The researcher guided them through the informed consent form. Participants were told that participation was voluntary and that they may discontinue at any time throughout the study (Annexure 4).

Photography

A local photographer was invited to attend the meeting as a guest speaker to share his professional expertise on: how to use a camera; how to take photographs; subject matter and theme selection; special consideration and human subjects.

❖ How to use the camera: Most of the participants had little or no experience using a camera. To ensure standardisation all participants used the same make of disposable camera containing preloaded 27 exposure film. The photographer explained specific details about the camera, for example, how and when to use the

flash, how to advance the camera to take the next picture, how to handle and safely store the camera.

❖ How to take photographs: The photographer spent time with the group exploring specific techniques. Two cameras were set aside for practical. Participants gained knowledge in photographic techniques like lighting, balance, contrast, composition, capturing the viewer's attention and other photographic techniques.

❖ Subject matter and theme: Some participants felt hesitant to begin and were unsure about how to capture photographs of people with disabilities. The researcher encouraged them to try this new and creative approach. The photographer suggested ideas about how participants could arrange photographs to represent their ideas and how they could capture images that are unplanned and natural, yet perfectly represent an experience with the CBR programme. This discussion was intended to make participants feel that there is no right or wrong image to capture a subject, but rather prepare them to take better pictures. The aim was to capture both the strengths and the weaknesses of the CBR programme as they experience it.

❖ Special consideration and human subjects: Participants were informed about the ethics of taking photographs of other people. The photographer and the researcher practiced with the participants on how to obtain informed consent of people as subjects of photographs and how to use a written consent form. Participants were then issued with photo release forms for subjects to sign (Annexure 5).

Each participant was issued with the following materials:

- ❖ 1 x 27 exposure disposable digital camera.
- ❖ Photo reflection sheets to record their experiences as reflected by the photographs taken (Annexure 6).
- ❖ Photo-release forms for the photographed subjects to sign as consent to be photographed.
- ❖ Handout on ethical considerations that participants needed to adhere to throughout the process.

A work plan with deadlines was presented to participants and agreed upon (Annexure 7).

Phase 2

This phase involved taking of photographs by the participants, collection of the cameras and signed consent forms, development of the exposed film, and reflection. There was a five-week timeline. Participants were allowed eleven days to take their photographs and to return their cameras and the subject release forms to the rehabilitation instructor for that district who then gave them to the researcher. About midway through the time period, the researcher telephonically reminded the participants of their deadlines and gave advice where necessary. After nine days the researcher received the cameras and then had the exposed films processed (developed). Each participant's set of photographs was saved and coded on separate compact discs (CDs). This master set of CDs was retained in safe-keeping by the researcher. Processing of the photographs took two days.

During week three the first day was a one day meeting between the researcher and the participants to discuss the photographs and note areas that needed to be improved in photographing. The researcher supplied the participants with another set of photo-voice materials (27 exposure digital camera; photo reflection sheets; photo-release forms; a hand-

out on ethical considerations). This was to refine their photographic shooting and their skills of photo-voice. The participants were given a ten day deadline to submit the cameras for film processing. After this deadline the researcher received the cameras and then had the exposed films processed (developed). Each participant's set of photographs was again saved and coded on separate compact discs (CDs). This master set of CDs was retained in safe-keeping by the researcher. Processing of the photographs took two days.

During week five the participants were allocated three days to select six photographs from the two CDs that best responded to the initial framing questions, and, that they were willing to share. The local councilor's office and the local primary school were requested to allow the use of their computers as the images of each participant`s CDs needed to be viewed in order for them to select the photographs they considered to be the most significant and meaningful to describe the CBR programme. The selected photographs had to be suitable to share with a broader audience because of the story each one told or the way the images reflected the framing questions. The participants were requested to complete a reflection sheet to describe, and, to provide the rationale for their selection of each photograph.

Participants then returned the completed reflection sheets with indications of the photographs' numbers they had chosen. Thereafter one set of the six selected photographs was enlarged. Each photograph was put on a flip chart and matched with its description from the completed photo-reflection sheet. These were mounted onto poster boards in a uniform manner.

The meetings were a perfect opportunity to build group relationships. Participants shared what they had learned and helped each other with tips and tricks for taking better

photographs. It also helped participants to check-in with group members for support. They became familiar with their camera settings and practiced taking photographs that visually represented their ideas about the subject. Participants were encouraged to discuss their feelings about taking pictures, to share their experiences and, to talk about any challenges they may have experienced. The group spent time looking at, and discussing, the pictures they have taken. This discussion helped to stimulate ideas about the pictures.

2.3.4 Pilot testing

Strydom (2002) states that a pilot study is very important for successful execution and completion of a research project. The main reason being that, a researcher would fully understand the proposed research and therefore would be able to identify errors that might arise in the actual project. Yegidis and Weinbach (2002) define pilot testing as a process of testing a data collection method with few a persons who the researcher believes would mirror the research participants to confirm or refute the reliability of the instrument. In this study pilot testing, over a three days, was done with three people with physical disabilities in the Khomas region. Framing questions for data collection were piloted to ensure that they met the objectives of the study.

In terms of the results of the pilot testing the researcher envisaged the following modifications to the data collection method: set enough time frames (at least two weeks); ensure time management; factor in the costs of purchasing sufficient disposable cameras as well as costs of processing the photographs and telephone calls respectively. The researcher deemed intended research method to be adequate and appropriate for the study.

2.3.5 Data analysis

According to Henning et al. (2004, p. 101) the "true test of a competent qualitative researcher comes in the analysis of the data, a process that requires analytical craftsmanship and the ability to capture understanding of the data in writing". The origin of the research term 'analysis' is traced back to the German word 'analusuein' which means, literally, to unloose or undo. This unloosening enables the emergence of the hidden voice and the freeing up of meaning (Jones, Torres & Arminio, 2006).

The researcher was the facilitator of the data analysis. There are three main ways to carry out participatory analysis of the data: selecting photographs, contextualizing, and codifying (Wang & Burris, 1997). These stages of analysis are as follows:

Selecting photographs

This helps to open the door for dialogue (Wang & Burris, 1997). The process allows participants to choose photographs that they think reflect their community strengths and struggles; photographs to be included as photo-voice evidence, and photographs they feel are representative of their experiences, are included during this stage.

Contextualising

Participants contextualize the photographs by telling stories about what the photographs mean to them. They relate their stories through dialogue with group members and through journaling. It is during the dialogue and guided discussion that participants can voice their individual and group experiences. The acronym VOICE ('voicing our individual and collective experience') reminds participants to think not just about their own life conditions, but also about shared life events and conditions (Wang & Burris, 1997).

Codifying

This is a process of identifying and sorting data into categories of issues, themes or theories. When codifying an issue of concern it is important that the concern targeted for action is one that can realistically be achieved (Wang & Burris, 1997). For example, when examining the issue of people with disabilities, themes that may arise include accessibility to buildings, information, transport, health services. The group needs to determine realistic outcomes and desires.

2.3.5.1 Selection of photographs and contextualizing

In this study the selection of photographs and contextualising took place simultaneously. There were three parts to this portion of the process namely: pure appreciation of one another's photographs; small-group work to tell a collective story; sharing of small-group issues and themes presentations.

Pure appreciation of one another`s photographs

On arrival at the workshop participants were encouraged to circulate through the room to view and appreciate the photographs and reflections and to talk with other participants about their experience of taking and selecting photographs. At the same time the researcher circulated through the room to communicate with participants to explain and ask probing questions and to take field notes.

Small-group work to tell a collective story

Participants were divided into three small groups of two participants according to the area of the Okamatapati community where they resided. The groups' members were instructed to work together to select at least six photographs from their individual photo-boards that best responded to the framing questions. The researcher reminded each group to use the hand-out of probing questions (Annexure 8) to guide them in choosing their pictures. Each group then used photographs to create a team photo-board with underlying issues and themes. The researcher then used a LCD projector to project the selected photographs onto a big board.

Sharing of small-group issues and themes presentations

Each group was allocated 20 minutes to present their findings to all the groups. Each group was instructed to link specific picture/s with each of their identified themes. The other participants were requested to refrain from asking questions during this process; they could however make a note of their clarifying questions and their own stories to share later in the final discussions.

2.3.5.2. Codifying

This was done through full group discussion to develop collective themes. At this stage all participants could share their individual, and collective, experiences as they related to specific photographs, and revised the underlying issues and themes. The researcher asked probing questions to guide the analysis of the data. A cluster of sub-themes was identified to form key themes. Participants took ownership of the discussions and the thematic analysis. Final themes and sub-themes were then identified. The researcher deemed the data saturated when no new statements, regarding the meaning of the photographs, were made and all the participants reached an agreement on what was discussed. At the end of the discussion, the

researcher guided the participants to design their own photo- gallery that would be shared with the larger community.

The discussions and the workshop were closed with some discussion questions:

- ❖ What did you learn about yourself, this group, and the community?

- ❖ What are our next steps?

The researcher then provided each participant with a copy of the relevant CD and hard copies of the photographs to distribute to the subjects they used as a way of appreciation.

2.4 Trustworthiness

Streubert and Carpenter (1995, p. 318) define trustworthiness as a process to "establish validity and reliability of qualitative research. Quality research is trustworthy when it accurately presents the experience of the study participants". The qualitative data the researcher collected and described in this study are the experiences of people with physical disability who are participating in the CBR programme in the Okamatapati community. Trustworthiness of the data was established by means of the findings that reflected reality as it is subjectively perceived by the subjects in this study.

The four general criteria, namely truth value, applicability, consistency, and neutrality, described by Lincoln and Guba (1985) and the strategies of credibility, transferability, dependability and confirmability were applied for this study (Morse & Field 1996).

2.4.1 Measures for trustworthiness

To overcome the perception that there is lack of control over the validity and reliability of the research findings, trustworthiness was developed (see Table 2.4). The implementation of

Lincoln and Guba's (1985) trustworthiness strategies for the qualitative approach are displayed in Table 2.5.

Table 2.4: Trustworthiness: criteria and strategies for the trustworthiness of a qualitative approach

Criteria of trustworthiness	Strategies applied
	Qualitative approach
Truth value	Credibility
Applicability	Transferability
Consistency	Dependability
Neutrality	Confirmability

Credibility

Presentation of faithful descriptions focuses on the confidence in the truth. A study is viewed to be credible if the research findings show: a logical relationship: are grounded in and substantiated in the narrative: the original population considers the reports to be accurate (Huberman, 1994). Credibility was assured by prolonged engagement until the scope of data was adequately covered and, in-depth information on the experiences of people with physical disabilities, was obtained. Triangulation and debriefing were also applied. Triangulation refers to the use of different sources or different methods in data gathering (Lincoln & Guba, 1985). The researcher collected data using a photo-voice method with focus group discussions with participants from three different locations of the Okamatapati community. Literature control was done comparing participants` views against those of others reported in the literature to strengthen or support the participants` views.

Lincoln and Guba (1985, p. 305) define peer debriefing as a " process for exposing oneself to a disinterested peer in a manner paralleling and analytical session and for the purpose of

exploring aspects of the enquiry that might otherwise remain only implicit within the enquirer`s mind". Throughout the study, the researcher was assisted by two experts in qualitative research, who were also the researcher`s supervisors, to ensure the maintenance of high level of standards.

Transferability

It is not up to a researcher to judge his/her own study in terms of the transferability of a study`s findings (Lincoln & Guba, 1985; Streubert & Carpenter, 1995). A researcher`s responsibility is to provide a database so that potential users can evaluate the transferability of the findings. In this study the latter are relevant and could be of use in Namibian CBR programmes, or those in other countries, since they could be employed to improve programme planning and development. Furthermore, transferability is ensured by purposive sampling and dense description (Kloppers, 2008).

Dependability

Ulin, Robinson, Tolley and McNeill (2002) argue that dependability is reliant on a sound research process that is consistent and has been undertaken within the paradigm and methodology as proposed. A study is dependable if it can be audited. The researcher took field notes, used a work plan, and maintained and updated a log book throughout the study which could also be used should the data require auditing. In a nutshell all research records are available for peer scrutiny.

Confirmability

Brink (2006) states that confirmability provides a guarantee that the findings, conclusions, and recommendations, agree with the data and that this agreement can be testified by

auditors. The researcher endeavoured at all times to link the data analysis to views expressed by the participants. The photographs and photo-release forms that were selected by the individual participants were presented to them to check before data analysis commenced.

The strategies of establishing trustworthiness, with their criteria and implementation in this study as adapted from Lincoln and Guba (1985), are summarized in Table 2.5 below.

Table 2.5: The implementation of Lincoln and Guba's trustworthiness strategies for the qualitative approach

Strategies to ensure trustworthiness for the qualitative approach		
Strategy	**Meaning**	**Measures**
Credibility	Prolonged and varied engagement in the field	-Researcher engaged with participants for a sufficient time to gain trust. Field notes were taken.
	Triangulation	-Participants from 3 different locations of study area collected data, categorized it in themes and subthemes and presented to the whole group.
	•	-Literature check was done by the researcher.
	Debriefing	-Experts in the field (two research supervisors) validated the content of the study.

Transferability	•	-The findings of the study can be meaningful to all CBR stakeholders, PWDs, their families and the community.
	•	
	•	
	•	
	Thick description	-The researcher provided a clear description of the methods and the results
	Purposive sampling	-Participants were handpicked according to the physical ability of the participant to handle a camera effectively.
		-Only participants who met the inclusion criteria were selected.
Dependability	Audit	-The raw data was codified, by identifying and sorting data into categories of key themes and subthemes.
Confirmability	Audit trail	-Data were photographed, transcribed, and analysed to develop themes and subthemes.
		-The researcher took field notes and had a work plan, and a log that was maintained throughout the study.
	Reflexivity	-The researcher constantly reflected on his position, own values and behavior in order to avoid influencing

		responses.

2.5 Summary

This chapter focused on the study's research methodology; its design and method were discussed. Non-probability purposive sampling, with inclusion criteria to handpick the people with physical disabilities since they are a minority population, was described. A photo-voice method was used for data collection and analysis.

Using Lincoln and Guba's model of trustworthiness, measures for ensuring trustworthiness, were discussed according to the criteria of: truth, value, applicability, consistency and neutrality. Strategies for ensuring trustworthiness of this qualitative study were described as: credibility, transferability, dependability and confirmability. The results of the photo-voice method and the literature control are discussed in Chapter 3.

CHAPTER THREE

RESULTS FROM PHOTOVOICE DISCUSSIONS AND LITERATURE CONTROL

"*I discovered early that the hardest thing to overcome is not a physical disability but the mental condition which it induces. The world, I found, has a way of taking a man pretty much at his own rating. If he permits his loss to make him embarrassed and apologetic, he will draw embarrassment from others. But if he gains his own respect, the respect of those around him comes easily"* (Alexander de Seversky, n.d.).

3.1 Introduction

The previous chapter focused on this study's research methodology and design, and measures for ensuring the trustworthiness of the selected qualitative approach. It was argued that the research methods are relevant since the aim was to elicit the experiences of people with physical disabilities who participate in the community based rehabilitation (CBR) programme in Okamatapati community, Otjozondjupa region.

This chapter describes the results of the photo-voice method with supporting literature control.

The key themes categorized are:

- ❖ Secure livelihood with sub-themes of skills development, decent work, self employment, social protection, financial and material resources;

- ❖ Health services with sub-themes of reaching the unreachable and marginalized community, rehabilitation, assistive devices;

- ❖ Environmental barriers with sub-themes of architectural barriers, communication barriers;

- ❖ HIV/AIDS and disability with a sub-theme of CBR and HIV/AIDS.

Even though some of the themes only elicited one sub-theme from a focus group's discussion reflected in the text, the other participants supported and approved of the selected photographs and statements made.

3.2 Results of photo-voice discussions

The results of the photo-voice discussions are presented in Table 3.1.

Table 3.1: Key themes and sub-themes of the study elicited from experiences of people with physical disabilities who participate in the CBR programme in Okamatapati community, Otjozondjupa Region

KEY THEMES	SUB-THEMES
Secure livelihood : Secure livelihood is an important entity to alleviate poverty that has a strong association with physical disability.	There were four different views on secure livelihood: ❖ **Skills development:** CBR programme enables people with disabilities to access work opportunities, by actively promoting and facilitating the acquisition of relevant knowledge, skills and attitudes. ❖ **Decent work:** The CBR programme helps people with disabilities to find employment. ❖ **Self employment:** The CBR programme encourages and supports self-employment by assisting

	people with physical disabilities and their families, either individually or in groups, to access skills development as well as financial and material resources.
	❖ **Social protection:**
	The CBR programme facilitates the access of people with disabilities to mainstream, or specific, social benefits and promotes the provision of social protection measures.
	❖ **Financial and material resources:**
	❖ The CBR programme through its awareness raising programmes has managed to gain support and mobilize financial and material resources from the community, NGOs and the government for the benefit of PWDs.

Health services: Enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.	The following health services were experienced : ❖ **Reaching the marginalized and the unreachable community:** The CBR programme is the main vehicle through which marginalized and unreachable people with complex health problems have reached referral health services facilities. ❖ **Rehabilitation:** CBR can promote, support and implement rehabilitation activities at the community level and facilitate referrals to access more specialized rehabilitation services ❖ **Assistive devices:** CBR programme is facing challenges in facilitating the availability of these devices from specialised centres and also to initiate the production of devices in the community using locally available resources ❖
Environmental barriers: It is important to create an environment in which all people can	The following were viewed as environmental barriers : **Architectural barriers:**

participate in a dignified manner and with maximum independence.	Architectural structures should be accessible to PWDs. Absence of architectural barriers enables PWDs to be self-reliant, boosts their self-confidence and avoids unnecessary delay. **Communication barriers:** It is important that a good communication system is incorporated in the CBR programme and accessible to all people with physical disabilities.
HIV/AIDS and disability: The CBR programme can be more effective if it incorporates a component of HIV/AIDS. CBR can be effective in raising the profile of disability in HIV/AIDS programmes and services.	The following emerged: **CBR and HIV/AIDS:** The inclusion of HIV/AIDS in the CBR programme is needed for prevention, education, access to testing, care and treatment.

3.2.1 Key themes and sub-themes

A discussion of the four key themes and their sub-themes is presented below.

3.2.1.1 Key theme 1: Secure livelihood

Most of the participants expressed secure livelihood as their number one priority. They felt that poverty amongst them worsens their disability. These statements are supported by (WHO, UNESCO, & ILO, 2004) when they stated that there is a strong correlation between disability and poverty. Poverty leads to increased disability which in turn leads to increased poverty. It is quite shocking how poverty weighs heavily on people with disabilities. The Department for International Development (2000) observed that 50.0% of disabilities are preventable and directly linked to poverty. Narayan and Petesch (2002) observed that poverty violates the fundamental human rights of PWDs, depriving them of the basic necessities of life including, health, education, safe water, food, shelter, and clothing, including means of livelihood.

Accessing livelihood opportunities is one of the key factors in eliminating poverty. A secure livelihood is pivotal in a CBR programme; it is essential to ensure that both youth and adults with disabilities have access to training and work opportunities at community level (Carney, 2002). One of the aims of the CBR programme is to facilitate employment for people with disabilities, as well as their families, so that they can secure the necessities of life and improve their economic and social situations. To be able to gain employment people with physical disabilities need to acquire skills.

3.2.1.1.1 Sub-themes of secure livelihood

Skills development

People with physical disabilities need skills to engage in livelihood activities. In Okamatapati community limited access to basic education makes them unqualified to join skills training courses. These disadvantages may frequently result in a lack of skills, as well as low confidence, low expectations and achievement. However, despite these challenges, the Okamatapati CBR programme recorded some positive initiatives in placing people with

physical disabilities in local apprenticeship courses. Some local business people in Okamatapati community are sensitive to the plight of people with physical disabilities to gain skills as shown in Photograph 1 (Figure 1) on the next page. The content of the photograph and the statements are evident of the positive reaction towards the CBR programme regarding skills development.

Figure 1 (Photograph 1): Local businessman providing bakery courses to people with physical disabilities

The photograph indicates a positive experience of the participant regarding skills development in training as stated below:

When you have a disability none consider you serious. I have tried to apply for financial assistance through the local councilor to go for vocational training, but I continue to be told that we have a long list of people who need bursaries or that the colleges are full. I have tried to seek employment with local business people, but they view you as a nuisance; as a person who cannot do anything right; and above all most believe that a person with a disability can bring bad luck to their business. The CBR committee approached a local bakery owner (in the figure 1 above) to assist with training some people with physical disabilities on bakery. The bakery agreed and took five of us free of charge. Through the work of the CBR programme I have managed to gain skills that can secure my life. I'm so excited to be empowered with such skills as I already see myself useful in the community.

Literature supports skills development for people with disabilities to enable them to participate in livelihood activities. One of the major objectives of CBR is to enable people with disabilities to access work opportunities, by actively promoting, and facilitating, the acquisition of relevant knowledge, skills and attitudes (WHO, UNESCO, ILO, & IDDC, 2010).

Some of the global studies done by the WHO focused on skills development of people with disabilities. In Malawi, the Malawi Council for the Handicapped (MACOHA) initiated a system of vocational skills training in their CBR programme. In the above mentioned studies rural communities were targeted, youth and adults with disabilities were identified and their vocational interests determined. Master trainers in the community were contacted and encouraged to take one or more apprentices with disabilities for a one or two year period. As an incentive, the CBR programme provided each master trainer with training and production materials. A variety of master trainers participated in the scheme; for example, bakers, tailors, tinsmiths, carpenters, metalworkers, bicycle repairers, women engaged in tie-dye and knitting. Selected master trainers were invited to upgrade their own skills through participation in training courses offered by a vocational rehabilitation centre operated by MACOHA. Some of the trainees started their own activities upon completion of their apprenticeship, while others were employed by their trainers, (WHO, UNESCO, ILO, & IDDC, 2010).

The WHO conducted several case studies in different countries to share best practices of CBR programmes. In India, a case study was done by the WHO, UNESCO, ILO, and IDDC (2010, p. 12) on vocational training centres.

India has one of the best practises that support skills development in vocational training centres. Vocational training centres run by The Leprosy Mission in India for young people affected by the disease, teaches a wide variety of technical skills, such as, motor mechanics, tailoring, welding, electronics, radio and TV (television) repair, stenography, sericulture, offset printing and computing. Students learning these skills graduate with qualifications recognized by the government. The centres also make a strong point of teaching other types of skills, especially business management and core life skills. These centres have a > 95% rate of job placement for their graduates. There are three main reasons for this success. First, employers are looking for candidates with a strong sense of responsibility and this is inculcated through the core life skills training; local employers know that graduates of The Leprosy Mission centres have high personal standards. Second, this mission has very active job placement officers who have excellent relationships with local businesses. Third, the mission centres have a strong alumni association which: keeps graduates in touch with each other and with their centres, helps new graduates to find jobs and, helps those in jobs to keep them.

The capability of people with physical disabilities is the biggest challenge for CBR programmes. On the other hand, people with physical disabilities have to prove themselves, through hard work and credible performance, in any given job opportunity. Skills development can also be acquired through self effort instead of waiting for the initiative of the CBR programme (WHO, UNESCO, ILO, & IDDC, 2010).

In China a case study by WHO, UNESCO, ILO, and IDDC (2010, p. 15) focused on a person with a physical disability.

> Zou was born into an ordinary immigrant peasant family from Yi Chang in Hubei province of China in 1951. He cannot move his arms because of serious malformation and has to depend on his feet for all daily living skills. He had no chance to study in a school. He learned different skills, but the income was not enough for his survival. He started learning watch repairing, for which he had to train and develop dexterity in his feet. He trained his toes to act like fingers by attracting ants with sugar and then picking the ants up with his toes. After several years of arduous effort, he was good at watch repairing and opened a watch-repairing shop.
>
> So Zou now earns his living and supports his family by watch repairing. His daughter graduated from university and became a nurse. Zou is enthusiastic about public services for people with disabilities and launched a telephone hotline to provide psychological services and counselling for people with disabilities at his own expense. Zou is a role-model for many people with disabilities in his province. He also says that although professionals play an important, sometimes critical, role in the course of rehabilitation, the final achievement strongly depends on the mind-set of the person with disability and his/her willingness to break the shackles.

These case studies indicate the positive outcomes of the involvement of CBR programmes in the lives of people with physical disabilities.

Skills development is a powerful tool for economic empowerment of people with disabilities. This was shown by one of the people with physical disabilities in the Okamatapati community in Photograph 2 (Figure 2) on the next page, who was trained through a HIV/AIDS project.

Figure 2 (Photograph 2): Person with a physical disability and also is a CBR volunteer who received a certificate in community HIV/AIDS training

The woman in the photograph was a participant who requested another participant to photograph her as she wanted to share her gratitude towards the benefits of the CBR programme by stating:

> I am one of the CBR volunteers and also a person with a disability.
> This is my certificate I received when I got an opportunity to train as a
> community health worker for HIV/AIDs. The CBR programme has

facilitated for me to be chosen for this course. I'm very grateful for the work that the CBR programme is doing for people with physical disabilities. Today I have knowledge and skills in the field of HIV/AIDs and disability. I'm also receiving an allowance from the HIV/AIDS programme .With that little money I am now able to buy basic food for my family.

The participant`s sentiments echo those of Rifkin and Pridmore (2001) as they attest that information (education) is power and people who lack information, lack power and lack choices about how to improve their lives or control what happens to them. It is through education, either formal or informal, that people with physical disabilities can gain knowledge and skills needed to perform functions, tasks or carry out some socio-economic activities for personal and community development. However, some participants in this study reported that the majority of them are unemployed and are denied employment opportunities even when they have met necessary skills and requirements. Consequently, they have no stable income and have to depend on the mercy of family members, well-wishers, and charity groups, for handouts to sustain their livelihood. Some also expressed the need to start their own projects and to be equipped with skills that meet the current market.

When one acquires skills the next step is to look for a decent work. According to the experience of the researcher, most CBR practitioners face a lot of resistance with employers as they refuse to employ people with physical disabilities. It is a challenge since the private and informal sectors, which are likely to control about 50% of job opportunities in most African countries, are ignorant of capabilities and possibilities of people with disabilities.

Decent work

Decent work is work which dignifies and does not demean. It is also described as work that involves opportunities for productivity and delivers a fair income, security in the workplace and social protection for families, better prospects for personal development and social integration, freedom for people to express their concerns, organize and participate in the decisions that affect their lives and equality of opportunity and treatment for all women and men (ILO, 2005).

Participants reported that they also need decent work. They felt that society views them as second class citizens and thus label them as people who cannot take up any decent work. Not all types of work are desirable; it is important to distinguish between decent work and work which exploits and perpetuates poverty and lack of dignity. However, the implementation of the CBR programme produced positive results as evident in the statement on the next page. Photograph 3 (Figure 3) and comments show a positive experience of the CBR programme placement of people with physical disabilities in employment.

Figure 3 (Photograph 3): Person with a physical disability employed by a construction company

A person with a physical disability who was employed by a local construction company through the CBR programme. This photo was selected to illustrate the collaboration between the CBR programme and the local businessses. This fact is verbalised by the participant as follows:

> *This lady has a physical disability of her fingers. She is also a member of the CBR committee. The CBR programme has improved her quality of life. Firstly it was the home exercises, and now the CBR committee recommended her to work for the construction company which is building a new police station. Regardless of job vacancies indicating that people with disabilities should be encouraged to apply, there are still a lot of people with disabilities in Okamatapati who are being denied jobs. Most don't know how to match jobs with qualification, where to find jobs and even how to apply. It is important for the CBR programme to help compile employers that offer jobs and the*

qualifications that they need. This helps our people to know which jobs

are available and what skills they require.

Literature supports the right of people with disabilities to decent work. The rights of people with disabilities to work is laid out in international instruments, such as the Discrimination Employment and Occupation Convention, adopted by the International Labour Organization (ILO) in 1958 (No. 111), the ILO Vocational Rehabilitation and Employment Convention, 1983 (No. 159) and the United Nations Convention on the Rights of Persons with Disabilities. However, the right to work is often not respected and people with disabilities encounter many barriers in trying to find and keep work. This United Nations convention makes provision for state parties to recognize the rights on an equal basis with others. This includes the right to the opportunity to gain a living by work freely, chosen and accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities, (UN, 2006).

Article 23(1) of the Universal Declaration of Rights by the UN also reflects that: "everyone has the right to work, to free choice of employment, to just and favourable conditions or work and to protection against unemployment" (UN, 1948, n.p). In reality there are still some institutions in Namibia that ignore these international instruments. The unemployment rate among PWDs is an overwhelming problem in developing countries, statistics reflect up to 80% of unemployment in some countries (ILO, 2002).

Universally, Organisations of People with Disabilities advocate for employment of people with physical disabilities. A case study conducted by the WHO, UNESCO, ILO, and IDDC (2010, p. 38) in Lebanon reveals the following:

The Lebanese Physically Handicapped Union (LPHU) sees employment as its chief responsibility on behalf of people with disabilities in Lebanon, where the formal sector of the economy is strong and wage employment is the best option for people with disabilities. LPHU's employability projects aim to achieve three main outcomes:

❖ A change in attitude of the private sector, with employers regarding people with disabilities as potential employees who have productive capacity and purchasing power. An important indicator is the percentage rise in employment of people with disabilities in private enterprises.

❖ An increase in the capacities of people with disabilities by, for example, increasing the access of persons with disabilities to mainstream vocational and technical training programmes that are adapted to meet the needs and situations of people with disabilities as well as the realities of the labour market.

❖ A change in government policies and practices, for example by: government agencies effectively implementing the law on disability rights; national policies shifting from an exclusionary charity-based approach to one that is inclusive; the national employment office becoming better equipped to work with people with disabilities to assist them in finding employment.

To achieve these outcomes, LPHU researches where people with disabilities are employed and in what circumstances; builds relationships with potential

employers; arranges training of people with disabilities to match the skills demanded by employers. LPHU has established employment advice centres for people with disabilities. These centres function as reference points for employers as well as jobseekers with disabilities. Their task is to get in touch with employers to determine what skills they are looking for and then assist people with disabilities to acquire the necessary skills. LPHU also has a website for jobseekers with disabilities, which aims to match jobseekers with job opportunities.

An understanding of the legal and policy issues related to the employment of people with disabilities is important. The following case study by the WHO, UNESCO, ILO, and IDDC (2010, p. 14) shows evidence that employment can also be promoted through policy.

To mainstream people with disabilities into regular occupation, the Employers' Confederation of Barbados developed a policy document: *"Promoting the employment of persons with disabilities"*. During the launch, the Barbados Minister of Social Transformation, Mr Trevor Prescod, emphasized that implementing the strategies outlined in the document required an intersectoral coordinated approach. "Therefore, the many sectors – public, private and nongovernmental – must be enthusiastic enough to make sure the programmes are implemented in a timely manner", he stressed. The Minister said that to facilitate collaboration, the Cabinet had provided broad-based support for the National Disabilities Programme by setting up a National Advisory Committee on the Rights of Persons with Disabilities which will,

among other things, monitor and report on the progress of people with

disabilities in spheres of economic and social activity.

The participants reported that the majority of them are unemployed and are denied

employment opportunities even when they have met necessary requirements.

Consequently, they have no stable income and have to depend on the mercy of family

members, well-wishers and charity groups for handouts to sustain their livelihood.

Some also expressed the need to start their own projects and to be equipped with skills

that meet the current market.

Matching the qualifications of people with physical disabilities to vacancies was

reiterated by the participant in Figure 3. Training can be provided to help develop these

job seeking skills, for example: how to write curriculum vitae; look for jobs in the

newspapers, through family members and other contacts; fill in application forms;

develop telephone or letter-writing skills; and perform well in a job interview (WHO,

UNESCO, ILO, & IDDC, 2010).

A case study conducted in Cambodia revealed that the Business Advisory Council

(BAC), which is a voluntary group of business leaders working together to promote

employment for people with disabilities in Cambodia, identifies job vacancies through

its members and then links with a national nongovernmental organization, the National

Centre for People with Disabilities, to identify jobseekers with disabilities to match the

vacancies (WHO, UNESCO, ILO, & IDDC, 2010). Apart from skills development and

decent work, self employment is also very important to people with disabilities.

Self-employment

This is a term applied to economic activities in both the formal and informal economies which are owned, operated and managed by an individual or a group (WHO, UNESCO, ILO, & IDDC, 2010). There is a wide spectrum of different types of self-employment, identified by the activity, complexity and number of people involved. There are three broad categories of self-employment: income-generating activities; small and medium enterprises; and self-help groups and group enterprises. These businesses are involved in one or more of the three activities: production, providing a service, or trading.

Albright (1993), views self-directed employment as an option that is of increasing interest to people with disabilities both in economically developed and developing countries. In developing economies, most people with disabilities turn to self-employment because of a lack of opportunities in the job market. Although many would prefer to have a job with a regular income, self-employment is often the only option available. The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN, 1993) recognises that all countries should ensure the provision of adequate income support to persons with disabilities, who have temporarily lost or received a reduction in their income, or have been denied employment opportunities. Unfortunately, in developing countries, this is often not the case.

Self-employment is the most obvious choice of livelihood for people with disabilities in poor communities. Even though people with disabilities choose it, self-employment presents considerable challenges. It places different demands on the individual compared with wage employment. To succeed in self-employment, a person needs: good levels of initiative, determination and tenacity; good entrepreneurial skills, to relate well to customers and to have a good business sense and quality concept. These qualities can be learnt through appropriate training and it is essential for CBR programmes to facilitate, and if necessary, arrange such training. The role of CBR is to encourage and support self-employment by assisting people with disabilities and their families, either individually or in groups, to access skills development as well as financial and material resources. The Okamatapati CBR programme has met with successes and failures with regards to encouraging and supporting self-employment of people with physical disabilities. Photograph 4 (Figure 4) on the next page displays positive experiences of people with physical disabilities with regards to the encouragement they get from the CBR programme.

Figure 4 (Photograph 4): Persons with a physical disability who were trained in bakery now self-employed

The photo depicts some of the people with physical disabilities who acquired skills after being send for bakery training. The following are the participant's comments:

The Okamatapati CBR programme is encouraging people with physical disabilities to stand up and start small projects to fend for their families. These women were trained in bakery and bussiness management and now they are self-employed. They sell sweets, muffins at schools in Okamatapati. This is helping them to fend for their children. Despite earning little from selling sweets and muffins, these women demonstrates that a low income does not necessarily lead

to personal poverty. In the absence of any Government support, such

local, community based support mechanisms are essential for millions

of people with disabilities in low-income countries.

The statement above clearly shows that self-employment helps to economically empower persons with physical disabilities; through taking initiatives and playing a leading role in their families and day-to-day decision making and management process. Literature supports self-directed employment as one of the ways that people with physical disabilities can liberate themselves from economic hardships. The Self-Help Association of Paraplegics, (SHAP) in Soweto, South Africa, is one good example of self-directed efforts to empower, develop, and create employment opportunities for young persons with physical disabilities. SHAP operates a factory, which employs 130 disabled people working on a sub-contract basis, doing packaging and assembly work, repairing sophisticated mechanical and electronic devices, such as cameras and calculators etc. The government and indigenous companies in South Africa admire and support this association for their fundraising efforts for self-support (Toit, 1991).

Another good example of a self-directed effort worthy of mention is that of the Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV) initiative in Chakoria, Bangladesh. SARPV was founded in 1989, by Mr. Shahidul, a person with a physical disability. SARPV runs a skills development and credit programme called: Build own small enterprise project (BOSEP). It aims to empower and support poor disabled persons in the district, who want to be successful entrepreneurs, but are lacking relevant skills and funds to realise their dreams. Although Caritas-Netherlands and UN ESCAP largely fund SAPRV, its ability to integrate its activities to suit the culture and needs of the people in this area makes it original. Business skills are taught

to members and loans provided to groups of disabled members after successful graduation. Members of the association are encouraged to work together with family members and other able-bodied persons in the community in carrying out respective economic activities (Alan, 1997). The Okamatapati CBR programme is encouraging similar initiatives in their community, to enhance economic empowerment of people with physical disabilities.

Social protection

Social protection measures are intended to provide a safety net to protect people against poverty and loss or lack of income through illness, disability or old age. Article 28 (UN, 2006) of The Convention on the Rights of Persons with Disabilities requires states to recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability. It further notes the particular need to pay attention to the ability of women and girls with disabilities, and older persons with disabilities, to access programme benefits and those programmes aimed at ensuring an adequate standard of living. It spells out what is required to enable people with disabilities to enjoy this right, including access to food, clothing, clean water, affordable services, devices and other assistance for disability related needs, social protection and poverty reduction programmes, adequate training, counselling, financial assistance and respite care, public housing programmes, and retirement benefits and programmes,

The role of a CBR programme is to facilitate the access of people with disabilities to mainstream or specific social benefits and promote the provision of social protection measures. Positives experiences with the CBR programme in this study were evident as

most of the people with physical disabilities have been facilitated to obtain disability grants from the government. Photograph 5 (Figure 5) on next page shows a person with a disability withdrawing his monthly disability grant.

Figure 5 (Photograph 5): Person with a physical disability withdrawing his monthly disability grant

Figure 5 reveals the positive experience of the people with disabilities with regard to disability grants. The comments of the participant being:

> *Okamatapti didn't have a banking facility so it was even more difficult*
>
> *for people with physical disabilities to access public transport to go to*
>
> *the nearest town to collect their monthly disability grants. The CBR*

programme lobbied through the local councillor to have a Post Office Bank in Okamatapati and this was successful.

We thank the CBR programme for such an initiative for facilitating the Post Office Bank to come to Okamatapati. Now every person with a disability can collect their disability grant through the Post Office Bank.

We used to wait under the tree for a vehicle to come from Windhoek with our disability grants. Some people with severe physical disabilities would miss their payments as the people who did the payments stay only one day and go back with the money of those who fail to come. The CBR programme has facilitated many people with disabilities in Okamatapati to obtain their disability grants.

Though some of the people with physical disabilities are getting disability grants, there are still some who do not even know how the process works. This study revealed that most children with cerebral palsy are not getting disability grants. This is because either the parents do not know how to apply or they do not seem to care. They felt that the CBR programme should widely communicate the process of applying for a disability grant.

People with physical disabilities in the Okamatapati community are in need of disability grants and are supported by Article 28 of the Convention on the Rights of Persons with Disabilities, which recognises the need of people with physical disabilities

to get social protection (UN, 2006). However, literature contradicts the idea of governments that give disability grants. The ILO (2002) reiterated that the objective should be to reduce poverty of persons with disabilities by means of 'unlocking their economic potential', and not by handing out welfare. In Namibia, PWDs get disability grants, however, such a system was found, by other countries, to be unsustainable. It is far cheaper to get PWDs into employment, than to hand out welfare, even if that means spending money on modifying the workplace. Costs in terms of accessibility, technical devices, and workplace accommodations, are to be seen as investments and not as unproductive social welfare expenditure (ILO, 2002).

It is therefore important to seriously consider the negative cost of not enabling people with disabilities to be economically active. The presence of a PWD in a family affects the whole family, especially if the main breadwinner is a PWD. If PWDSs are not economically active, the whole family suffers the consequences.

Financial and material resources

Most people with physical disabilities in the Okamatapati community echoed the same sentiment that to secure the livelihood of all PWDs is very crucial in raising their quality of life. However, this cannot be achieved without the involvement and participation of all stakeholders; the government, parastatals, non-governmental organisations (NGOs), members of the community, the labour market and PWDs themselves in pooling up resources. CBR programmes need to increase sensitization of the public on disability issues and rights of PWDs.

The Okamatapati CBR programme through its awareness raising programmes has managed to gain support and mobilise resources from the community, NGOs and the government for the benefit of PWDs as shown in Figure 6 on next page.

Figure 6 (Photograph 6): This depicts six (6) hectares of land that was allocated to the CBR programme by the local headman

Figure 6 reveals the support that the CBR programme is getting from the local authorities. The comments of the participant being:

This a logo for the CBR programme that was designed by one of the people with physical disabilities. The words "Omundu Omundu" means a person is a person regardless of what he/she looks. We thank the headman for giving the CBR programme 6 hectares of land to start gardening project and build our offices. These are positive experiences of the support that the local authority is giving us.

Apart from the local authorities, the CBR programme is also receiving financial and material support from the relevant government ministries and local companies; such support is evident in the two photographs below. The chairperson of the Okamatapati CBR committee expressed her gratitude regarding the great support the CBR programme has received so far from the respective ministries and local companies as shown in Photograph 7 (Figure 7) on next page. This support will be utilised for building CBR offices on the land depicted in Figure 6.

Figure 7 (Photograph 7): Chairperson of the CBR committee after receiving 60 bags of cement that were donated by CENORED for building their CBR offices

Figure 7 shows the support the CBR programme is getting from local comapanies. The comments of the participant being:

This is the chairperson of the CBR committee. PWDs in particular with physical disabilities if given hope they can do wonders. Through their works the CBR programme has received a lot of support. In the picture are 60 bags of cement that were donated by a local electricity company called CENORED for building CBR offices. The Otjozondjupa Regional Council supported with N$150 000.00 to help buy all building materials needed for the offices. Ministry of Works, Communication and Transport drew up a plan for the offices.

In addition Namwater also helped them by putting tapped water at the site as shown in Photograph 8 (Figure 8) below.

Figure 8 (Photograph 8): Tapped water erected on the six hectares of land allocated for the CBR programme

Figure 8 also shows the support the CBR programme is getting from local comapanies. The comments of the participant being:

> *This tapped water was put by Namwater in recognition of the wonderful work the CBR programme is doing. This is one of the wonderful experiences we are having with the CBR programme. Now we can start a gardening project which the Ministry of Forestry promised to fence and initiate for a month before handing over to us.*

This direct comment shows evidence of full support of the respective government ministries and local companies in the CBR programme. This is a great achievement by the Namibian government. The IDDC (International Disability and Development

Consortium, n.d.) members recognize that, despite the wide adoption by many UN agencies and international NGOs of the CBR approach during the last two decades, as well as its significant contribution to the well being of disabled persons, it remains mainly an NGO supported, small-scale programme with limited involvement of governments.

While good intentions help to start CBR programmes, they are never enough to run and sustain them. Overall, experience shows that government-led programmes or government-supported programmes provide more resources and have a larger reach and more sustainability, compared with civil society programmes. However, programmes led by civil society usually: make CBR more appropriate and work in difficult situations; ensure better community participation; and a sense of ownership. CBR has been most successful where there is government support and where it is sensitive to local factors, such as culture, finances, human resources and support from stakeholders, including local authorities and disabled people's organizations (WHO, UNESCO, ILO, & IDDC, 2010).

Literature also confirms the importance of financial support to PWDs. In Nigeria, Services for People with Disabilities gave loans to 40 persons in 2003, under its Revolving Loan Fund. Loans ranged from 1000Naira (7 USD) to 50,000Naira (370 USD). Loans were determined by the client's disability condition, nature of the business and economic situation of the PWDs/family, among other requirements. PWDs whose income generating projects (IGPs) require substantial capital were given part grant and part loan (Caswell, 2003).

Besides resources, PWDs also need technical support from CBR programmes in order to succeed with their IGPs. Areas of support include elaborate business plan, teaching basic bookkeeping, monitoring progress, evaluation of the execution process and offering advice on areas that need improvement. PWDs should also be encouraged to cultivate the habit of saving, either with the programmes or with local community banks. This provides relief in times of any difficulties, it helps should it be necessary to expand,   as well as raise the status of PWDs (Malcolm, 1996).

3.2.1.2 Key theme 2: Health services

The WHO (2006), in its constitution, states that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition. Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (2006) also addresses the right to health for people with disabilities and requires state parties to "recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination of disability". Articles 20 and 26 of the United Nations Convention on the Rights of Persons with Disabilities (2006) also address issues of accessibility and rehabilitation respectively, and state clearly the measures that state parties should undertake to ensure that people with disabilities are able to access health services that are gender-sensitive, including health-related rehabilitation (UN, 2006).

Despite these instruments being proclaimed, people with physical disabilities in the Okamatapati community are not enjoying their full right to health services for several reasons.   However, the Okamatapati CBR programme has been instrumental in

supporting people with physical disabilities in attaining their highest possible level of health. The CBR programme has contributed greatly to the health of people with physical disabilities in Okamatapati community. Literature has always overlooked the contribution of CBR to community health development. Emphasis in evaluation is correctly placed on how the CBR programme has improved the quality of life of PWDs and their families, but in doing so, CBR's contribution to general community health development is overlooked. Key sub-themes of health services that came out of the study that had both successes and failures are: reaching the marginalised and the unreachable, medical care, rehabilitation and assistive devices.

3.2.1.2.1 Sub-themes of health services

Reaching the marginalised and the unreachable community

The CBR programme has been the main vehicle, through which marginalised and unreachable people with complex health problems, have reached referral services. Without this programme the needs of these people would not have been met; most community health workers often conduct outreach programmes that focus on simple health problems, or on health education or immunization. They do not reach those who are hidden or cannot readily come forward. Hence through CBR, persons with physical disabilities can access the same health care services as others. As evident in this study most of them were persuaded to go to the local clinic for treatment and further referral. Photograph 9 (Figure 9) on next page shows a positive experience of the Okamatapati CBR programme with regards to reaching the marginalised and the unreachable community.

Figure 9 (Photograph 9): A San child who is receiving home exercises from CBR volunteers
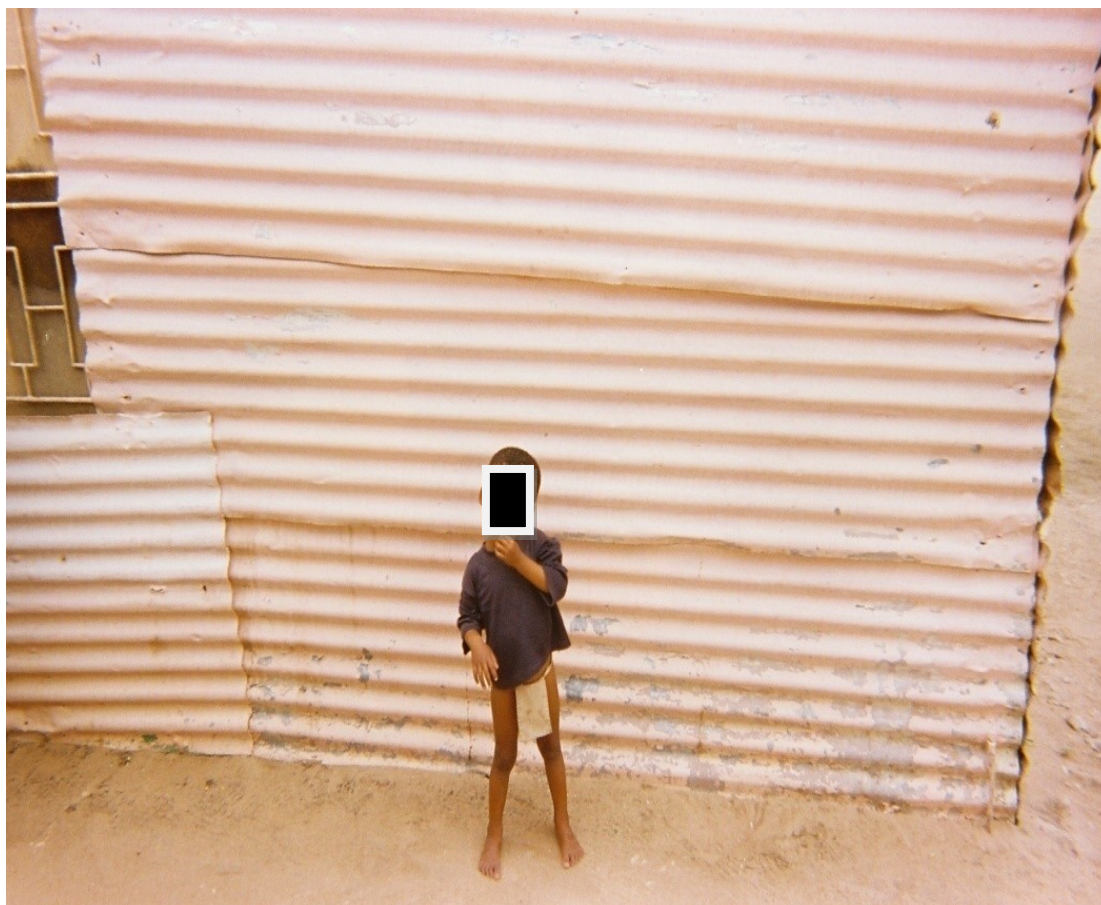
The CBR programme has managed to provide home visits even to the unreachable San community. The comments attached to this photograph are:

This is a child of the San people. San people are nomads and it's very difficult to locate them. This child together with several others were discovered when the CBR volunteers did a door-to-door identification and screening of the San community. This child is receiving home exercise from the CBR volunteers. He used not to stand. This is a positive experience that the CBR programme is doing to this San community that is unreachable.

Apart from the San community, in Okamatapati community there are a lot of people with physical disabilities who are too feeble or too old to move, who are receiving assistance at home through community CBR workers. HIV/AIDS programmes usually do a lot of community outreach in Okamatapati community. Together with CBR, HIV/AIDS programmes have reached poor people with complex health problems in their homes. Photograph 10 (Figure 10) on next page reveals evidence of some of the good works of the CBR programme. An old man with multiple deformities of the limbs was discovered in his house. All he needed was the repair of his orthopaedic shoes and crutches in order for him to gain mobility again.

Figure 10 (Photograph 10): One of the marginalized people with physical disabilities

Through CBR programme home visits this old man with multiple deformities of the limbs was discovered in his house. The comments of the participant being:

> *This is a man who has been lying in bed for a long time without being able to walk. His artificial shoes are torn and his pair of crutches is long broken such that mobility at this house is a challenge. He proclaimed that he was once visited by a health worker two years ago and had indicated that he need replacement of both his artificial shoes and his pair of crutches. He was discovered by the CBR volunteers*

when they did their door-to-door identification and screening of people with disabilities.

The statement of this participant is supported by literature as Becker (2005) states that evidence shows that people with disabilities often experience poorer levels of health than the general population. The United Nations High Commissioner for Human Rights and the WHO (2008) in their Fact Sheet No 13, also confirm the above sentiments when they stated that people with disabilities face various challenges to the enjoyment of their right to health. This man should have been identified earlier by the community health programme; it was however, the CBR programme that brought a turnaround in his life. Transport was sought to take him to the nearest hospital to give him new shoes and crutches and also to register him for the government disability grant.

Literature indeed supports that CBR can be a vehicle to reach far remote areas. In other African countries CBR has contributed to reach the unreachable. Nganwa, Ddamulira and Mwesigye (2004) observed that community health services should reach all and CBR has facilitated this process in situations where health programmes lacked the ability either to intervene, or to reach the people. In Eritrea, it is through the CBR programme that the only psychiatrist in the country is able to provide mental health services. In one of the district CBR programmes in Uganda, 40.0% of all those referred for surgery successfully received it. Most of the surgery was either orthopaedic or neurological and without CBR the surgeons would never have seen these clients. More importantly, people in dire need but with very little capacity, accessed corrective surgery that they would never have received without CBR (Nganwa et al., 2004).

In Kenya, the CBR programme was regarded as an important step to bring physically disabled persons and their families out of isolation (AMREF, 1987). An evaluation verified that home visitors were committed to the project and these visitors were accepted by the parents as well. The Guyana CBR programme in Uganda proved acceptable to key administrators in the country (O'Toole, 1988). All relevant professionals accepted invitations to participate, as resource persons, in the CBR programme. Mothers nearly unanimously welcomed the presence of the home visitors. The concept of simplified rehabilitation proved acceptable to administrators, rehabilitation therapists, and the parents. As a result disabled persons in these regions warmly responded to the simplified rehabilitation methods the CBR programmes offered. Many parents became aware of what resources from their own environment could be used to help their children achieve new developmental goals.

Rehabilitation

UN (1993) in its Standard Rules on the Equalization of Opportunities for Persons with Disabilities state that rehabilitation measures include those which provide and/or restore functions, or compensate for the loss or absence of a function or a functional limitation. Rehabilitation may range from more basic interventions, such as those provided by community rehabilitation workers and family members, to more specialized interventions, such as those provided by therapists.

The role of CBR is to promote, support and implement rehabilitation activities at the community level and facilitate referrals to access more specialized rehabilitation services. Most people with physical disabilities in this study have appreciated better rehabilitation services the CBR programme has brought. Most of the cerebral palsy

children have gained from home rehabilitation programmes as shown in Photograph 11

(Figure 11) on next page.

Figure 11 (Photograph 11): Child with cerebral palsy receiving rehabilitation at home

Through the CBR programme home exercise programmes this child has benefited a lot in mobility. The comments of the participant being:

> *This child has cerebral palsy. CBR volunteers come here so often to give home exercises programmes and leave a rehabilitation plan with the mother. CBR volunteers in Okamatapati received technical support from Volunteer Service Overseas (VSO) physiotherapist and the medical rehabilitation worker at the nearest district hospital, who both resigned. Her stiffness is now better and she is now able to sit with the help of a corner sit that was made by the CBR volunteer. She had problems with toileting as they don't have an accessible toilet. The CBR volunteer made a commode that she uses when she wants to go to toilet. The CBR volunteer put her on the waiting list for*

wheelchairs at Okakarara District Hospital, Rehabilitation Department.

The statement above shows the benefits of bringing rehabilitation services to the doors of people with disabilities using the CBR programme. An evaluation by the WHO, UNESCO, ILO, and IDDC (2010, p. 2) of the Thailand rehabilitation services shows evidence of the benefits of taking health and rehabilitation services to the community:

> Thailand has a long and successful history of primary health care which, over time, has evolved through many innovative strategies and activities. In many provinces, primary health care is based around networks of satellite units called primary care units, which are connected to and supported by large central hospitals. In 2006, one of these hospitals, Sichon Hospital, introduced community-based rehabilitation (CBR) to their network of primary care units. The Tha-Hin primary care unit is part of this network. It is located in a rural area and has a team of health personnel including a family doctor, a pharmacist, nurses and health workers. Before CBR was introduced, this team mostly carried out general health promotion and prevention activities. However, with the addition of CBR, the team also became responsible for identifying people with disabilities and addressing both their general and their specific health-care needs.
>
> The major focus of CBR was to provide health services for people with disabilities on their "doorsteps". A home health-care scheme was established (which is also for older people and people with chronic health conditions), providing a direct link to Sichon Hospital.

Home visits are conducted on a regular basis by members of the Tha-Hin team and a physical therapist from Sichon Hospital, enabling people to avoid unnecessary and costly travel. A protocol was also established for home-based rehabilitation. Local volunteers and family members were trained to provide basic rehabilitation (i.e. daily living skills training) to people with disabilities and were encouraged to promote inclusive education for children with disabilities. The multidisciplinary approach has ensured that all people with disabilities are able to access health care and rehabilitation services in their communities as well as referral services at Sichon Hospital when needed. A 2008 evaluation by the hospital concluded that the CBR programme had been effective in providing a range of health-care services for people with disabilities and their families, including early identification of people with disabilities and early intervention, health promotion and rehabilitation including functional training and provision of assistive devices. Overall, quality of life has been enhanced for all people with disabilities with improvements in their independence, mobility and communication skills. Parents of children with disabilities have also been provided with better support. Good working relationships have been established between all key stakeholders (Sichon Hospital, the primary care unit and the community) and inclusion of local volunteers and mobilization of other resources has created a sense of community empowerment and ownership.

In a case study in Kenya, the WHO, UNESCO, ILO, and IDDC (2010, p.46) revealed some of the benefits of rehabilitation services:

> The Association for the Physically Disabled of Kenya (APDK) has been providing comprehensive rehabilitation services in Kenya for the past 50 years, reaching over 500 000 people with disabilities. As a result of several partnerships, APDK has been able to establish a national rehabilitation network consisting of nine main branches, 280 associated outreach centres and many community-based rehabilitation programmes; these provide services such as therapy, assistive devices and support for surgical interventions.
>
> One of APDK's successful partnerships has been with the Ministry of Medical Services (formally the Ministry of Health). Over the past 30 years, APDK has worked closely with this Ministry to ensure that quality rehabilitation services are accessible to as many people as possible. Six of the nine APDK branches are located within government hospitals and the Ministry of Medical Services has provided over 50 health workers, mostly therapists and technicians, to work in these branches. The Ministry provides the salary for most of these health workers while APDK funds the programme costs. APDK established their first CBR programme in their Mombasa branch in 1992. Since 2000, they have extended these programmes to the major slums in Nairobi in order to reach those people with disabilities who are most vulnerable. CBR programmes provide home based rehabilitation and are an important referral link to APDK

outreach centres and branches. With financial support from CBM and Kindernothilfe, APDK has employed 32 CBR personnel to work in these programmes while the government has funded several therapy positions.

These successful examples demonstrate how community-based rehabilitation can be a vehicle that links the door of the person with physical disability in the community and the institutional rehabilitation services. This striking link improves the health status of people with physical disabilities, all aimed at improving their quality of life. The enhanced health status that CBR brings to people with disabilities was revealed by a study in Ethiopia. The Ministry of Labour and Human Welfare (1998) in its evaluation of the Debub CBR Programme in Ethiopia, concluded that the second most common effect of CBR on people with disabilities was recorded as improved health status.

A critique of rehabilitation of people with physical disabilities must include the importance of assistive devices. Though positive experiences were noted with rehabilitation, the study revealed that assistive devices for people with physical disabilities are still a great challenge.

Assistive devices

There are several publications that promote the availability of assistive devices. For example, The Convention on the Rights of Persons with Disabilities, Articles 4, 20 and 26, require states to promote the availability of appropriate devices and mobility aids and provide accessible information about them (UN, 2006). The United Nation Standard Rules on the Equalization of Opportunities for Persons with Disabilities also

call upon states to support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them (UN, 1993).

Despite all these calls to make available assistive devices, people with physical disabilities in developing countries, Namibia included, still face a big challenge in gaining access to these devices. This study discovered that the Okamatapati CBR programme is facing challenges in facilitating the availability of these devices from specialised centres as well as trying to initiate the production of devices in the community using locally available resources. Photograph 12 (Figure 12) on next page underscores the challenges of obtaining assistive devices.

Figure 12 (Photograph 12): A man with paraplegia in need of wheelchair replacement

Accessing assistive devices is one of the biggest challenges that the CBR programme is facing. The comments of the participant attached to this photograph are:

> *This man was assisted by the CBR programme to get this wheelchairs some years back. Now the wheelchair is small such that he need the assistance of someone to move around. He was told acquiring wheelchairs at the hospital is a long process. Bacause of the small size of the wheeelchair he now have lower back pain and was told by the nurse to acquire a lumber corset from orthopaedic technical services when he visited the local clinic. The mobile orthopaedic technical units that used to provide outreach services to Okamatapati has long*

stopped. The rehabilitation department at the nearest District hospital keep on informing him that they are still waiting for the Orthopaedic Technical Services in Windhoek to deliver the corset. Orthopaedic technical service advice on assistive devices seems to be difficult for our CBR volunteers as they have not received any training on this. We request the Okakarara District Hospital to fill the post of Medical Rehabilitation Worker. The one that was there used to transfer a lot of skills on mobility training.

The sentiments of critical shortage of assistive devices stated above is supported by the WHO (2008) when they revealed that in many low-income and middle-income countries, only 5–15% of people who require assistive devices and technologies have access to them.

In other countries, they have alternative ways of accessing assistive devices. The National Disabled People's Organization in Lebanon launched a production unit for wheelchairs and other assistive devices, such as, crutches, walkers, toilet chairs, orthopaedic shoes and specialized seating systems. They also created five distribution, repair and maintenance workshops around the country to facilitate access to these devices. The production unit and repair workshops employ people with disabilities. The disabled people's organization has also ensured an adequate national budget for assistive devices. CBR programmes can now refer people who need assistive devices to these centres to access assistive devices (WHO, UNESCO, ILO, & IDDC, 2010).

Literature discourages the idea of people with disabilities, to just wait to be sent assistive devices from specialised services, but, instead recommends that efforts should be made to use locally available resources to make their own devices. CBR programmes can identify local artisans and facilitate them to be trained in partnership with technicians. It is unrealistic to expect people living in rural areas to travel to specialized centres to have their devices repaired hence many people stop using their devices when they experience problems. Local artisans can be trained to make small repairs to assistive devices such as orthoses, prostheses and wheelchairs, for example repair orthoses by replacing straps, screws or rivets (WHO, UNESCO, ILO, & IDDC, 2010). However, it is important to note that assistive devices remain specialized devices. They entail technologies that must be carefully designed, produced and selected to ensure they meet the individual's needs. Poor selection and design can lead to many problems including frustration, discomfort and the development of secondary conditions. Some of the wheelchairs in Okamatapati community were donated but were of the wrong sizes. While this may have short term benefits, it can cause potentially life-threatening pressure sores. The need for professional rehabilitation workers, such as medical rehabilitation workers, to measure wheelchairs cannot be overlooked.

The statement above reveals that the post of the district medical rehabilitation worker is vacant yet this cadre is crucial in transferring knowledge to CBR volunteers and people with disabilities. In Namibia it is unfortunate that the training of these medical rehabilitation workers ceased before all the crucial district level posts across the country were filled. In other countries like Lesotho, the CBR programme is advocating for the revival of physiotherapy assistants, a cadre that was active and dwindled due to lack of support. Physiotherapy assistants will not only serve PWDs but all those in the community who require physiotherapy.

3.2.1.3 Key theme 3: Environmental barriers

The United Nations Convention on the Dignity and Rights of Disabled People has provided among others four chapters which cover all the aspects of life of people with disabilities. This includes preconditions for equal participation, target areas for equal participation, implementation measures and the monitoring mechanism. The Convention recognises that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (UN, 2006). The Namibian government ratified the UN Conventions on the Dignity and Rights of Disabled People. The government therefore shares the same concern raised in the Convention and it created some enabling environment for operationalisation of the actions to support PWDs. The National Policy on Disability was adopted by the National Assembly of Namibia in July 1997. The developmental objective of this policy is to "achieve a full social integration of people with disabilities in society". The achievement of this development objective will be made possible through the provision of accessible environments to people with physical disabilities. However in far outlying areas like Okamatapati community issues of accessibility to people with physical disabilities have not been properly addressed.

Environmental barriers were reported to be the biggest problem that the Okamatapati CBR programme is failing to address. The major barriers of access that were reported in Okamatapati were architectural barriers and communication barriers.

3.2.1.3.1 Sub-themes of environmental barriers

Architectural barrier

Architectural barriers for PWDs in buildings include lack of ramps, railings, signage, Braille print, adequate spacing, slip resistant flooring, accessible toilets and chairs, switches, shelves, wash basins, taps and telephones at an accessible height. This kind of infrastructure helps PWDs to be at ease and do their routines with minimum or no support. Apart from becoming self-reliant, such an internal atmosphere boosts their self-confidence and avoids unnecessary delay.   In public places there is a need for ramps and hand rails, kerb ramps in pavements; seats, taps, telephone booths, wash basins at an accessible height, Braille print, road signals with adequate timing, audio visual announcements and usage of bright colours, space for wheelchair users, accessible parking space, sign language, slip resistant grab bars and flooring, modified play area or equipment and rules. The following four photographs (Figure 13, 14, 15, 16) and verbatim statements illustrate the challenges that people with physical disabilities are experiencing with regard to architectural barriers in Okamatapati community.

Figure 13 (Photograph 13): No ramp for accessibility to the house

The comments of the participant being:

> *We still praise the CBR programme for facilitating people with disabilities to obtain houses through the Government Social Housing Scheme. However the houses don't have ramps. We request for ramps to be put and the toilets inside to be accessible.*

Figure 14 (Photograph 14): Sink basin too high to be accessible for a person in a wheelchair

The comments of the participant being:

> *This sink is too high for a wheelchair user.This makes people with disability dependent and further worsens their disability.They beg for help everytime even with simple things like fetching water for yourself. Lots of request have been send to authorities but it seems what comes from a person with a disability is not important. This is really frustrating us. We deserve a decent life like everyone else in this country.*

Figure 15 (Photograph 15): Local clinic with no ramp and hand rails for accessibility

The comments of the participant being:

I am a person on wheelchair. Since this clinic was build long time ago it has never being accessible to most people with physical disabilities. They preach the gospel of "health for all" and "vision 2030" but they are not setting a good example. The CBR committee has tried to sensitise them on accessibility but all has been in vain. This is not the only building that provides service in this area that is inaccessible. It's high time this is corrected we are tired.

Figure 16 (Photograph 16): Lack of ramp and hand rails at a local public building

The comments of the participant being:

> *Although the CBR programme has done a lot in other areas it has failed on accessibility to buildings. Most of the community meetings and functions are held at this building yet its not accessible. If I dont not get an assistant to bring me here I miss out of important community meetings.*

When health care and health care environments are experienced as being inaccessible, persons with disabilities are at risk of not having their health care needs fully met. Moreover, these barriers subtly convey messages about the value and normalcy of persons with disabilities, possibly reinforcing feelings of deficiency and

disempowerment. "Such internalized oppression, particularly when individuals are experiencing illness or injury, when their identities are fragile and in flux, can add unnecessary distress. At a minimum, such messages are not therapeutic, producing a preventable harm" (Kirschner, Breslin, & Lezzoni, 2007, p. 1122).

Of particular concern is the inaccessibility of medical equipment, such as examination tables and diagnostic equipment. Many health care facilities do not have height-adjustable examination tables, appropriate lifting devices, and weight scales that can accommodate wheelchairs, and most diagnostic equipment, such as mammography machines, are inaccessible to persons with limited mobility (Kroll, Jones, Kehn, & Neri, 2006). Research also indicates that hospital settings often fail to provide beds, hoists, and chairs that can accommodate obese persons (Pain & Wiles, 2006). The inadequate provision of assistance to transfer patients, from, for example a wheelchair to examination table, is further experienced as a barrier by persons with physical mobility limitations (Kroll et al., 2006; Pain & Wiles, 2006).

Inaccessible environments are associated with unmet health care needs and with inadequate provision of preventive health care in particular (Kroll et al., 2006). In a survey of physically disabled women in Ontario, 10% never had a PAP test or pelvic examination; they cited their inability to access the examination table as the main impediment (Cooper & Yoshida, 2007). The perception of inaccessible equipment, such as mammography machines, is often enough to inhibit women with disabilities from pursuing preventive health care (Schopp, Sanford, Hagglund, Gay, & Coatney, 2002).

In Okamatapati community most of the people with physical disabilities reported they experienced a problem of accessing the examination table.

Literature confirms that indeed accessibility can limit people with physical disabilities to participate fully in their environments. The results of a study done by (Momin, 2004) revealed that PWDs suffer various forms of barriers including: access to employment, obtaining appropriate work, retaining work, receiving appropriate wages, discriminating attitude, appropriate skills, lack of educational qualification, inaccessible environment and transport systems. The architectural barriers shown in Photograph 16 are clear evidence that architectural barriers can limit the ability of people with physical disabilities to participate effectively in economic activities. People with physical disabilities have great potential that could be tapped and harnessed for community development, given appropriate opportunities, attitude and approach.

Communication barriers

This study revealed that communication barriers have been not been fully addressed by the Okamatapati CBR programme. People with physical disabilities with communication barriers in Okamatapati community face a lot of hardships in socialization. There is an inappropriate school of thought stating that people with communication disabilities cannot communicate or do not know how to communicate. However, the opposite holds true since any one and every one communicates in day-to-day living. However, a society that claims to be communicative or communicable, does not bother to absorb or understand what a   disabled person is communicating.

Major communication barriers in Okamatapati community include: a lack of Braille material, manuals, magazines, newspapers and scribe facilities for people with visual impairment, and lack of sign language and sign language interpreters for people with hearing impairment. Apart from these, the study revealed that there is an immense need for disabled friendly curriculum and examination system, which involve a variety of options and adaptations in schools. However, the major communication barrier was reported to be at the clinic when people with physical disabilities seek health services. This is shown in Photograph 17 on next page.

Figure 17 (Photograph 17): A person with physical disability at a local clinic

Communication problems between health care providers and some of the people with physical disabilities is a great challenge that the CBR programme is facing. The comments of the participant being:

> *This person has a communication problem. The CBR programme has failed to sensitise health care providers to have their health information in accessible formats and for the health care providers to orally communicate sufficient and appropriate health information. Our hearing impaired people need interpreters to accurately convey their problems, and the visually impaired people need braille material e.g. tablets packets instructions and condom instructions need to be in Braille. Our health needs are not been met satisfactorily. Most of the times, most of the deaf people are turned away because of communication barriers.*

Effective communication is a cornerstone of health care, and is often cited by persons with disabilities as the most important factor in quality health care (O'Day, Killeen, Sutton, & Lezzoni, 2005). When communication is impaired, physicians report difficulty understanding symptoms, making health assessments and diagnoses, and determining appropriate treatment plans (Hoffman, Yorkston, Shumway-Cook, Ciol, Dudgeon, & Chan, 2005). Miscommunication can also impair understanding of health information, medical instructions, prescribed medications, and medical and surgical interventions, and can lead to poor adherence to treatment recommendations (Sullivan, Heng, & Cameron, 2006; Hoffman et al., 2005). O'Hearn (2006) for example reports that deaf persons misunderstand up to one-third of what is said in an un-interpreted medical encounter, and research conducted by Reeves and Kokoruwe (2005) found that 37% of deaf persons communicating without a sign language interpreter gained no better understanding of their health condition from the medical encounter.

Health information that is not available in accessible formats, as well as the failure of health care providers to orally communicate sufficient and appropriate health information, create further barriers to health care for persons with physical disabilities. Deficits in the provision of health information in formats accessible to persons who are blind or have low vision are well-documented, including a lack of Braille, large print and audiotape information (Smeltzer, Sharts-Hopko, Ott, Zimmerman, & Duffin, 2007). Health information is often written at a level that is not optimal for persons who are deaf, who have, on average, a fourth-or fifth grade reading level, and whose knowledge of medical vocabulary approximates, on average,

that of non-English speaking persons (Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006). This also applies to persons with intellectual disabilities, who may require simplified language and graphic depiction of health information (Brown, 2005). The study noted that plain language health information is also important when health care providers are relying on support workers to be the communication liaison with other health care providers in the system.

Persons with physical disabilities are further at risk of not receiving the same amount of health information from health care providers compared to that of able-bodied persons. Research conducted (Armour, Campbell, Crews, Malarcher, Maurice, & Richard, 2007) found that when compared to able-bodied counterparts, persons with disabilities are less likely to receive information on smoking cessation programs. Somerset, Campbell, Sharp, and Peters (2001) found that persons with multiple sclerosis are less likely to receive information on exercise and fitness.

Adequate support measures is sufficient to neutralize the impairment so that it does not constitute a disability, for example, if the mobility problems of a physically disabled person are resolved by adequate transport and accessibility, there will in principle be no difference between this person and any other non-disabled person. The same holds true for a person with communication problems. Consequently, this person, in principle, does not need any social assistance or protection and only needs the guarantee that opportunities are equal (ILO, 2002).

3.2.1.4 Key theme 4: HIV/AIDS and disability

One of the major goals of the last two decades of the disability movements has been to shift the conception of 'disability' from a medical to a social model. When we adopt this notion of socially constructed disability, then HIV/AIDS falls squarely into the domain of disability issues: "HIV/AIDS is a medical condition, yet its implications are social and political (though people with HIV/AIDS) are regarded as sick… (consequently) their experiences parallel the experiences of disabled people" (Shakespeare, Kath, & Davies, 1996, p. 196).

Hanass-Hancock and Nixon (2009), state that responses to human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) are often targeted as key populations that are believed to be at increased risk, such as migrant workers, sex workers, men who have sex with men, injecting drug users and indigenous people. However, one of the world's most vulnerable populations are individuals who live with permanent physical, mental, intellectual or sensory impairments, and they have almost been entirely overlooked (Groce, 2005). The recent Joint United Nations Programme on HIV/AIDS by the UNAIDS, WHO and Office of the High Commissioner for Human Rights (OHCHR) (2008) joint policy brief on disability and HIV, recognizes that people with disabilities are a key population at high risk of exposure to HIV. However, governments and policy-makers rarely consider disability issues in HIV/AIDS policies and plans. This issue and a number of other barriers make HIV prevention, treatment, care and support programmes and services unavailable and inaccessible to people with disabilities.

This study revealed that the issue of HIV/AIDS and disability has been overlooked in the CBR programme. CBR can be effective in raising the profile of disability in HIV/AIDS programmes and services.

3.2.1.4.1 Sub-themes of HIV/AIDS and disability

CBR and HIV/AIDS

Although research has focused on the disabling consequences of HIV/AIDS, there is very little documented information about HIV/AIDS for individuals with disability prior to infection. There is evidence to suggest that people with disabilities face inequalities in accessing health information and services.

People with physical disabilities in this study revealed the same sentiments stated above, that HIV/AIDS awareness are not included in CBR programmes and therefore PWDs are generally left out when it comes to issues of HIV/AIDS. Photograph 18 below revealed the sentiments of the participants about how the CBR programme is failing to address their HIV/AIDS issues.

Figure 18 (Photograph 18): A person with physical disability at a HIV/AIDS testing and counseling centre

It is important to include HIV/AIDS programmes in the CBR programme. One of the participants stated the following:

> *People with physical disabilities have families. They are also sexually active and therefore at risk of HIV/AIDS. The CBR programme has ignored our specific needs regarding prevention, education, access to testing, care and treatment. We need information about this deadly disease in the form that we all understand. For some of us who are deaf they need an interpreter and this reduces confidentiality and thus turns away most deaf people. We also need a platform to air our barriers with regard to HIV/AIDS, prevention, treatment, care and support.*

Literature supports the criticism that HIV/AIDs awareness programmes are not included in CBR programmes. There has been an increasing number of requests for further information from women with disabilities who would like to be better informed about the virus (Smith, Muuray, Yousafzai, Kaseba, 2004). People with disabilities perceive themselves to be marginalized from the global campaign to prevent the spread of HIV/AIDS.

Lack of accessibility as an issue reported in this study also contributes greatly to HIV/AIDs information accessibility. HIV information and messages are often not presented in accessible formats. For example, when prevention campaigns are conducted by means of newspapers and billboards, then blind people are excluded; when such campaigns are radio broadcasts then deaf people are excluded; and when campaigns use detailed and complex information then people with intellectual impairments may be excluded. According to the literature, people with disabilities, may not benefit fully from HIV and related sexual and reproductive health services for the following reasons: service providers may lack knowledge about disability issues, or have misinformed or stigmatizing attitudes towards persons with disabilities (South African AIDS Council, 2008). Services offered at clinics, hospitals, and in other locations, may be physically inaccessible, lack sign language facilities or fail to provide information in alternative formats such as Braille, audio or plain language (Action on Disability and Development, 2005).

 People with disabilities, particularly in the developing world, experience barriers to accessing health information and services. These can arise from restrictive cultural

norms (Smith et al., 2004), service limitations and lack of communication skills by staff (Ubido, Huntigton, & Warburton, 2002), poverty (Elwan, 1999), lack of mobility aids (May-Teerink, 1999), inaccessible buildings (Barnes, Mercer, & Shakespeare, 1999), marginalization in the community (Lang, 1998), illiteracy and lack of education (Helander, 1998) and gender inequality (DFID, 2000).

In this study most people with disabilities reported that the main reason they, and others like them in Okamatapati community, are been excluded from most HIV and AIDS programmes, is because they are often seen as human beings without a sexual life and therefore not potentially affected by HIV and AIDS. People with disabilities are often perceived as asexual individuals because they are viewed as being innocent or childlike, are thought to be unable to have intimate relationships, and/or are considered to have fewer sexual needs. However, this is a myth, as many people with disabilities are as sexually active as people without disabilities and therefore they are also at risk of being infected with HIV (Rohleder, 2009). Rohleder (2009) further states that low self-esteem and feelings of being unattractive or undesirable might lead to risky sexual behaviours. For example, disabled adolescents are often pressured into sex because of their need for social acceptance and inclusion, and therefore have a limited ability to negotiate safe sex (Groce, 2005).

Indeed people with disabilities have a lot of barriers to accessing HIV/AIDS prevention, treatment, care and support programmes. The above participant in Figure 18 also reiterated the need for a platform to air grievances regarding the barriers to HIV/AIDS prevention, treatment, care and support. It is unusual for policymakers to suggest that time, energy and resources should first be given to non-disabled

populations (World Bank, 2004). Where antiretroviral medications are scarce and services and support are limited, people with disabilities often report being placed last on the list of those entitled to care (World Bank, 2004). In settings with limited access to antiretroviral therapy and post-exposure prophylaxis, persons with disabilities may be considered a low priority for treatment (Groce, 2004). Where persons with disabilities are receiving HIV treatment, health professionals may not pay enough attention to potentially negative drug interactions between HIV treatment and the medications that persons with disabilities are taking. Some medications may actually worsen the health status of persons with mental health conditions, including depression (Catalan, 2005).

Research conducted in Mozambique on disability and HIV found that one reason people with disabilities are routinely excluded from HIV and AIDS policies and programmes is a refusal or reluctance to regard people with disabilities as sexual beings. The report shows this to be a further dimension of the stigma and discrimination directed towards people with disabilities. However, in South Africa a positive step has been taken to include people with disabilities in their national AIDS strategic plan in 2007-2009. This was prompted by a combination of leadership from champions within the government, the strong organization of the disability sector and self-representation in the South African National AIDS Council (International Disability and Development Consortium, n.d.).

However, in light of all these challenges that people with physical disabilities may face, there is clear support in policy since the UN (2006) in Article 25 of its Convention on the Rights of Persons with Disabilities   commits state parties to "provide persons with

disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other people, including in the area of sexual and reproductive health and population-based programmes", and in Article 26 to "take appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life".

Persons with disabilities have the right to participate in decisions which affect their lives, and should be fully involved in the design, implementation and evaluation of HIV policies and programmes, according to Article 4(3) (UN, 2006).

3.5 Summary

The results of the photo-voice method are discussed in this chapter as well as literature control. All findings were categorized into themes and sub-themes.

- ❖ Theme 1 discussed the secure livelihood of people with physical disabilities. It was found that there is a strong correlation between disability and poverty. Participants reported skills development, decent work, self employment, social protection and financial and material resources as the major pillars that can help them realize secure livelihood.
- ❖ Theme 2 covered health services. Participants viewed CBR as the main vehicle through which marginalised people (for example, the San) with complex health problems have been able to reach referral services. Their experiences with the CBR reaching the unreachable were unsurfaced. Rehabilitation and assistive devices were the other sub-themes that were reviewed.

- ❖ Theme 3 covered environmental barriers. Participants felt that this was the biggest issue that the CBR programme is failing to address. Two main environmental barriers identified were architectural barriers and communication barriers.

- ❖ Theme 4 discussed HIV/AIDs and disability. The participants felt that HIV/AIDs and disability were not yet addressed by the CBR programme. The study showed that people with physical disabilities were often not seen to be at risk of HIV or AIDS and therefore their specific needs regarding prevention, education, access to testing, care and treatment were being over-looked or ignored.

CHAPTER FOUR

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

"Disability is a matter of perception. If you can do just one thing well, you're needed by someone" (Martina Navratilova, n.d.).

4.1 Introduction

The research results and literature control were presented in the previous chapter. This chapter covers conclusions regarding the research findings, the attainment of the research objectives, and recommendations, as well as limitations of the study.

The purpose of the study was to gain insight and a comprehensive understanding of the experiences of people with physical disabilities who are participating in the CBR programme in Okamatapati community.

The objectives of the study being:

❖ To explore and describe the experiences of people with physical disabilities who participate in the CBR programme in Okamatapati community.

❖ To identify possible areas of improvement in the CBR programme in order to effectively address the needs of people with physical disabilities in Namibia.

4.2 Conclusion

Objectives were set to determine the experiences of people with physical disabilities who participated in the CBR programme in Okamatapati community. The following conclusions

were drawn based on the set objectives and according to the key themes and sub-themes that emerged from the study.

4.2.1 Objective 1: To explore and describe the experiences of people with physical disabilities who participate in the CBR programme in Okamatapati community

4.2.1.1 Conclusions

The photo-voice research design was used to meet this objective. Photo-voice entailed taking photographs, participating in group meetings, recording discussions, guided dialogue, journaling, and exhibition feedback. A two-phased data collection was done according to the practical guide to photo-voice method (Palibroda et al., 2009). For this study the researcher was the facilitator during the entire process of data collection and analysis. Phase 1 included an orientation meeting, the photo-voice process, group objectives, informed consent to participate in the study and photography. Phase 2 involved the photograph taking process, collection of photos, development of the photos, and reflection of the photographs. The participants undertook the data analysis by means of participatory analysis that included selecting photographs, contextualizing and codifying them. This was done using focus group discussions. The focus groups process had two parts: the small focus groups; a joint focus group of all small groups. The researcher deemed the data saturated, when no new statements regarding the photographs were made, and all the participants reached an agreement on what was discussed.

Four key themes with their sub-themes emerged from the data analysis regarding the experiences of people with physical disabilities who participate in the CBR programme in the Okamatapati community. These were **secure livelihood** with subthemes of skills development, self-employment, decent work and social protection; **health services** with

subthemes of reaching the marginalised and the unreachable, rehabilitation services, and assistive devices; **environmental barrier**s with subthemes of architectural barriers and communication barriers; **HIV/AIDS and disability** with subtheme of CBR and HIV/AIDS.

4.2.2 Objective 2: To identify possible areas of improvement of the CBR programme in order to effectively address the needs of people with physical disabilities in Namibia

4.2.2.1 Conclusions

This objective was met through full group discussion with all the participants to develop collective themes**.** The participants identified final themes, sub-themes, and areas of positive outcomes and possible areas of improvement of the CBR programme were elicited. It may be concluded that the participants experience positive outcomes of the existing CBR programme such as skills development, decent work, financial and material resources, and managing to reach the unreachable, such as communicating with the San population. Possible areas of improvement of the CBR programme will be discussed under the key themes elicited during the focus group discussions.

Secure livelihood

A secure livelihood is pivotal in a CBR programme. It is essential to ensure that both youth and adults with disabilities have access to training and work opportunities at community level (Carney, 2002). Self-employment for people with physical disabilities is one of the sub themes of secure livelihood that was identified as an area that need to be addresses. Employment was experienced as a key element to the lives of people with disabilities. The facilitation of access to loan schemes for IGPs was viewed as important for the promotion of the ability of self-employment of people with disabilities.

Health services

The results of the study reflect that rehabilitation services are very minimal due to lack of a district rehabilitation officer. According to the World Health Organisation's standards, there should be at least two rehabilitation workers stationed at the district level for community based services. The results of the study also reflect that the CBR programme in Okamatapati community is facing challenges, in facilitating the provision of assistive devices from specialised centres, as well as training CBR volunteers on the production of assistive devices in the community, using locally available resources.

Environmental barriers

The results of the study reflect that there is a great need to improve architectural and communication barriers, respectively. Health care providers should examine their own beliefs for assumptions and biases that might lead them to consider certain types of information to be irrelevant to people with physical disabilities. The availability of print, audio, and visual health information materials, in formats that are accessible to people with physical disabilities should also be evaluated and deficiencies addressed. All public buildings and houses of people with physical disabilities should be accessible in terms of or with regard to mobility/wheelchairs/crutches.

HIV/AIDS and disability

The study reveals that people with physical disabilities are often excluded from HIV prevention projects/programmes as well as AIDS health care efforts as a result of an

aggregation of various taboos and myths in the Okamatapati community. Participants felt that HIV/IDS training should be part of the CBR programme

4.3 Recommendations

Several recommendations were made as a result of the research study. These recommendations will not be made according to the themes elicited because they complement each other and they are interlinked in the activities of the CBR programme.

❖ It is recommended that the Okakarara district hospital should employ rehabilitation officers as a matter of urgency, to effectively implement the CBR programme.

❖ At a regional level it is recommended that the post of control rehabilitation officer be filled soon. This position is key to steering operational services as it translates, and links policies generated at national level into operational programmes at district and sub-district levels.

❖ National level co-ordination and allocation of adequate resources are other elements identified with successful CBR programmes. A national level co-ordinating body is recommended to ensure multi-sectorial collaboration which is needed for an effective CBR programme. As such, a national coordinating committee, consisting of representatives from the various ministries that collaborate to support CBR can be formed. The Ministry of Health and Social Services could take responsibility for coordinating support for the CBR programme.

❖ It is recommended that a loan scheme system be established by The Ministry of Trade and Industry, government agencies, as well as NGOs, for people with

physical disabilities to help with self employment. These loans should be availed annually through the CBR committee.

❖ Modifications to physical environments, such as the addition of appropriate signage ramps, signs etc. for accessibility by the regional and local council. The CBR committee should be given the mandate to facilitate the maintenance of these physical structure

❖ The office of the prime minister, disability unit, could develop national accessibility standards. All CBR volunteers across the country could then be trained on these accessibility standards so that they can do awareness programmes in the community on accessibility to public buildings and transport. The National Disability Council of Namibia (NDC) can act as the monitoring body for accessibility of all buildings and public transport for PWDs. NDC can issue compliance certificates to all owners of public transport and buildings. They can introduce fines for building/construction companies (and introduce penalties for designers/project engineers) that construct public buildings disregarding the regulations on accessibility within the law on planning and constructing public buildings.

❖ The government through Ministry of Works and Transport can establish a fund to cover expenses for adjustment of workspace for persons with disabilities.

❖ The government, as a long term solution, should introduce fee-waivers, reduced transport fares, and reduced import taxes and duties on durable medical goods and assistive technologies for PWDs.

❖ Specialized rehabilitation services, for example ophthalmology, audiology, orthopaedic technical services, physiotherapy, occupational therapy and speech

and language therapy should be decentralized by the Ministry of Health and Social Services to regional and district level. This will help to improve service delivery by reducing patient waiting time for rehabilitation services as shown in Photograph 12 (Figure 12, p.92)

❖ A monthly in-service training/education programme could be offered to community CBR volunteers by the district rehabilitation officer. The national level can help in budgeting for these trainings.

This program may include the following:

❖ Early identification of disability and rehabilitation at community level

❖ Mobility training and sign language interpretation for health care providers.

❖ Conducting community disability surveys.

❖ Implementation of the UN Conventions of the rights of persons with disabilities and the National Disability Policy of Namibia.

❖ Skills training in setting up income generating projects

❖ HIV/AIDS prevention, treatment and health care.

❖ HIV/AIDS home-based care workers should train CBR volunteers in basic health care techniques.

All levels of government will be informed through presentations and distribution of research report to heads of departments. It is envisaged that the core of the results be presented to the relevant offices by means of meetings and formulation of a plan of action to implement relevant aspects of the results in line with the policies and procedure of the different structure regarding CBR programme.

4.3.1 Recommendations for future research

Further research is needed in the following areas:

- ❖ Factors affecting the access of PWDs to general community health care services.

- ❖ The attitudes of the community about disability and the reasons motivating the families to get involved in CBR programme.

- ❖ The expected outcome of rehabilitation and the perceptions about the importance of rehabilitation for families of people with disabilities.

4.4 Limitations of the study

Restrictions in the study that may have decreased the credibility of the study (Burns & Grove, 1995) are discussed below.

4.4.1 Limitations with regard to the participants

The position of the researcher in the organisation might have influenced the responses of the participants. They may have thought that the researcher had power in the ministry, and therefore there may have been raised expectations of responding positively. Another limitation is the "Pygmalion effect" which could have affected the outcomes of the results if the participants had answered positively with regard to their experiences, because they thought the researcher expected them to answer positively (Babbie & Mouton, 2001, p. 221).

4.4.2 Limitations with regard to the sample

The sample comprised of people with physical disabilities whose ages ranged from 15 years to 65 years. They were not visually impaired nor were they deaf and dumb. They all had to be able to use a camera and describe the photographs taken by them personally. They had to be literate in English (basic) and had to have been involved with the CBR programme for at least one year. The inclusion criteria excluded people with physical disabilities, such as: the

visually impaired; the deaf and dumb; persons with hand tremors and/or multiple deformities of the hands that might have hindered them in taking photographs; all persons who were less than 15 years old and more than 65 years old. According to literature the ideal sample size for photo-voice method is 7-10 people. But the researcher could only manage to get 6 people who could meet the inclusion criteria.

4.4.3 Limitations with regard to literature

Some of the cited sources are not current. The researcher had a problem in obtaining literature especially on previous research on the experiences of people with physical disabilities on the CBR programmes. There is no evidence in the literature of studies undertaken in Namibia in terms of the experiences of people with physical disabilities participating in CBR programmes.

4.4.4 Limitations with regard to data collection

The disposable cameras did not have the selection option for the participants to photograph themselves where they needed to share their experiences. In order to do this they had to rely on family members to photograph them, such as in the case of Photograph 2 (Figure 2, p. 52).

4.5 Concluding remarks

The purpose of the study was to gain insight and a comprehensive understanding of the experiences of people with physical disabilities who are participating in the CBR programme in Okamatapati community. It is concluded that people with physical disabilities who are participating in the CBR programme in Okamatapati community are aware of the positive experiences the CBR programme affords them. They also revealed the gaps in the CBR programme which need to be remedied to ensure their quality of life is uplifted.

The participants identified secure livelihood as their number one priority which needs to be addressed. The study revealed a prevailing bleak situation in terms of environmental barriers. Architectural and communication barriers were pointed out as the major ones to access. Although there were positive comments that the CBR programme reaches the unreachable, the study revealed that rehabilitation services and accessibility of assistive devices were viewed as a drop in the ocean. The study also showed that HIV/AIDS programmes are not included in the CBR programme.

The active involvement of PWDs, their families and the community in assessing CBR programmes can contribute towards establishing an inclusive and enabling society in which people with disabilities can flourish. Assessments of the CBR programmes surely help the CBR programmes to evolve toward relevance and effectiveness.

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ANNEXURES

Annexure 1: Research Proposal Approval by University of Namibia
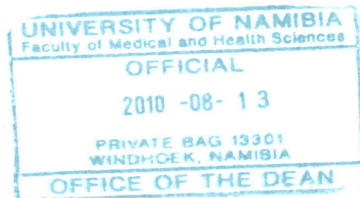
UNIVERSITY OF NAMIBIA

Private Bag 13301, 340 Mandume Ndemufayo Avenue, Pionierspark, Windhoek, Namibia

FACULTY OF MEDICAL AND HEALTH SCIENCES

Letter of permission: Post graduate students

UNIVERSITY OF NAMIBIA
Faculty of Medical and Health Sciences
OFFICIAL
2010 -08- 1 3
PRIVATE BAG 13301
WINDHOEK, NAMIBIA
OFFICE OF THE DEAN

To: Post graduate students
From: Prof A van Dyk

Date: 13 Aug 2010 ....

Dear Student: Mr T Shumba ....(sn 200938703)..................

The post graduate studies committee has approved your research proposal.

Experiences of people with physical disabilities who participate in the community based rehabilitation (CBR) programme in Okamatapati village Otjozondjupa region

You may now proceed with your study and data collection.

It may be required that you need to apply for additional permission to utilize your target population. If so, please submit this letter to the relevant organizations involved. It is stressed that you should not proceed with data collection and fieldwork before you have received this letter and got permission from the other institutions to conduct the study. It may also be expected that these organizations may require additional information from you.

Please contact your supervisors on a regular basis.

Prof A van Dyk

Annexure 2:

Approval to Undertake research by Ministry of Health and Social Services

9 - 0/0001

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198	Ministerial Building	Tel: (061) 2032562
Windhoek	Harvey Street	Fax: (061) 272286
Namibia	Windhoek	E-mail: amuheua@mhss.gov.na
Enquiries: Mr. A. Muheua	Ref.: 17/3/3/AP	Date: 15 November 2010

OFFICE OF THE PERMANENT SECRETARY

Mr. T. W. Shumba
P. O. Box 13198
Windhoek
Namibia

Dear Mr. Shumba,

Re: Study – Experience of people with physical disabilities who participate in the community based rehabilitation program in Okamatapati village, Otjozondjupa region.

1.   Reference is made to your application to conduct the above-mentioned study.

2.   The proposal has been evaluated and found to have merit.

3.   Kindly be informed that approval has been granted under the following conditions:

3.1   The data collected is only to be used for academic purpose;
3.2   A quarterly progress report is to be submitted to the Ministry's Research Unit;
3.3   Preliminary findings are to be submitted to the Ministry before the final report;
3.4   Final report to be submitted upon completion of the study;
3.5   Separate permission to be sought from the Ministry for the publication of the findings.

Yours sincerely,

MR. K. KAHUURE
PERMANENT SECRETARY

"Health for All"

Annexure 3: Photo-voice ethics: safety, impact, and obligation

Photo-voice is, by design, intended to include participants in participatory inquiry. They become documentary photographers at their site; their objective is to take pictures of activities, events, symbols, and people (photo subjects) that best respond to the framing (trigger) questions. The impact of this work can extend to include:

❖ The photo-voice photographers,

❖ The photo subjects, and

❖ The broader community that experiences the stories and photos through the

Community Gallery

Although safety and ethical considerations will vary across situations and rarely lend themselves to standard solutions, we can benefit from consideration of the following issues and questions.

Safety

Photo-voice participants are asked to photograph the work of their community. They may document elements of strength and issues of concern. Recording these elements for public dissemination could have negative repercussions for the participant – as the photo is being taken or after the photo and explanation of it have been disseminated. Here are some concerns and what we will instruct photo-voice participants to do in practice.

Key concerns

❖ Potential risks to photo-voice photographers from putting themselves in dangerous settings or situations.

❖ Potential risks to photo-voice photographers from photo subjects.

❖ Potential risks to photo-voice photographers from being identified in connection with their photos and stories.

Your practice

Give careful thought to the context and content of your photos – the communities in which you live, the issues you will be exploring and the situations you might get into while documenting your work.

❖ Because you know your neighbourhoods better than we do, we encourage you to use your street sense.

❖ "Shooting smart" – maintaining your personal safety – is of highest priority. No photo is worth personal danger.

❖ Remember that there are alternative ways to present issues (e.g., through abstract representation).

❖ Take your photos in public spaces (from which participants can photograph without being seen as trespassing) versus private property

Subjects of Photographs

The evaluation team and the photo-voice participants have an ethical responsibility to their photo subjects. We want to emphasize that photo-voice photographs are meant for dissemination. For this reason, there is no point in taking photos that cannot be shown for lack of the subject's permission through the release form. Here is our key concern and what we instruct photo-voice participants to do in practice.

Key concerns

❖ Potential risks to photo subjects from being identified in connection with particular situations or activities in photos.

Your practice

As a documentary photographer, you must respect the privacy of others. If someone does not want his or her picture taken, don't take it.

❖ It is essential that photo subjects sign a release form to be photographed. We have included forms. For children or youth under the age of 18, you will need approval from a parent or guardian. This is provided for on the release form. Please make more copies if you need them.

❖ Please emphasize to photo subjects that the photographs are meant for dissemination. Photos cannot be shown without a subject's release.

❖ Again, there are ways to portray issues of concern that don't require showing individuals

Impact on Your Community

Key concerns

* Potential risks to your community as a whole through generating conflict around issues or negative image.

Your practice

Because of your background using a number of dissemination tools, we are confident that you understand the importance of weighing potential for collective good against potential for both individual and collective harm.

Obligation of the Evaluation Team

Key concerns

* The photo-voice process puts the evaluation team in a close partnership with site participants. The effectiveness of our work is based on bonds of trust and our commitment that participant stories and voices be meaningful.

* At the same time, we know that you are invested in the photo-voice process and data. Because of the many potential uses for these data, we will share stories in a variety of ways for a variety of purposes

Your practice

* Because of your background using a number of dissemination tools, we are confident that you understand the importance of weighing potential for collective good against potential for both individual **and** collective harm.

* We will strive to build a participatory component through ongoing phases of analysis.

* You will be a part of the decision-making process in how the photos and stories will be disseminated.

❖ We will strive to balance agendas through finding "both/and" solutions and multiple avenues for dissemination that meet the needs of various stakeholders.

Annexure 4: Participants informed consent

Informed consent form

(For participants of Research Project)

Researcher / Investigator: Tonderai Washington Shumba

Telephone: 061-2032632

Mobile   :   0813631898

Academic Affiliation: University of Namibia

Faculty of Medical and Health Sciences

Ministry affiliation: Ministry of Health & Social Services

Rehabilitation Division

Researcher / Investigator `s Statement

The purpose of this consent form is to provide the information needed to help you decide whether or not to participate in this Research Project. Included is information on the importance and benefits of the research, possible risks, and your rights as a volunteer participant. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent". Please read the form carefully and feel free to ask any questions you may have.

Purpose of the Research Project

The purpose of the Research Project is to gain a better understanding of the experiences and concerns of people with physical disabilities and members of the Community Based Rehabilitation Committee in Okamatapati. The Photo-Voice process will be used to gather information. The purpose of taking photos, and asking for an explanation of the photo, is to help you tell your story with your own pictures. There are three goals of this research -

1. To enable you as a person with a physical disability to record and reflect on disability issues which have /have not been addressed by your Community Based Rehabilitation programme

2. To promote discussion about important disability issues through taking photographs and talking about them.

3. To engage policymakers about disability issues that are important to you as a person with physical disability

It is hoped that the results of this research will help us better understand issues surrounding Community Based Rehabilitation as a programme and provide recommendations for future

efforts. This information may be of assistance in improving the quality of life for persons with disabilities.

Procedures

If you choose to be in this study, you will be asked to attend a one day training workshop about Photo-voice method, use of cameras, and the responsibility of taking photographs. In the workshop we will discuss ethics, ways of seeing photographs, and the idea of giving back photographs to the community members as a way of expressing appreciation and respect. During the workshop you will be asked questions like "What is an acceptable way to approach someone to take their photograph?", "Should pictures be taken of people without their knowledge?", "What kind of responsibility does carrying a camera involve?", "What types of photographs do you think are private or personal?" and "To whom might you wish to give photographs, and what might be the implications?".

You will be provided with a camera and film for the research. The researcher will develop your pictures and provide you with copies for discussions. The best photographs will be selected for the research project.

The photo-voice process will ask that you spend 1 week taking photos with one roll of film (27 exposures) and then deliver the camera back to us. We will develop your photos and return them to you. We will then ask you to select and reflect in writing on six of your pictures that you believe are most meaningful in their description of the work of the fellowship and that you would want to share with a broader audience. You will return the photos and reflections to us. You will then participate in a 1-day learning workshop that will engage you and other participants in the photo-voice process through a facilitated discussion

and analysis. During this full-day session, we may be audio taping and video recording the conversations and taking field notes. At any time, you can request that the recorders be turned off. The recordings and transcripts will be kept in a locked file cabinet, and your identity (if you choose not to be identified by name) will not be disclosed (we will use "site participant").

Potential Risks, Stresses, or Discomfort

Some people may feel taking pictures is an invasion of their privacy. Some people feel a little self-conscious when they are photographed. Some people may not want to have their photo taken. No photographs identifying specific individuals will be released without a separate written consent of the photographer and the identified individuals. No picture is worth taking if it makes someone feel uncomfortable.

Because of the small number of participants (6), identity might be discerned; therefore, only limited confidentiality can be guaranteed. However, your privacy will be protected to the maximum extent allowable by law. Please know that participation in this project is voluntary and that you may choose at any time not to participate.

Benefits

This research project aims to benefit the CBR programme and the community as a whole. You may not directly benefit from taking part in this study; however, we believe that this research will give you a creative way to express yourself by identifying disability issues that are important to you.

Other Information

Taking part in this study is voluntary. You can stop at any time. Information about you is confidential. Study information will be coded and linked between your name and the code in a separate, secured place until the final document of the research is ready for submission. If the results of this study are published or presented, your name will not be used. Although the researcher will take every precaution to safeguard your confidentiality and privacy, it cannot guarantee.

If you have questions about this research study, please contact Tonderai W. Shumba at the telephone numbers listed above. If you have any questions about your rights as a research participant, please contact the University of Namibia Faculty of Medical and Health Sciences (+264 (0)61 206 3828)

_____

Signature of Researcher /Investigator   *Printed Name*

Date....................................

Participant's Comment

This research project has been thoroughly explained to me. I hereby volunteer to take part in this research project. I have been given an opportunity to ask questions and may ask further questions during the research process. If I have questions about my rights as a research subject, I can contact the University of Namibia Faculty of Medical and Health Sciences, +264 (0)61 206 3828.

I will receive a copy of this consent form.

❖ The facilitators have my permission to focus observations on my interactions with other participants during the photo-voice process.

- ❖ The facilitators have my permission to access the photos, photo reflections, and other documents I develop as part of the reporting process.

- ❖ The facilitators have my permission to use audiotape and video recording equipment for group and individual conversations during the photo-voice process.

- ❖ The facilitators have my permission to use audiotapes, video recorders, and photographs that may include me in presentations, as long as they do not identify me by name or through other background information without my consent.

Your signature below indicates your voluntary agreement to participate in this research.

_____

Signature of subject   *Printed Name*

Date.....................

Copies to: Researcher / Investigator's file

            Participant

Annexure 5: Subject informed consent

Informed consent form

(For person to be photographed)

(was translated into Otjiherero)

Photograph Consent Form

I, _____, hereby permit photographs of myself

to be used in research projects about experiences of people with physical disabilities. This

research is being done in conjunction with the Okamatapati Community Based Rehabilitation

Programme. I give permission to the investigator and photographers to use these photographs

for use in all relevant Community Based Rehabilitation research for the purposes of

education, communication, promotion and increasing understanding of disability issues.

I have read and understand this consent form and agree to its terms knowingly and

voluntarily.

_____

Signature   Date

Witness Signature   Printed name

Date...............................

(In the event an Individual cannot understand this form – a witness will explain the content

and confirm it was read and understood by the individual photographed)

_____

Parent/Legal Guardian Signature   Printed Name   Date

(Required for a child under the age of 18)

_____

Photographer's Signature   Date

Annexure 6: Photo reflection sheet

Research Topic:

Participant code number:

Photo Number:

Date:

Site location number:

Brief description of photo:

Why do you want to share this photo?

What's the real story this photo tells about the CBR programme?

How does this relate to your life, your family and the lives of people in your community, or both?

Annexure 7: Programme outline for data collection

Week	Action	Responsible person/s	
1	Issuing of photo-voice materials (27 exposure digital camera; photo reflection sheets; photo-release forms; handout on ethical considerations Begin data collection	Researcher	
2	Continue data collection Deadline: Submission of cameras on the last Friday of week 2	Researcher and Rehabilitation Officer for Otjozondjupa region	
3	One day discussion of the photographs taken Issuing of another batch of photovoice materials (27 exposure digital camera; photo reflection sheets; photo-release forms; handout on ethical considerations	Researcher and Rehabilitation Officer for Otjozondjupa Region	

	Continue data collection		
4	Continue data collection Deadline: Submission of cameras on the last Friday of week 4	Researcher and Rehabilitation Officer for Otjozondjupa region	
5	One day discussion of the photographs taken Three days of selection of six best pictures by each participant and completion of photo reflection sheets One day workshop for data analysis to come with group themes and subthemes.	Researcher	

Annexure 8: Probing questions

a) Potential probes for individual photos

Clarifying Questions

❖ Please tell me more about what's going on in this picture (may want to point out a particular activity or relationship in the photo).

❖ Please tell me more about the people in this picture. Why did you want to focus on them?

❖ Tell me more about why you took this picture.

Probing Questions

❖ How does this picture (or photo montage) reveal your experiences with the CBR programme?

❖ I see that this picture highlights a group meeting. How, in light of the photo and your experiences working with this group, do you believe both individual and collective leadership was learned in your group?

❖ I see that in this photo, you highlight [insert activity]. Tell me more about this activity and how it [insert: individual experiences, collective experiences; bridged differences; created new pathways for community participation, community change, new policies and practices, etc.].

❖ What particular partnerships were forged here? Can you explain what's new about this partnership?

❖ If you had taken a similar picture of these people/this activity, say, 5 years before, would the picture show something different? What improvements would you envisage?

❖ I see that this picture shows (insert place). Please tell me more about this place and why it's important to your group's work (probe for economic, political, cultural context, tensions and concrete group activities that addressed these).

❖ What does this photo **not** show? In light of your photo composition, what impact do you believe that you, as a member of this group, have made on your community? What impact has the collective group made? (Encourage the participants to draw on the photo as they present their response. Probe in the area of finance, culture and language, school-family-community partnerships, education, etc.)

❖ How is your photo composition different from and similar to the others in this cluster?

b) Potential probes for small-group discussions

Clarifying Questions

❖ Please explain to me why your team selected these six photos.

❖ Can you tell me more about how these six pictures work together – that is, what story do you intend to tell?

Probing Questions

❖ As you look over all these pictures, how are they similar and how are they different?

❖ What different stories are the pictures telling? What stories are they not telling?

❖ Why did you or your team select this as one of your six key photos?

❖ How does the composition illuminate the collective leadership for community change around the theme of [insert theme from probing questions]?

❖ I see that in the photo your team selected, you're highlighting [insert activity/activities here]. Tell me more and, in particular, how the photo speaks to [insert: individual

experiences, collective experiences, bridging differences, creating new pathways for community participation, community change, new policies and practices, etc.].

❖ What activities in these photos do you believe will endure in your community?

❖ How have the activities you highlight in your story affected other community activities?

❖ If the sky were the limit, what would be your next steps to further the work of your group in your community? What might hinder this way forward?

c) Potential probes for full-group discussion

❖ How does this picture (or cluster of pictures) tell the viewer what experiences are and the impact it has on [insert theme: secure livelihood, health services, environmental barriers and HIV/AIDS and Disability?

❖ How does this picture (or cluster of pictures) show differences (of race, class, ethnicity, gender, etc.) within a community and how these differences can be bridged?

❖ What challenges are being highlighted here? How are they being addressed successfully or unsuccessfully?

❖ As you build and reflect on these collective photos, how does it speak to creating systemic changes in a community? To what end?

❖ How does this story reveal elements of replication, adaptation, and growth of your group within and across communities?