

**AN INVESTIGATION INTO THE IMPACT OF A COMMUNITY-
BASED REHABILITATION INTERVENTION STRATEGY ON
PERSONS WITH PHYSICAL DISABILITIES IN AN URBAN
AND RURAL SETTING IN ZAMBIA**

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DECLARATION

I, the undersigned, hereby declare that the work contained in this research thesis is my own original work, that I have not previously submitted it in its entirety or in part to any other university for a degree or examination in any other university and that quoted material has been indicated and acknowledged by complete references.

Signature:

Date:

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ABSTRACT

The decentralisation of health care services in the primary health care system poses a challenge to the delivery of care to the communities in Zambia. Little is being done in the Ministry of Health to incorporate community-based rehabilitation (CBR) in the mainstream of primary health care service delivery despite rehabilitation being regarded as the fourth component of primary health care.

According to statistics, there are 256 690 (2.7%) persons with disabilities in Zambia, of which 38.8% are persons with physical disabilities. There are various community-based rehabilitation programmes in the country trying to meet the needs of persons with disabilities but these programmes have not been evaluated to determine the impact which CBR has on the lives of persons with disabilities. This study aimed to determine the impact of a community-based rehabilitation intervention strategy on persons with physical disabilities in an urban and rural setting in Zambia. It is hoped that the results of this study can be utilised as a means to lobby the Zambian government to become involved in the rehabilitation process.

An experimental study was done using a community-based rehabilitation intervention strategy on 66 persons with physical disabilities, of which 62% were male and 38% female, from Lusaka urban and Chipata rural community-based rehabilitation programmes. The researcher completed a self-compiled questionnaire during a personal interview with the participants/proxy. The questionnaire comprised demographic data and an assessment of the disability status of persons with physical disabilities regarding movement, functional activities and their integration into the community. Perceptions of persons with physical disabilities or their proxy as regards their disability status and experiences were also assessed by means of two open-ended questions in the questionnaire.

The community-based rehabilitation intervention strategy was conducted for six (6) months by the community rehabilitation workers who visited participants once a week. Data was analysed both quantitatively and qualitatively to determine the impact of a community-based rehabilitation intervention strategy and to test the null hypothesis.

The results of this study showed that in Lusaka on one hand, persons with physical disabilities had improvements in movement, functional activities and integration level. On the other hand, Chipata showed that persons with physical disabilities had improvements only regarding integration into the community. However, combined scores showed that community-based rehabilitation had an impact on persons with physical disabilities regarding movement, functional activities and integration into the community. The study also showed that there was a correlation between integration and movement, and integration and functional activities. There was no correlation between integration and caregiver provision and dependency, whereas there was a negative correlation between perceptions and integration.

Based on these findings, it is recommended that the Ministry of Health takes up the responsibility of spearheading and coordinating community-based rehabilitation programmes and incorporating the activities in the existing structures of primary health care.

OPSOMMING

Die desentralisasie van gesondheidsorgdienste in die primêre gesondheidstelsel hou 'n uitdaging vir dienslewering aan gemeenskappe in Zambië in. Die Ministerie van Gesondheid doen nie veel om gemeenskapsgebaseerde rehabilitasie (GBR) by die hoofstroom van primêre gesondheidsorg dienslewering in te lyf nie, ten spyte daarvan dat rehabilitasie as die vierde komponent van primêre gesondheidsorg beskou word.

Daar word beraam dat daar 256 690 (2.7%) mense met gestremdhede in Zambië is, waarvan 38.8% mense met liggaamlike gestremdhede is. Daar is verskeie gemeenskapsgebaseerde rehabilitasieprogramme in die land wat poog om in die behoeftes van mense met gestremdhede te voorsien, maar hierdie programme is nie geëvalueer om die impak van GBR op die lewens van mense met gestremdhede te bepaal nie. Hierdie studie het ten doel gehad om die impak van 'n gemeenskapsgebaseerde rehabilitasie-intervensiestrategie vir mense met liggaamlike gestremdhede in 'n stedelike en landelike omgewing in Zambië te bepaal. Daar word gehoop dat die resultate van hierdie studie gebruik kan word om druk op die Zambiese regering uit te oefen om by die rehabilitasieproses betrokke te raak.

'n Eksperimentele studie is gedoen deur 'n gemeenskapsgebaseerde rehabilitasie-intervensiestrategie op 66 mense met liggaamlike gestremdhede van die Lusaka stedelike en Chipata landelike gemeenskapsgebaseerde rehabilitasieprogramme toe te pas. Twee en sestig persent (62%) van die respondente was manlik en 38% vroulik. Die navorser het tydens 'n persoonlike onderhoud met deelnemers of hulle gevolmagtigdes 'n selfopgestelde vraelys voltooi. Die vraelys het uit demografiese data en 'n bepaling van die mense se gestremdheidstatus ten opsigte van beweging, funksionele aktiwiteite en hulle integrasie in die gemeenskap bestaan. Persepsies van mense met liggaamlike gestremdhede of hulle gevolmagtigdes rakende hulle gestremdheidstatus en ervarings is ook deur middel van twee oop vrae in die vraelys bepaal.

Die gemeenskapsgebaseerde rehabilitasie-intervensiestrategie is vir ses (6) maande toegepas deur gemeenskapsrehabilitasiewerkers wat die deelnemers een maal 'n week besoek het. Data is sowel kwantitatief as kwalitatief ontleed om die impak van 'n gemeenskapsgebaseerde rehabilitasie-intervensiestrategie te bepaal en die nulhipotese te toets.

Die resultate van die studie het aangedui dat mense met liggaamlike gestremdhede in Lusaka verbetering ten opsigte van beweging, funksionele aktiwiteite en vlak van integrasie getoon het. Mense met liggaamlike gestremdhede in Chipata, daarteenoor, het slegs ten opsigte van integrasie in die gemeenskap verbetering getoon. Gekombineerde tellings het egter getoon dat gemeenskapsgebaseerde rehabilitasie ten opsigte van beweging, funksionele aktiwiteite en integrasie in die samelewing 'n impak op mense met liggaamlike gestremdhede gehad het. Die studie het ook getoon dat daar 'n korrelasie tussen integrasie en beweging, en integrasie en funksionele aktiwiteite bestaan. Daar was geen korrelasie tussen integrasie en versorgervoorsiening en -afhanklikheid nie, en daar was 'n negatiewe korrelasie tussen persepsies en integrasie.

Op grond van hierdie bevindinge word aanbeveel dat die Ministerie van Gesondheid verantwoordelikheid vir die leiding en koördinasie van gemeenskapsgebaseerde rehabilitasieprogramme aanvaar en hierdie aktiwiteite by die aktiwiteite van bestaande primêre gesondheidsorgstrukture inlyf.

DEFINITION OF TERMS

The following terms are used in the study:

1. Caregiver

Any member of the family or community who lives with and provides continuous attention, assistance and support to a person with disability (Jones, Charlesworth & Hendra, 2000; Anderson, Linto, Edward & Wynne, 1995).

2. Community

A group of people living in one geographical area who share a common function or interest of significant importance in their lives to induce recognition among them of a common bond which draws them together in association and organisation (York, 1997).

3. Community-based rehabilitation (CBR)

The strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disability. Community-based rehabilitation is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services (UNESCO, WHO & ILO, 1994; Wirz, 2000).

4. Community involvement

A situation when people are part of the identification of a problem, a possible solution, planning, decision-making process, implementation and the evaluation of the outcome of that process (Chimere-Dan, 1996).

5. Community participation

The organisation of activities by groups of persons who have disabilities in conjunction with others to increase their ability to influence social conditions, and in doing so to improve their disability life situations (Peat, 1996).

6. Disabilities

This term is used as an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with the health condition) and that individual's contextual factors (environmental and personal factors) (WHO, 2001).

7. Disablement

A global term that reflects all the diverse consequences that disease, injury, or congenital abnormalities may have on human functioning at many different levels. The term 'disablement' does not distinguish among the different types of consequences (Jette, 1994).

8. Empowerment

A process by which knowledge is produced by community stakeholders in order to mobilise collective action for emancipatory structural and personal change (Stewart & Bhagwanjee, 1999).

9. Handicap

The disadvantage experienced by an individual as a consequence of impairment or disability. However, the term will not be used in this study as it has been altogether abolished by International Classification of Functioning, Disability and Health (ICF) and replaced by "participation restriction" (WHO, 2001). "Handicap" will only be used to differentiate the previous definitions of disability terms.

10. Impairment

Loss or abnormality in body structure or physiological function. Abnormality strictly referring to a significant variation from the established statistical norms (WHO-International Classification of Functioning, Disability & Health, 2001).

11. Medical model

Focuses on disability as a disease state of an individual problem and deviation from the norm, the disabled being biologically and psychologically inferior to those who are able-bodied, not fully human and so not able to make decisions for themselves (Lang, 1998).

12. Persons with disabilities (PWD)

Persons who have any type of disability, without referring to specific impairment (WHO, 2001; Rozario, 1997).

13. Persons with physical disabilities (PWPD)

Persons with neuromuscular and musculoskeletal impairments (WHO, 2001; Mulholland, Packer, Laschinger, Olney & Panchal, 1998).

14. Physical disability

Any physical condition which results from a disease/illness or injury, congenital or acquired, on the neuromusculoskeletal systems of the body. This results in an individual being unable to perform certain activities, for example limited movement, functional restrictions and eventual inability to participate in societal activities (WHO, 2001).

15. Rehabilitation

Utilised in the context of the definition by White and Johnstone (2000) and WHO (1994) as being a dynamic process of planned adaptive change in

lifestyle in response to unplanned change imposed on the individual by disease or traumatic incidence focusing on care and not cure. In the social context, rehabilitation will be referred to as a holistic and integrated programme of medical, physical, psychological and vocational interventions that empower a disabled person to achieve a personally fulfilling, socially meaningful and functionally effective interaction with the world (Banja, 1990).

16. Social integration

The principle which emphasises the right of persons with disabilities to use the services and facilities which are available to other members of society (Malcolm, 1997).

17. Social model

Focuses on society, and social barriers such as inaccessible buildings, unusable transport systems, pejorative social attitudes, prejudice and institutionalised discrimination; disability as a social-cultural rather than as a biological construct (Lang, 1998).

LIST OF ACRONYMS

ADL	Activities of Daily Living
AIDS	Acquired Immuno-Deficiency Syndrome
CBR	Community-Based Rehabilitation
CSO	Central Statistics Office
DIHRWR	Disability Issues and Human Rights Workshop Report
DRCSA	Disability Rights Charter of South Africa
EHCMB	Evelyn Hone College Management Board
HIV	Human Immuno Virus
IBR	Institution-Based Rehabilitation
ICF	International Classification of Functioning, Disability and Health
ILO	International Labour Organisation
INDS	Integrated National Disability Strategy

MCDSS	Ministry of Community Development and Social Services
MoE	Ministry of Education
MoH	Ministry of Health
MRPD	Ministry Responsible for Persons with Disabilities
MSTVT	Ministry of Science, Technical and Vocational Training
NGOs	Non-Governmental Organisations
NHPS	National Health Policy and Strategies
NPD	National Policy on Disability
NWHIC	National Women's Health Information Centre
OSDP	Office on Status of Disabled Persons
PDA	Persons with Disabilities Act
PHC	Primary Health Care
PWD	Persons with Disabilities

PWPD	Persons with Physical Disabilities
TEVETA	Technical Education, Vocational and Entrepreneurship Training Authority
UK	United Kingdom
UN	United Nations
UNDDP	United Nations Decade for Disabled Persons
UNESCO	United Nations Education, Scientific and Cultural Organisation
USA	United States of America
WHO	World Health Organisation
WPA	World Programme of Action
ZANCALD	Zambia National Association for Children and Adults with Learning Disabilities
ZFORD	Zambia Federation for the Disabled
ZNAD	Zambia National Association for the Deaf (now ZNAHH)

ZNADW	Zambia National Association for Disabled Women
ZNAHH	Zambia National Association for the Hard of Hearing (previously ZNAD)
ZNAHI	Zambia National Association for the Hearing Impaired
ZNAPH	Zambia National Association for the Physically Handicapped
ZNAPS	Zambia National Association for the Partially Sighted

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Movement, functional activities, caregiver provision and dependency, integration and perceptions of PWPd as regards their disability status and experience

CHAPTER 1

1.1 INTRODUCTION

This chapter presents the background of the study. It gives a brief overview of the community-based rehabilitation programmes in Zambia in order to provide insight into the basis for this study. The problem statement and the main aim of the study are also outlined. Furthermore, the significance and rationale for the study and the conceptual framework is described and the hypotheses are stated.

1.2 BACKGROUND OF THE STUDY

In 1990, the Zambian National Census reported that there were 69 073 Persons with Disabilities (PWD) in a national population of 8.09 million, i.e. an overall crude disability prevalence of 0.85% of the population. In 1996 there were 145 000 PWD, constituting 2% of the population, and in 2000 the National Census showed that there were 256 690 persons with disabilities out of 9.7 million people, constituting 2.7% of the population (CSO, 2003). This disability prevalence rate is seemingly insignificant, although rising, and would therefore be of little concern to government and civil society. It is, however, an apparent gross undercount compared to World Health Organisation (WHO) figures, which estimate that approximately 10% of citizens of any given developing country are disabled (WHO, 1994). This apparent inaccurate quantification of the extent of the problem in Zambia marks a very serious shortcoming for planners of health and in particular rehabilitation services. The lack of accurate figures on the part of government renders it unable to accurately recognise the needs of persons with disabilities. This could be due to several underlying factors. One such factor is a lack of awareness of the rights of persons with disabilities, as they are not empowered to openly express their needs in the community. Another reason is insufficient political will on the part of government. Additionally, persons with disabilities are not accorded

any representation at any level of policy decision making through which their needs could be expressed (DIHRWR, 1998).

In Zambia strong cultural beliefs associated with negative attitudes towards persons with disabilities further aggravates the plight of PWD. The insufficient political will of government results in the visible failure to treat social problems, including disability issues, in a holistic manner. This leads to a tendency to provide inadequate and ad hoc remedies for deeply rooted social issues which require both national and universal solutions (DIHRWR, 1998).

There are several disability organisations in Zambia which have tried to advocate the rights and needs of Persons with Physical Disabilities (PWPD). The Zambia Federation for the Disabled (ZFD) is an organisation established by PWD to coordinate the activities of all the various disability organisations in Zambia. The efforts of all these organisations and the government have not really touched the lives of persons with disabilities, especially in the rural areas. Even for the urban areas, services are inadequate and are not based on the principles of basic needs and human rights (DIHRWR, 1998).

The Zambian government, through the Ministry of Community Development, passed The Persons with Disabilities Act No. 33 of 1996. This act enabled the government to establish an Agency for PWD which operates under a Board of Directors with representations from all stakeholders, namely the Ministry of Health (MoH), Ministry of Science Technology Vocational Training (MSTVT), Ministry of Education (MoE), Ministry of Community Development Social Services (MCDSS) and the disability associations mentioned earlier. This Agency has not met the expectations of PWD in the country. It has tried to source funds from the MCDSS to give to disabled groups for business activities in order to gain self-sustenance and independence. The Persons with Disabilities Act (PDA) of 1996 holds hope for Zambia only if it can be translated

into action, as one of its mandates is to translate strategies into actions and it has the powers to do so (DIHRWR, 1998; PDA, 1996).

The MCDSS (1996) acknowledges that the Zambian government recognises its responsibility to provide public services but that commitment to the actual provision of services is limited due to inadequate resources (MCDSS, 1996 & 2002). This, and the belief that disability is a non-life threatening condition, is the main reason for non-commitment by government and the low priority attached to disability issues, as opposed to other conditions such as Human Immuno Virus / Acquired Immuno Deficiency Syndrome (HIV/AIDS), malaria and tuberculosis (MoH, 1992).

Despite the decentralisation of health care services to the community through the primary health care (PHC) strategy, the MoH continues to emphasise the medical model of health care delivery with the primary focus on curative rather than preventive and rehabilitative aspects. In addition, the MoH has no policy on rehabilitation services, despite the latter being regarded as the fourth integral component of PHC. The type of service delivery by the MoH reflects the limited commitment by the public sector (MoH, 1992).

1.3 PROBLEM STATEMENT

Despite recognising its country's disabled people, the Zambian government, through the Ministry of Health, has no clear strategies towards equalisation of opportunities for people with disabilities, in prevention, except vaccinations for the five communicable diseases in children, i.e. polio, measles, tuberculosis, diphtheria and tetanus (MoH, 1992). The apparent lack of accurate quantification of the extent of the disability problem in Zambia causes the government health planners to be insufficiently informed. This has led to inadequate rehabilitation services for disabled individuals, including PWP. In Zambia, no appropriate strategy for an effective rehabilitation service for PWD, especially PWP, has been identified. Presently, there are efforts by

Non-Governmental Organisations (NGOs), the community, the families and persons with disabilities themselves to implement community-based rehabilitation programmes. There is a perception that CBR programmes do assist PWD with regard to rehabilitation. On the other hand, these programmes have not been evaluated to determine their impact on the lives of PWD. The PWD, their families as well as rehabilitation professionals identify this as a problem. Hence, this study attempted to evaluate the existing CBR programmes with the hope of utilising the results as a strategy for the advocacy for the implementation of rehabilitation programmes by the Zambian government.

1.4 AIM

The aim of the study was to determine the impact of a CBR intervention strategy aimed at improving functional independence and integration in the community for persons with physical disability in an urban and rural setting in Zambia.

1.5 RESEARCH QUESTION

What was the impact of the CBR strategy on PWPD in relation to movement, functional activities, caregiver provision and dependency, and social integration into the community in an urban and rural setting in Zambia?

1.6 HYPOTHESES

The researcher hypothesised that:

1. CBR organisation and operational structure contributed to the integration of PWPD into the community;
2. The level of integration of PWPD into the community was related to movement, functional activities and caregiver provision and dependency, and perceptions;
3. The impact of the CBR intervention on PWPD was related to movement, functional

activities, caregiver provision and dependency, perceptions of PWPD as regards their disability status and experiences, and integration of PWPD into the community.

1.7 THE NULL HYPOTHESES

The null hypotheses were that:

1. CBR organisation and operational structure did not contribute to the integration of PWPD into the community;
2. The level of integration of PWPD into the community was not related to movement, functional activities and caregiver provision and dependency, and perceptions;
3. The impact of the CBR intervention on PWPD was not related to movement, functional activities, caregiver provision and dependency, perceptions of PWPD as regards their disability status and experiences, and integration of PWPD into the community.

1.8 OBJECTIVES OF THE STUDY

- 1.7.1 To describe the two study areas, Lusaka (urban) and Chipata (rural), and the two CBR programmes from those two areas used in the study;
- 1.7.2 To collect demographic data on participants from the two study areas;
- 1.7.3 To evaluate the existing CBR programmes in Lusaka and Chipata to establish the level of integration of PWPD into the community in relation to movement, functional activities, caregiver provision and dependency, and perceptions of PWPD with regard to their disability status;
- 1.7.4 To expose PWPD to a six-month CBR intervention strategy;
- 1.7.5 To re-evaluate the Lusaka and Chipata CBR programmes to establish the level of integration of PWPD into the community in relation to movement, functional activities, caregiver provision and dependency, and perceptions;

1.7.6 To determine the impact of CBR intervention on PWPD in an urban and rural setting in relation to movement, functional activities, caregiver provision and dependency, perceptions and integration of PWPD into the community;

1.7.7 To make recommendations to:

- the CBR programme managers
- the Ministry of Health
- the Ministry of Community Development and Social Services
- the District Health Management Teams from the two study areas
- the international donors of the two CBR programmes
- the community rehabilitation workers in the two CBR programmes
- the clients in the two CBR programmes
- UN agencies (WHO, ILO, UNESCO, UNICEF)
- the researcher

1.9 CONCEPTUAL FRAMEWORK

This study evaluated the existing CBR programmes in the Lusaka urban and Chipata rural areas in Zambia. The aim was to determine the impact of a CBR strategy on PWPD with the aim of enhancing social integration of PWD into the community. The study focused on neuromusculoskeletal impairments as the cause of the physical disability. WHO (2001) describes neuromusculoskeletal impairments as those involving the structures and functions of the nervous, muscular and skeletal systems of the body and that these structures are the basis for stability, mobility and functional activities.

The 1980s have been described as a period in which social policies, awareness and adjustment programmes were needed to prevent disability and equalise opportunities for PWD. One of these instruments is the International Classification of Impairment and Disability and Handicap (ICIDH) of 1980 which was formulated as a tool for the classification of disease (Hurst, 2000; Pfeiffer, 2000). People with disabilities expressed the inadequacy of ICIDH and ICIDH-1 in addressing wider contextual issues

such as the negative attitudes and environmental barriers experienced by persons with disabilities (Simeonsson, Leonardi, Lollars, Bjorck-Akesson, Hollenweger & Martinuzzi, 2003; Pfeiffer, 2000). ICIDH was criticised as blaming the victim even though the disadvantage is not caused by the impairment or the disability but imposed by society (Pfeiffer, 2000) hence its revision and replaced by the ICIDH-1 and later, ICIDH-2. The ICIDH-2 instrument has now been replaced by the ICF of 2001. The ICF has been formulated to provide a unified and standard language and framework for the description of health and health-related states of functioning (WHO, 2001).

Another instrument is resolution 37/52 of December 1982, where the General Assembly of the United Nations adopted the World Programme of Action concerning persons with disabilities. This resolution requested member states to establish well-functioning and effective national committees or similar bodies in order to attain the multisectoral objectives contained in the World Programme of Action (Disability Rights Unit, 2000). Internationally, various initiatives and instruments were developed to try to address the needs of PWD. The environment refers to the physical and social surroundings within which the disability exists, including the definition of the situation by other people and the reactions or expectations of significant family or peer group members.

The ICF of 2001 showed that there are various interactions which come to play in the process of impairment, activity limitation and functioning and participation restrictions within the environment, as shown in Figure 1 below.

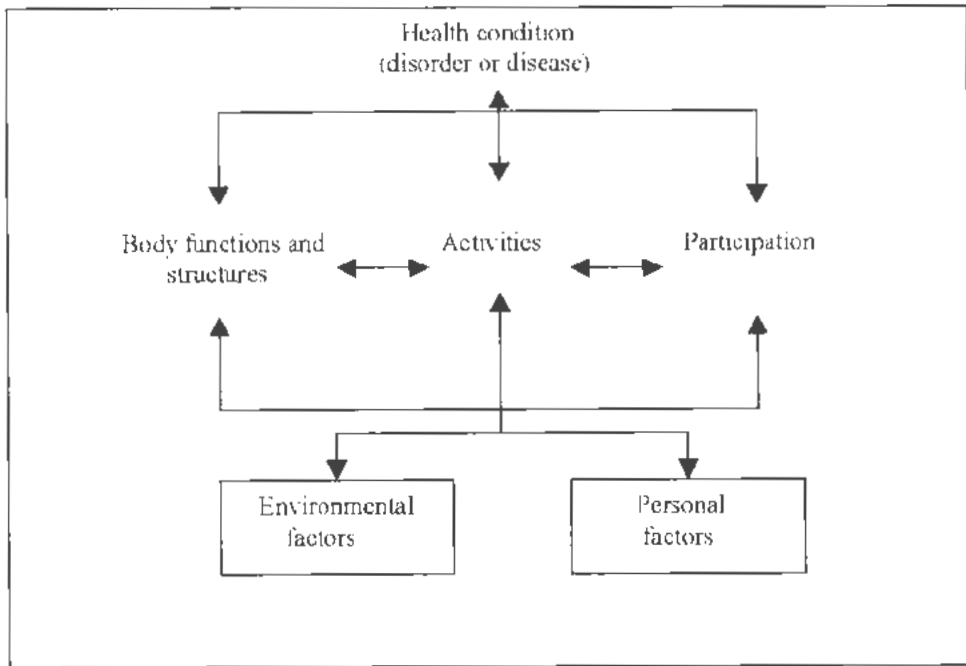


Figure 1.1: Interaction between the components of ICF (Source: WHO, 2001)

Figure 1.1 illustrates that an individual's functioning in any environment is a result of a complex relationship between a health condition and contextual factors (environmental and personal factors). The presence of impairment is not necessarily the cause of any activity limitation. On the other hand, the presence of an environment which restricts the participation in the activities in the family could lead to eventual impairment, e.g. mental depression. Thus the concept of disability can also be attributed to personal factors, e.g. character, in addition to the existing notions of disease. It is obviously true that not all forms of disability are as result of illness or disease. The assumption can then be made that impairments do not always lead to disabilities but could still lead to restriction of participation, and that severity of related impairments, disabilities and handicaps are not always constant (Bury, 2000).

It is therefore apparent that such a model as described by ICF could be a useful tool for researching rehabilitation outcomes and perhaps developing factors which may help to predict early in the rehabilitation process the potential for selecting the appropriate rehabilitation strategy for PWD. Thus, programmes could be adjusted earlier to meet the additional needs of particular individuals. For the purpose of this study it would be assumed that community-based rehabilitation can deal with the personal and environmental factors in our communities.

While working in collaboration with CBR programmes in both urban and rural settings, the researcher noted that CBR appears to be one of the strategies from which PWPD derive considerable benefit in the form of provision of rehabilitation services such as counselling, community support, provision of local affordable appliances and eventual integration into community life. The researcher therefore wishes to evaluate the impact of CBR intervention strategy aimed at improving functional independence and social reintegration. Georgievski (2000) reports that the Croatian-Canadian Project for the Development of Rehabilitation in the Community envisaged that CBR is an appropriate strategy for promoting social integration. It has also been gradually realised that rehabilitation cannot remain the exclusive task of institutions, and that most rehabilitation services have to be provided in the community in order to ensure increased coverage at affordable cost.

In support of this assertion, Lundgren-Lindquist and Nordholm (1996) observe that, because of the emphasis on community infrastructure to provide rehabilitation assistance to PWD within the community, CBR is seen by many as a totally rural programme. However, CBR calls for a full and coordinated involvement of all levels of society, including the community, intermediate and national, in order to achieve the goal of full representation and empowerment of persons with disabilities. Hanson, Nabavi and Yuen (2000) state that regained life satisfaction is reintegration into the community on both micro (individual) and macro (societal) level through community-based rehabilitation. It is therefore necessary to develop delivery programmes that are

balanced, realistic and tailored to the needs as the best answer for PWD, so that they make a valuable contribution to the enrichment of our social, economic and cultural life.

Therefore CBR may be the best answer to the majority of PWD, but it is of great importance that persons with disabilities are carefully assessed and given equal opportunities for development of their full potential. Community-based rehabilitation programmes have been initiated in many of the developing countries; however, not all of these are sustained over a period of time. In countries where a large proportion of the people live in poverty, such as Zambia, governmental priorities may not emphasise the needs of disabled people (Lundgren-Lindquist and Nordholm, 1996).

In Zambia, the government's health vision is the development of a health care system which provides Zambians with equity of access to cost-effective quality health care as close to the family as possible. This means the provision of better management for quality health care for the individual, the family and the community. In order to facilitate the attainment of this vision, the government has adopted the primary health care strategy as the most appropriate mode (MoH, 1992).

Moreover, the government recognises that achieving a healthy society is not primarily a medical issue but rather a political and socioeconomic one; hence the prominence given to intersectoral collaboration with other ministries in the implementation of health reforms. However, since the health services play an important role in achieving "Health for All", the MoH strives to enhance preventive, promotive, curative and rehabilitative services as a major mode for achieving its vision, with the individual taking responsibility for his own health with the support of the family and the community (MoH, 1992).

Using the health vision as basis, the MoH has set out health goals to be achieved as the PHC strategy is being implemented and applied. Even though there is no outlined policy on disability management, one of the health goals entails "ensuring effective

programmes against common causes of mental disability" (MoH, 1992). Yet another health goal entails "promoting strong, supportive family relationships and communities" (MoH, 1992). This principle is supported by Mann (1997a) who reports that a large proportion of health services are supplied to the ill and the disabled within the framework of the home and the community. He states that health and social services are best utilised by the disabled and ill people in their own home environment where physical, emotional and social needs are met. Mann (1997b) further states that the framework of our care can change from that of an institution to the home.

York (1997) also supports this principle and observes that the family and the community have common ties which include services such as churches, schools, health centres and shops found within the community. These services build interests, address problems and cultivate common needs which bind the community together. He further reports that not all residents use all the services, but states that the various networks in the community must have the different services available. Not every resident has to share every interest, be aware of every problem or equally feel every need but the interests, problems and needs must be common to significant overlapping community groups to bring about solid interaction.

All the outlined issues of the family and community support the notion that human interaction, including that of PWD, takes place in the home and community which can embrace social, health, economic and emotional or psychological needs. According to Hale and Wallner (1996), satisfactory home care depends on variables such as environmental barriers, social support, family function, financial resources, intellectual and emotional adaptability, and changes in social roles and the use of time. It is true then that disabled individuals, and especially PWPD, are best cared for and supported in the home by family and community members who share and understand the same interests and needs.

Stricklin (1997) reports that in recent years, however, the informal family home care has been profoundly affected by seriously changed circumstances – regarding family

economy; the decrease in family size; the ageing of generations; the increased proportions of older people without family members; and, most of all, the need for increasingly sophisticated methods of care not usually available from family members. In home care services, the family is treated as a social system with cultural values, structural and developmental needs where individual needs are identified, intended outcomes are stated and health interventions are jointly planned and organised. This serves as another reason why governments, including Zambia, should include in their policies the developmental issues concerning the disabled in the community, taking into account their local resources, knowledge and skills within the framework of the family.

The above issues, confirmed by the experiences of the researcher as a physiotherapist both in public and private sector institutions, raised many questions regarding the needs of PWD, and in particular those persons with neuromuscular and musculoskeletal impairments, i.e. persons with physical disabilities (PWPD). Some of the questions raised are: What are the needs of PWPD? Who should empower PWPD to be able to express their needs? Which rehabilitation strategy will best benefit PWPD?

These questions inspired the researcher, who is a physiotherapist and lecturer at Evelyn Hone College (EHC), a tertiary institution training, among others, health professionals in rehabilitation related courses. Having worked as a clinical physiotherapist and lecturer specialising in disability and rehabilitation for over twenty years, it has been necessary to face the issues pertaining to persons with disabilities who are part of the community in which we live.

Thus, the concepts of this study are built on the fact that disability exists in our communities, that different perceptions regarding disability prevail in different communities and, above all, that various interacting factors cause PWD to have limited activity and functional participation restrictions in the communities within which they live. Some of these limitations could be addressed by implementing a comprehensive

strategy such as CBR. In Zambia, there is a need to lobby the government to take ownership of these CBR programmes. However, how could the government take ownership of a strategy whose efficacy hasn't been proven? Hence the need to evaluate the existing CBR programmes in Zambia and supply the government with evidence that CBR does have an impact on the lives of PWD and should be adopted as a strategy to address the rehabilitation needs of Zambia.

1.10 SIGNIFICANCE OF THE STUDY

The study will provide information for the Ministry of Health and rehabilitation team members in Zambia on the impact of CBR intervention in relation to perception, movement, functional activities, caregiver provision and dependency, and integration into the community.

The study will also provide information on the evaluation of the CBR intervention strategy on PWPD in an urban and rural setting in Zambia. The two different demographic locations of the study areas will give insight into the different needs of PWPD within their different environments. This information will help health planners, rehabilitation workers, therapists, PWPD themselves and the community to understand and use their human rights for the benefit of all. Internationally, the information will help other CBR programmes in Africa and other developing countries with further improvement of their programmes. This information will also be a tool for further research on the improvement of the CBR intervention strategy in developing countries with inadequate resources like Zambia.

1.11 CHAPTER SUMMARY

In this chapter, the background of the study was reviewed. According to the CSO, there were 256 690 (2.7%) PWD in Zambia's 2000 National Population Census (CSO, 2003). WHO's global estimate is that 10% of any developing country's population is disabled, i.e. 988 559 in Zambia's case. It is assumed then that the figures revealed by

CSO do not depict Zambia's actual disability prevalence. However, despite this population of disabled people in the country, the Zambian government, through its decentralised health reform system, has not formulated any policy on rehabilitation to meet the needs of PWD.

The conceptual framework is based on this background of a non-existent rehabilitation policy. Despite this non-existence of policy, NGOs, PWD, their families and some health professionals have established CBR programmes in some parts of the country. These CBR programmes have not yet been evaluated to determine the impact on the lives of PWD, especially PWPD.

The aim of the study is therefore to determine the impact of a CBR strategy on PWPD in an urban and rural setting in Zambia, and use the results as a tool for advocating the formulation of a comprehensive policy on rehabilitation by the Zambian government.

This study is significant in that it can be a useful document for health workers, trainers of health professionals, students, PWD, their families and the community in the execution of their work and responsibility to one another.

The study will be discussed in detail in the following chapters:

- Chapter 2 is a literature review, focusing on the concepts of disability, functioning and participation restrictions in the context of IFC. Prevalence of disability internationally, in Africa and in Zambia will be reviewed, focusing on physical disability, the causes and impact of disability, especially regarding sociocultural and economic factors. Rehabilitation will be discussed, with emphasis on CBR, its concepts, the merits and demerits of its planning and implementation, and related to other countries and the Zambian situation;
- In Chapter 3 the methodology of the study is outlined, stating the main aim, objectives, study design and instrumentation;
- The results of the research are presented in Chapter 4;

- These results are discussed in Chapter 5;
- Chapter 6 provides a conclusion to the study; and
- Some recommendations are made in Chapter 7.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The focus of this study is to determine the impact of a CBR intervention strategy in an urban and rural setting in Zambia. The literature presented in the study is largely on an international level with limited reference at local level due to a lack of adequate and relevant research material on this topic in Zambia. The literature review has been divided into three parts: the general overview on the research topic; disability concepts and the prevalence of disability globally and in Zambia; and issues pertaining to rehabilitation with emphasis to community-based rehabilitation.

2.2 GENERAL OVERVIEW

Disability and rehabilitation, specifically community-based rehabilitation (CBR), are defined and related aspects are examined. Community-based rehabilitation is discussed in reference to rural and urban Zambia. An attempt is made to establish prevalence of disability internationally and in Zambia in order to gain an understanding of the extent of disability problems. Physical disability is discussed in relation to functional independence and caregiver provision and dependency of PWPDP. Issues pertaining to the integration of PWPDP into the community are also examined. The Zambian disability situation is then discussed in relation to the organisation of health services, health financing and disability policies in Zambia and other countries. This is done in order to gain a better understanding of the Zambian situation regarding rehabilitation, and more specifically CBR.

2.3 DISABILITY CONCEPTS

2.3.1 Definition of disability

The definition and measurement

Of disability is of increasing interest as people are living longer and chronic diseases and their effects, including disability, are becoming relatively more common. In many countries, the definition of disability varies among the health, educational, vocational and social services. Nonetheless, in 1980 the World Health Organisation (WHO, 1995) developed the International Classification of Impairments, Disability and Handicap (ICIDH-1).

In the context of the health perspective, impairment is defined as any loss or abnormality in body structure or physiological function, abnormality strictly referring to a significant variation from the established statistical norms. Disability is referred to as any activity limitations and participation restrictions (WHO, 2001). This definition of disability covers what was previously referred to as “handicap” and which is now referred to as “participation restriction”. The ICF focuses on the health domain and health related domains which describe the perspective of the body, the individual and the society within which the individual lives and operates (Bury, 2000).

Beckung and Uvebrant (1997) comment on the WHO definitions that impairment represents disturbances at the organ level. Disability reflects the consequences of impairment in terms of functional performance and activity by the individual. Disability thus represents disturbance at the level of the person, while a handicap is defined as a result of an interaction between an individual with an impairment or disability and the social, cultural or physical environment within which the individual lives.

These definitions indicate the progressive level of limitation of functional performance from an organ of the body, the individual himself and the outside environment, which involves other people. Unlike the ICIDH-1, the United Nations’ definition summarises a

great number of different functional limitations occurring in any population in any country of the world. The UN indicates that people may be disabled by physical, intellectual or sensory impairments and medical or mental illness. The term “handicap” is referred to as the loss or limitation of opportunities to take part in the life of the community on an equal level with others. This relatively refers to functional capability of an individual to participate in personal, family and community activities (UN, 1990).

According to Bury (2000) disability activists in the revised ICIDH-2 have preferred to define disability as “social oppression” brought about by discrimination and exclusion. This definition comprises characteristics of a “social model” which advocates that disability has nothing to do with the body but has everything to do with society. “Handicap” on the other hand is replaced by “participation”. However, Bury (2000) argues that the ICIDH-1 did not intend to characterise these relationships in a rigid or linear manner. A handicap, for example, is a function of social context in which people live, as well as the effects of impairment or disability. Thus, although the relationships between the different concepts have been worked through in a number of new ways, he is not sure what additional benefit this change will bring to researchers, persons with disabilities and others who wish to use ICIDH-2. As yet another definition is presented by the ICF it can be seen that the definition of disability concepts have undergone various stages of review.

It is important to note that even though the definition of “impairment” is still reflected, it has been encompassed in the disability process. Also, the ICF has abolished the use of handicap altogether and have replaced it with “participation restrictions”, denoting the problems an individual may experience in the involvement in life situations. The presence of a participation restriction is determined by comparing an individual’s participation to that which is expected of an individual without disability in that culture or society (WHO, 2001).

However, disability can also be defined according to legal implications of limitations incurred on an individual after impairment. According to Mehlman and Neuhauser (1999), the American law defines disability as a mental or physical impairment which substantially limits one or more of the person's major activities. The law defines a number of major life activities which are: caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working. The list is not exhaustive because, in some countries for example, sexual relationships among persons with disabilities and between the disabled and able-bodied people are not readily accepted culturally. This is because PWD are regarded as a low class that should not be married to able-bodied persons (Mehlman & Neuhauser, 1999). It should be noted that the ICF and other studies reflect the importance of cultural norms in the interpretation and definition of disability issues, especially for PWPD.

Another dimension of disability is the investigation of reasons for disability. Jette (1994) refers to reasons why a person becomes disabled or does not. These reasons are:

- how the individual defines the disablement situation and reacts to it (e.g. denial, depression)
- how others (e.g. spouse, children, friends) define disablement situation and set expectations for the individual (e.g. sex-role expectations)
- characteristics of the physical environment itself (e.g. environmental barriers)

These reasons seem to be in agreement with the WHO (2001) definition of impairment and disability where activity limitation and participation restrictions are embraced looking at the individual and the environment.

In addition, these outlined reasons correspond with WHO (1980) which clarifies that handicap is not a classification of individuals. Rather, it is a classification of circumstances in which PWD are likely to find themselves, circumstances that place

individuals at a disadvantage relative to their peers or those of their age when viewed from the norms of society. Jette (1994) further states that dimensions of handicap included in ICIDH are orientation, physical, independence, mobility, occupation, social integration and economic self-sufficiency.

Therefore, consideration needs to be given not only to the capacities of PWPD (a function of the underlying pathology, impairments and functional limitations) but also to the person's capacities in relation to relevant aspects of the situation, e.g. his or her social perspectives of the situation and those of the environment, in understanding the relational aspects of disability.

The various and diverse definitions lead to a better understanding of the complexity of disability issues which have an impact on the choice of rehabilitation strategy for PWPD and its implementation. It is therefore important to highlight this complexity of disability issues in terms of the prevalence of disability.

2.3.2 Prevalence of disability

Since the United Nations Decade of Disabled Persons, 1983-1992, knowledge about disability has increased. Several studies have attempted to establish the prevalence of disability in various parts of the world (Grimby, Finnstam, Nelson & Rasid, 1988). According to Greenwood (1985), there were 500 million disabled persons in the world; that is about one in ten people of the world population. Helander (1990) and the United Nations state that the world's estimated population of persons with disabilities is about 10% and the majority are living in developing countries. Studies in epidemiology suggest that about 10% to 15% of all children experience a chronic illness in childhood (Northan, 1997). An investigation carried out by the United Nations show that at least every second person on earth is physically handicapped in one way or the other (Bonn, 1997).

According to Marks (1997), reported estimates regarding the number of PWD in Britain and the United States of America vary enormously. Most official estimates recognise that persons with disabilities form one of the largest minority groups, with around 6.5 million disabled people in the United Kingdom (UK) and 3.5 million disabled in the United States of America (USA).

Statistics from different sources indicate that in Bangladesh, 8.5% of the population have disabilities. In a poor country like Bangladesh, where life is difficult for many able-bodied people, PWD are even less likely to be educated, employed or receive suitable medical care. Mortality amongst children with disabilities is much greater than amongst able-bodied children and the morbidity is also higher amongst disabled persons (Hosain & Chatterjee, 1998). Price and Marquis (1999) report on surveys undertaken in 1989 and 1991 in the Asian Pacific Cook Islands, in Western Samoa and on Malaita in Solomon Islands. The study indicated the incidence of disability being 3.5%, 2.5% and 3.2% respectively. The disabled workers surveyed in these countries have suggested that these figures are an underestimate because of an increase to an average of 5.6% in the 1994 survey.

According to Pongprapai, Tayakkanonta, Chongsuvivatwong and Underwood (1996) the Thailand National Statistics office reported in 1978 that 0.7% of the total population were disabled. In South Africa, Mweshi (1998) reports that there is a serious lack of reliable information on the nature and prevalence of disability. However, disability prevalence for the general population has been estimated to be approximately between 5% and 12.8% (South African Institute of Race Relations, 1997). However, the Department of Health Directorate: Chronic Diseases, Disabilities and Geriatrics reports that South Africa has a disability incidence of serious disability of 5.9% of the total population (Schneider, Claassens, Kimmie, Morgan, Naiker, Roberts & McLaren, 1999). However, McLaren and Philpott (1997) reports of the preliminary census figures of 1985 to be 12.7% for South Africa. The researchers acknowledge the difficulties in the available data and attribute the differences to the non-existence of central data

base. Another reason noted by the researchers is the lack of standardised rates for confirmed impairment of all types of disablement. All these difficulties affect the true incidence rate of disablement in the country.

In 1990, Zambia recorded a total of 69 073 PWD out of a population of 8.09 million, i.e. an overall crude disability prevalence of 0.85% of the population (CSO, 1990). In 1996 there were about 145 000 PWD, which constitutes 2% of the total population. The 2000 National Census indicated that there were 256 690 PWD out of a population of 9.7 million, constituting 2.7% (CSO, 2003). Out of this figure of 256 690, physical disability is the most common disability (39%). There are more male PWD (53%) than females (47%). The Western Province of Zambia has the largest proportion of PWD, i.e. 27 180 or 10.6% of the total population of PWD (CSO, 2003). It could be assumed that this figure of PWD in Zambia is an underestimation in relation to the WHO estimation that 10% of the world's population is disabled, and the majority of those in developing countries (WHO, 1994).

The last two censuses in Zambia indicate that disability incidence has increased from 0.9% of 7 383 097 in 1990 (1.1% of the rural population and 0.7% of the urban population) to 2.7% of 9 855 590 in 2000 (3.3% of the rural population of 6 416 423 and 2.1% of the urban population of 3 469 168). The incidence of impairment and resultant disablement might be high, in the rural areas than in the urban areas, especially those who become disabled as a result of disease. This could be attributed to the inadequate health facilities and services provided to the rural population. The few rural health centres are scattered around the country (MoH, 1992; MCDSS, 2003), which results in low child immunisation and inadequate antenatal and postnatal care compared with health facilities in the urban areas. Due to inadequate health facilities, especially in rural areas, the situation is worsened by not having a public ambulance system to deal with emergencies and acute care services. This situation aggravates the existing problems and very ill patients in the rural areas are unable to travel long distances to the nearest health centre for assistance. Additionally, due to the non-

availability of public ambulance system, many victims are most likely losing their lives and others end up with disabilities because of late interventions. A point worthy noting is that although disability prevalence seems low, the incidence might be high, since there is no mechanism of identifying those who become disabled after the burden of disease. This means that these people are not included in the number of disabled people and so the number of PWD will seem low.

However, the Zambian government has acknowledged through the Ministry of Community Development and Social Services (MCDSS, 2002) that prevalence and magnitude of disability in Zambia is difficult to ascertain because there are no explicit statistics on disability in the country (MCDSS, 1996, 2002; CSO, 2003). With a national population growth rate of 3.2% per annum, compounded by the country's poor socioeconomic situation, it could be assumed that the disability level is higher than the estimated figure. The 2000 National Census (CSO, 2003) indicates that the total population in Zambia is 9 885 591. According to WHO's estimated 10%, the Zambian population of PWD should then be 988 559. Because of inadequate information on disability prevalence in the country, it would not be possible to give an accurate estimate of persons with physical disabilities. Physical disability will now be analysed in more detail.

2.3.3 Physical disability

This study evaluated the impact of CBR programmes on persons with physical disability (PWPD) in Zambia's Lusaka (urban) and Chipata (rural) areas.

There are a number of definitions of physical disability;

- One of the definitions state that physical disability is a congenital disease, acquired illness or trauma that leaves a person with a physical limitation to perform an activity (Sam, Tsang & Wainapel 1996). This definition of physical disability parallels WHO's definition of disability, which states that disability is any restriction

or lack of ability to perform any activity in the manner or within the range considered normal for a human being.

- The NWHIC (1999) defines physical disability as any physiological disorder or condition, cosmetic disfigurement or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs and respiratory systems (including speech organs). Pedretti and Early (1998) define physical disability in the context of physical dysfunction, being an experience of loss; loss of function of a physical part, loss of body image dependent on the 'normal' functioning of that part, and loss of social roles and personal identity. In the context of body image, DeKlerk and Ampousah (2003) explain how physical disability creates personal and societal problems of appearance and attractiveness, particularly for women. This appearance phenomenon has a negative influence on the socio-psychological well-being of PWPD. Words (1998) further observes that PWPD have unique and individual needs in the areas of employment, education, environment, housing, personal services, health care and CBR. People with physical disabilities often deal with structural, attitudinal and other barriers to fully participate in life's day-to-day activities.
- Physical disability is defined by WHO (2001) as any physical condition which results from a disease/illness or injury, congenital or acquired, on the neuromusculoskeletal systems of the body. This results in an individual being unable to perform certain activities, for example limited movement, functional restrictions and eventual inability to participate in societal activities. The ICF clearly states that these limitations are affected by personal, social and environmental factors. This is supported by Soukup and Vollestad (2001), who conceptualise these dimensions to human functioning on three different levels: the body level, the person level and the society level. This means that if an individual has an impairment which affects the physical body, that person has to conceptualise the illness/disease/trauma and accept the residual impairment. Then society also has to adjust its perceptions and cultural beliefs and allow the PWPD to continue their

lives as before. It is on this level where society is seen as segregative and discriminating and having prejudicial attitudes which restrict opportunities for PWPD to participate in all activities in the community and society.

As PWPD may be faced with various problems – such as movement and activity limitations, participation restrictions (WHO, 2001), coping with fears and anxieties – a struggle to maintain a balance between conflicting needs and tendencies develop within them. In spite of recent UN appeals that all governments provide PWD with equal opportunities, PWPD still have to bear negative attitudinal behaviours and reactions from society. This has restricted their level of participation in the fulfilment of all life activities (Brown, 1997) and has made it difficult for them to achieve integration into the community as independent and productive individuals (Benavente, Palazon, Tamayo, Maran, Alaejos & Alcaraz, 2003). Speakman (1989) reports an expression from an American woman who stated that most able-bodied people would not want to marry anyone physically disabled, because they may believe that most other people would mind. This serves as an example of the negative attitude towards PWPD.

All the above issues regarding PWPD prompted the researcher to search for a better understanding of PWPD as regards their integration into the community in relation to movement, functional activities and caregiver provision and dependency. It is therefore imperative that each of these terms is highlighted in relation to the integration of PWPD into the community.

2.3.3.1 Movement

Movement is defined in the physiotherapy perspective as a holistic view of an individual as an active being who is able to change and thus gain health and well-being. Movement is a means of interaction between individuals as well as between person and environment that makes it possible for the person to cope with situations and fulfil his/her goals (Broberg, Aars, Beckmann, Emaus, Lehto, Lahteenmaki, Thys & Vandernberdhe, 2003). From this definition one can deduce the importance of

movement in the integration of PWPD into the community. Persons with disabilities need to use movement to interact with the environment around them. Activity limitations and participation restrictions set in (WHO, 2001) when PWPD are not able to move to interact within the community in which they live. It is therefore important that PWPD be provided with equal opportunities to be able to participate fully in community development activities. Community-based rehabilitation is a means of ensuring that the PWPD are given equal opportunities, since CBR advocates equal rights for all citizens of any given country (UN, 1990). Movement enables people to function within the environment where they operate. It is therefore an appropriate measure to assess the level of integration of PWPD into the community to establish the impact of a CBR intervention strategy.

2.3.3.2 Functional activities

WHO (2001), through the ICF, defines functioning as an umbrella term encompassing all body functions, activities and participation. Activity is an execution of a task or action by an individual. It would then be appropriate to argue that functional activities are those tasks or actions that an individual performs in the paradigm of participation in the fulfilment of social tasks, such as bathing, dressing, feeding, toileting, to name but a few. As performance of functional activities involves the social environment, many PWPD are confronted with various difficulties in accomplishing some everyday activities or assuming their former social roles (Desrosiers, Noreau, Rochette, Bravo & Boutin, 2002). These situations describe the medical model which labels the individual with failure (Lang, 1998). It would be assumed then that PWPD are expected to perform tasks to fulfil social roles as society demands, which does not conform to the social model of disability and functioning. Functional activities were therefore chosen to assess the level of integration of PWPD into the community in this study. If an individual encounters functional limitations and participation restrictions within the environment, most often he/she might need to be dependent on someone. Caregiver provision and dependency will now be discussed in more detail.

2.3.3.3 Caregiver provision and dependency

WHO (2001), through the ICF identifies the importance of caregiver provision to PWD to reach a fulfilment of participation into social life and contribute to the attainment of quality of life. Carers provide services as required to support individuals in their daily activities and help maintain their performance in various life situations, such as bathing, dressing and undressing, getting in and out of bed, going to school, visiting friends and preparing meals. Although WHO (2001) has excluded family members, extended family, friends and health professionals from being classified as caregivers, researchers such as Rosenbaum, King and Cadman (1992), Fehrsen (1995), Delargy, Parry and Burt (1998), Jones, Charlesworth and Hendra (2000), and Wade (2003), state that any individual providing care to one who is in need of it is a caregiver. These researchers have argued that there is a relationship between the level of integration into the community of PWD/PWPD and the presence or absence of a caregiver, attitudes of caregivers and the caregiver burden which the caregivers experience while providing care. Therefore it was decided to include caregiver provision and dependency in this study.

The Dorland Illustrated Medical Dictionary (1998) defines care as attention given to the needs of a patient or requirements of a situation. Delargy, Parry and Burt (1998) defines a carer as someone who lives with and assists a disabled/ill individual who cannot perform activities of daily living (ADL), which are getting up, dressing and undressing, feeding, bowel care, bladder care, movement, bathing and personal hygiene.

According to Rosenbaum et al. (1992) the components of caregiving are diagnosis of the disorders by health professionals, and structural and organisational aspects such as facilities and care that is accessible, available, coordinated and continuous. Fehrsen (1995) states that care needs to be continuous from the institution to the community where the individual lives. This care has to be personal and comprehensive according to the needs of the individual PWD.

As the disabled individual continues growing, the care demands as well as the care load increase. This puts an increased burden on the carer relating to the time taken to perform one particular task. Beresford and Lawton (1993) notes that having a disabled member of the family entails massive changes in a family's lifestyle and flexibility to alter other life philosophies to accommodate the time spent to care for the disabled. Therefore, the family plays an important role in accommodating the developmental needs of the individual with a disability and adapting to the demands of major events and changed social circumstances.

Anderson and Venter (1997) report that the birth of a child with a disability is often a precipitating factor in the break up of marriages, as children in Africa, for example, are seen as the family's future economic security. A child with an impairment is considered unlikely to become a future provider and fathers, fearing the birth of more disabled children, often simply look for another wife in the hope of having 'healthy' children. Mweshi (1998) reports on numerous studies of families with disabled individuals which have emphasised stress, frustration, crisis and chronic sorrow in these households as well as the life-long need to continuously readjust family roles, relationships and organisation, which all affect the care being given to PWD.

The relationship between poverty, impairment and disability is substantial and complex. It is another factor that affects caregiving (Coleridge, 1993; Miles & Medi, 1994; Philpott, 1995). Deprivation of basic needs can cause developmental delay and physical, psychological or intellectual impairment. Furthermore, having a disabled child often leads to further impoverishment as expensive 'cures' are sought and extra time is needed to look after the child (Anold, 1995). It is very common for women to be the sole providers for their disabled children. Not only do they have to manage without the financial support of their child's father, but they are unlikely to be able to seek paid employment if their child requires full-time care. In this situation, women are often unable or unwilling to provide the school fees to send their disabled child to school. All these issues affect the level of care the mother will give her disabled child, and will in

turn affect the level of integration of PWPD into the community (Anderson & Venter, 1997).

2.3.3.4 Integration of PWPD into the community

Integration of PWPD is the ultimate goal of CBR (Macdonald, 1993; Brown, 1997; Kassah, 2001;). Werner (1988) defines integration as a disabled individual leading a fully accepted and participating life in the community. Malcolm (1997) in turn defines integration as the principle which points out the right of persons with disabilities to use the same services and facilities available to other members of society.

Schneider et al. (1999) reports research findings which indicate that there are a number of factors important in determining whether a person experiences high, medium or low levels of integration. A linear analysis was undertaken to determine which factors are the most important. The results show that age of onset and number of disabilities are the two most crucial variables determining the level of integration of a disabled person within his or her family. The earlier the onset and the greater the number of disabilities, the less the person is likely to be integrated within the family. The later the onset and the fewer the number of disabilities, the more likely the disabled person is to be integrated within the family. These two factors override the effects of race, type of disability and sex in determining the level of integration. These findings highlight the problems caused by simply being disabled, without other factors contributing to the problem (Malcolm, 1997; Schneider et al., 1999).

Researchers are in agreement regarding the notion that the integration of PWPD into the community is dependent on several factors. WHO (2001) groups these factors – such as the provision of equal opportunities to perform, and inclusion into social, political and economic spheres of life – as individual/personal, social and environmental factors. One would assume that the level of integration of PWPD into the community could be determined by measuring the variables of movement,

performance of functional activities, and caregiver provision and dependency in the paradigm of CBR. Thus the assessment of the Lusaka urban and Chipata rural CBR programmes was used to establish the levels of integration of PWPDP into the community. As community integration is the highest rehabilitation outcome level, the level of integration of PWPDP into the community was utilised as a tool for measuring the impact of CBR intervention strategy on PWPDP in this study.

One fact remains constant: the number of persons with disabilities is steadily increasing due to factors such as poverty, inadequate education, inadequate health personnel and inadequate health facilities and services. Regarding these issues pertaining to disability, a brief outline of the process of disability is essential.

2.3.4 Disability process and its impact

2.3.4.1 Disability process

All persons with chronic illnesses and disorders have some form of pathology which may cause disability, for example muscle weakness that reduces movement in people with muscular dystrophy. The disability can progress from activity limitation in a few functions to preventing an individual from participating in certain activities, such as cooking or being unable to go and draw water from the well using a bucket. Mweshi (1998) reports that the limitation in participation becomes more evident and obvious when the individual's social environment is affected by the individual's physical environment. For example, in a rural setting an individual is expected to carry a bucket of water on the head from the well to the village, whereas tapped water is within reach in an urban setting.

Illness could cause an impairment in the normal structure and/or function of any part of the human body, which can result in an individual being unable to function as expected. Therefore an individual's performance in any given task might be affected by this impairment. This leads to the individual being disadvantaged regarding the

performance of day-to-day duties and tasks as expected by society (Coleridge, 2000). This limitation in performance also limits a person's level of integration in society, the uppermost aim of rehabilitation. The disability impacts on the individual as he/she is expected to perform in a certain manner in which, due to disability, he is not able (Lang, 2000). It may therefore be argued that the impact of the disability is influenced by society as society prescribes how one must perform certain tasks according to its norms. This corresponds with the statement of WHO (2001) that the basic constructs of the environmental component is the facilitating or hindering impact of features of the physical, social and attitudinal world. ICF illustrates the environmental construct by explaining that there are impairments which lead to no limitations in capacity and no problem in performance, other impairments leading to no limitations in capacity but to problems in performance, and still other impairments leading to no limitations in capacity but causing problems in performance. There is yet another construct where different impairments and limitations in capacity may lead to similar problems in performance, for example an individual with less severe quadriplegia may have the capacity to do the necessary job tasks, but may not be employed because the quota for hiring people with disabilities has been filled. This example illustrates one of the attitudinal barriers in employment of people with disabilities. All these aspects depend on the circumstances in which PWD find themselves and are confronted with.

2.3.4.2 Impact of disability

Integration into society is of key importance to the rehabilitation process of persons with disabilities including persons with physical disability. Anderson, Linto, Edward and Wynne (1995) state that the level of integration of PWD into society in Australia is affected by the impact of the disability on the individual. They note that one of the impacts of disability can be a result of the increasing financial constraints on the health care system, which has prompted a shift from institutional care to community care. This puts a burden on caregivers, since the individual is discharged from a health care institution still needing institutional care rather than community or family care. The family is sometimes reluctant to provide this care. This might be because of the

growing number of women in the workforce, who are seen as the largest number of caregivers in families and society as a whole.

In the USA, Tepper S, Sutton P, Beatty P and DeJong (1997) report that the Personal Assistance Services (PAS) are essential for some PWPDP to function and live independent lives. With proper assistance, people with severe disabilities are able to live independently, secure and maintain employment, and participate actively in their communities. Thus, the impact of the disability is less because the PAS has lightened the burden for the individual with disability, the family and the society.

Mweshi (1998) reports on stigma, deviance and attitudes towards disability as some of the issues that have a severely negative impact on the disabled individual. She quotes Leavitt (1992), who states that the concept of deviance may vary from one culture to the other and all types of individuals with disabilities are seen as deviant and thus stigmatised. Most contemporary literature seems to support the notion that the presence of stigma is expected to lead to a form of social response that is different from what might otherwise have been expected. Additionally, the tendency is for the transference of social contamination from a marked person to an unmarked person who interacts with him or her (Mweshi, 1998).

Pimm (1996) observes that parents and family members who would be caregivers of a child with a disability may at times suffer more from the stigma of the disability than the disability itself. Stigma relates to negative social evaluation and the meaning tagged on the child's differences from the able-bodied children as well as the negative social interaction arising from the evaluation and meaning. Parents have to live with prolonged stares from people and sometimes children with disabilities experience cruelty from family members and other children in the community. This generates a severe impact on the family and the child as he/she grows.

In some cultures, the birth of a disabled child in the family was associated with ill-luck and a curse upon the family, and there is evidence that these children were sometimes buried alive (Mweshi, 1998). However, Mweshi further reports that there is physical evidence that deformed children were not done away with in the Khoisan tradition. This can be associated with the fact that Khoisan people are very fond of children. Health professionals should be aware of such traditional beliefs and values retained by some South Africans when dealing with children with disabilities (Mweshi, 1998). Thus the knowledge of traditional beliefs will promote a better understanding of why some parents may be stressed or even depressed, creating a stronger negative impact on the caregiver, while others are not. This will also help health professionals find better methods of helping such families in reducing the impact of disability on the family with due respect to culture and traditional beliefs.

Attitudes, which are usually affected by cultural beliefs, values and practices, also have an impact on disability. Ethnicity and culture can influence the experience of caregiving and the culturally specific appraisals of the caregiving situation (Aranda & Knight, 1997). A community is subjected to many beliefs which regulate and control the behaviour of a particular given group and thus reduce or increase the impact of disability on PWD. Family members and caregivers are fundamental to the rehabilitation of the individual with disability since rehabilitation workers like physiotherapists have to depend so much on them for the management process, all in an effort to bring about situations where the impact of disability is reduced (Kolobe, 1992). It is therefore imperative for rehabilitation to be carried out with consideration to culture.

Cultural frameworks, however, are constantly evolving and many factors, such as socio-economic status, migration, history, sex, age, religion, have a profound effect on one's cultural way of life. These may also cause a negative impact on disability (Leavitt, 1996). Religion, for example, may play a role by affecting beliefs about the cause of the condition or disability as well as affecting the acceptance of rehabilitation.

A parent may hold a strong faith in the ability of a supreme spiritual being (such as God, Allah or Brahma) to cure a child with disabilities, thereby avoiding other forms of treatment and thus delaying positive progress; hence the impact of disability increases (Mweshi, 1998).

Another aspect of disability is its impact on disabled women's day-to-day life. Today's modern woman has a multitude of roles and responsibilities: caregiver, wife, mother, employee, friend and volunteer, among others. The fact that they are living with disabilities and varying conditions make these roles even more challenging because of physical or mental limitations. Various diseases and conditions produce some form of disability and a number of them disproportionately affect women (NWHIC, 1999).

The National Women's Health Information Centre (1999) reports that in general the severity of a disability is described in terms of how much that disability limits one's daily activities. Women are more likely than men to be limited in the amount or kind of major activity they can perform and they are open to all kinds of abuse at various stages of development. Thus a greater impact on disabled women's functioning capacity is created.

A deeper understanding of culture will help any rehabilitation professional to plan for PWPD as culture seems to be the centre of actions regarding attitudes and behaviours of people in society.

2.3.4.3 Socio-cultural beliefs and attitudes towards disability

Bauer (1989) defines culture as the set of customs and traditions, attitudes and beliefs about life that a group of people share and transmit to their descendants. Hubley (1994) defines attitude as a person's judgement of a behaviour as good or bad and worthy of carrying out. This judgement depends on the beliefs held about the consequences of that behaviour. Most cultures prescribe status and roles in terms of

age, sex, occupation and social level. For example, many cultures prescribe the pattern of behaviour expected of the father as head of the household. In rigid cultures, the behaviour inherent in this role may create problems when unanticipated disability prevents the father from performing as required.

Coleridge (2000) looks at culture as having a past, present and future, in a continuous process of evolution and transformation. Cultures reflect a consensus, but to a large extent also manifestations and often manipulations of power between different agents within a culture. Culture provides a key reference point for identity, which includes social identity based on region, nationality, gender, ethnicity, class and cast. This means that culture is learnt and not determined by biology. Above all, culture is the total manifestation of people's aspirations, values and behaviours.

Understanding disability in a socio-cultural context is therefore a critically important subject. The knowledge of traditional beliefs and practices towards disability is of vital importance if we are to plan and implement programmes that will make a real difference in the lives of PWD and the lives of the communities in which they live. Groce (1999) reports that culturally imbedded conceptual frameworks of disability affect the way in which individuals with disability see themselves and the world around them. They affect the way in which people in their world, such as members of their family, their community and their society, interact with them, and they are the basis on which societies implement policies and programmes that directly and indirectly affect their right to play meaningful roles in their communities.

Groce (1999) further reports that in almost all societies certain types of disabilities are far more acceptable than others. The acceptability of different types of disabilities does not seem, in a cross-cultural context, to be determined arbitrarily, but seems to be closely tied to how a society explains the appearance of different types of disability. For example, in a society where it is believed that mental retardation occurs by chance but

blindness is caused by sorcery, an individual with mental retardation may be easily integrated into the community but a blind person will be avoided by everyone.

Furthermore, Groce (1999) indicates that PWD are affected by what the social expectations are for these individuals when they reach adulthood. For example, in societies such as Oceania or New Guinea, where oration or ability to speak eloquently and persuasively in public forums is the way in which men gain power and prestige within the community, men with speech problems, hearing problems or intellectual impairments will be at a particular disadvantage. Women with similar impairments or men and women with other types of impairments may not face as severe social isolation or community discrimination. On the other hand, in societies in which most adults must engage in substantial amounts of physical labour in fields individuals with mobility impairments may be at a distinct disadvantage. Thus, cultural beliefs are important to understand, as they provide an overview of beliefs and attitudes of both the PWD themselves and the community towards PWD.

In the area of physical disabilities, attitudes have been found to vary. One aspect that seems to be of particular importance is the cause of disability (Auslander & Gold, 1999). In Israel, studies have found that people who are disabled from birth arouse pity or sympathy. On the other hand, disabilities incurred during military service arouse admiration. Attitudes such as these are formed to some degree out of individual experience and vary with personal background characteristics.

According to Speakman (1989) most able-bodied persons would not want to marry anyone who is physically disabled because, even though he may not mind marrying a PWPD himself, he may believe that most other people would mind, and thus agrees with the community.

Pfeiffer (1999) reports another aspect of a cultural oriented attitude in which many people with disabilities either will not or cannot admit to any problem because of the stigma attached to disability. This is attributed to society's tendency to make sweeping generalisations about all individuals with disability in a specific culture. This attitude causes PWD not wanting to be grouped with a category which they do not feel comfortable with.

When one rethinks the issue of community integration of PWPD in view of the cultural aspects outlined above, one has to be aware of and understand peoples' reactions to disability, in order to better cooperate with fellow health professionals, PWPD, families and the community.

2.3.4.4 Peoples' reaction to disability

Different types of disabilities have been found to elicit different types of reactions in people. Auslander and Gold (1999) report that several studies have shown that people have more positive attitudes towards physical disability than to developmental and/or psychiatric disability, in children as well as adults. Although it is necessary to acknowledge intra-cultural variations, as well as the characteristics of individual ambivalence, literature indicates that disabled people were already discriminated against in earlier times.

The Bible records in the Old Testament that "None of your descendants who has any physical defect may present the food-offering to me. This applies for all times" (Leviticus. 21:16-17). This serves as biblical justification of the stigmatisation of and discrimination against PWPD.

There are several New Testament references to the lame, blind and other disabled being discriminated against. People with dreaded skin diseases were regarded as being unclean, while the physically disabled and the blind were left begging on the

roadside (Luke 5:12-13, 18:35-41; Acts 3:1-8). Jesus' disciples ask him: "Teacher, whose sin caused him to be born blind? Was it his own or his parents' sin?" (John 9:1-3). This would support the assumption that sometimes negative attitudes are primarily religious or superstitious. Peoples' attitude towards a disabled person may depend on what they believe in, whether it is religious, cultural or social construct.

Disability can be considered a curse from God for the sins of the family or individual, or a result of invasion of the evil spirit (Leavitt, 1992; Acts 3:1-8). In countries where the Buddhist religion is predominant, the theory of retribution suggests that sin is responsible for a physical disability in one's present life. A sense of social stigma is attached to the family and they are considered to be responsible for PWD. In India, Hindus hold a similar belief. Although the stigma remains the Brahmin and Jain principle, they believe that a person's situation can be improved upon through exhaustive kindness and selfless service, and this belief has helped in the establishment of charitable organisations for people in need (Mweshi, 1998). It is therefore clear that culture is a cornerstone of all activities of societies, the construct from which their actions, perceptions and reactions are derived. Health professionals therefore have to bear in mind all the cultural implications of activity initiated in the community. Culture is also believed to influence the way communities participate and become involved in community developmental activities.

2.3.4.5 Community participation/involvement in rehabilitation

Historically, the attitudes, beliefs and behaviours of able-bodied persons have determined the opportunities and quality of life available to the community of PWD (Peat, 1996).

Boyce and Lysack (2000) report that in the late 1980s and early 1990s there was a dramatic shift internationally which saw the human rights of people with disabilities emerge as a community development issue. This was as a result of the realisation that

approaches such as the original CBR models encouraged passivity among the population and not community participation. This type of model encouraged the negative attitudes of able-bodied persons towards PWD because the community did not participate in any rehabilitation activity for the disabled family member. Thus, a joint position paper on CBR by UNESCO, WHO & ILO (1994) was formulated. It stated that the central and ultimate goal of CBR in the community is to build genuine partnerships between rehabilitation personnel, disabled persons and their families and to improve community attitudes towards PWD and that community participation enhances efficiency, equity and social cohesiveness.

Boyce and Lysack (2000) and Peat (1996) define community participation for CBR purposes as “the organisation of activities by groups of persons who have disabilities (or their family members/friends) in conjunction with others to increase their ability to influence social conditions and in doing so to improve their disability life situations”. Therefore positive attitudes of the community towards PWD can influence the level of community participation in CBR activities to enhance quality of life for PWD in the community.

Boyce and Lysack (2000) conceptualise community participation in three constructs. The first of these is community participation as “contribution”, which is a voluntary donation of people’s resources to a common good or goal (participation as instrumental means). Participation as contribution is intended to be initiated by authorities in a top-down fashion and does not necessarily imply that control and direction of activities pass to the local people. Any barriers to this type of participation are addressed by educational and motivational strategies. Secondly, participation is understood as “organisation”, which is the process of organising or arranging people in common activities (participation as both means and end) which are conceived and introduced by external agents such as the government bureaucracy while others emerge from the process of community members’ own efforts and involvement. In both cases, participation in this scenario values the process of organisational development

to achieve social integration of PWD, group cohesiveness and common objectives. Any barriers to this participation are believed to be derived from operational problems and are usually addressed by technical and resource mobilisation strategies. Thirdly, community participation is seen as “empowerment”, which is a more recent purpose and implies both the development of management skills in local people and the ability to make decisions which affect their lives (participation as a transformational end).

ESCAP (1997) reports that creating a positive attitude towards persons with disabilities is an essential component of CBR programmes to ensure equalisation of opportunities for persons with disabilities within their own community. Positive attitudes among community members can be created by involving them in the process of programme design and implementation, and by transferring knowledge and skills about disability issues to community members. Literature indicates that community involvement and participation are very critical aspects of community dynamics which encourages community empowerment and help people to take charge of their lives (Twible & Henley, 2000).

2.3.4.6 Community empowerment

It is true to suggest that community participation and involvement prepare communities and PWD for the empowerment process. Empowerment is defined as helping people gain the strength and gather the resources to bring about what they feel to be the good in a society (Twible & Henley, 2000). Empowerment is seen as helping people discover their own strength to pursue learning as a lifelong activity and as bringing the potential learning resources of the entire community. Empowering individuals provides them with the attitude and some of the skills which they will need to empower people within the community, the region and the nation. Thus empowerment can allow the development of social change and ultimately a new societal attitude towards the PWD. This knowledge must be utilised to foster the effective implementation of CBR.

Boyce and Lysack (2000) observe that empowerment assumes that people have a right to self-organise and that internal conflicts between social groups can be resolved at local level. "To address the issue of participation is to address the issue of power" (Boyce & Lysack, 2000). This participation construct of empowerment acknowledges the need for community members to exercise power and value social equity. Any barriers to this type of participation are believed to derive from social conflict and are often addressed through compromise on conflicting policies or by removal of social barriers through political reform.

The other important aspect of community empowerment is community involvement. Chimere-Dan (1996) discusses the definition of community involvement, its objective, who should participate, the significance of involving people, how people participate in any relevant activity, and cardinal issues to community participation in any programme. He reports that community involvement is when people are part of the identification of a problem, the identification of a possible solution, planning, the decision-making process, implementation and evaluation of the outcome of that process. The objective of community involvement is community empowerment, aiming at community ownership and responsibility. People will voluntarily opt to provide their knowledge and skill with the sole objective of enhancing self-reliance and self-determination, at individual and community level.

2.4 REHABILITATION

There are several hundreds of million people in the world who have permanent disabilities resulting from various impairments. The growing number of PWD in the world – who have experienced functional limitations, participation restrictions and discrimination, preventing them from participating in community activities and living like anybody else – has increased the need for rehabilitation services (Kay, Kilonzo & Harris, 1994; Allison, 1996). The limitations in participating in community life due to disabilities have encouraged PWD to demand rehabilitation services. French (1994a) reports that as early as 1890 PWD formed organisations to demand and press their

rights, recognition of their problems as PWD and a change of people's attitude towards PWD. WHO (1994) stresses that the demand focuses on PWD being assisted to develop or strengthen their physical, mental and social skills for independent living.

Economic, political and social changes in recent years have placed pressure on rehabilitative services in the health care system (Allison, 1996). In 1978, the concept of primary health care (PHC) was presented at Alma Ata. The four components of PHC services were identified as promotive, preventive, curative and rehabilitative. Studies of PHC delivery have been carried out in several countries, such as Mozambique, Nigeria, Kenya, Cameroon, Zambia and Tanzania, showing successes in some (Allison, 1996).

Rehabilitation is defined as a process which assists people with disabilities to optimise the use of their physical, mental and social abilities (Mitchell, 1999). According to Allison (1996), rehabilitation is the restoration to former health, which involves any procedure designed to restore functional capacity after physical disability or illness to allow the individual to participate optimally in the community. This means that rehabilitation is a multifaceted concept which involves health, education, social, psychological, economic, vocational and political aspects of the individual. Mitchell (1999) states that, in developed countries, PWD may have access to medical and educational services but do not have equal opportunities to participate in social and work activities. In developing countries, even basic rehabilitation services and equipment are lacking.

Rehabilitation is defined by White and Johnstone (2000) as being a dynamic process of planned adaptive change in lifestyle in response to unplanned change imposed on the individual by disease or traumatic incidence. The focus is not cure but on living with as much freedom and autonomy as possible at every stage and in which ever direction the disability progresses.

Stewart and Bhagwanjee (1999) reports that in the new national government's white paper on an Integrated National Disability Strategy (INDS) in South Africa rehabilitation services are conceptualised within a framework of human rights and development, aimed at facilitating the empowerment of all people with disabilities and promoting their fullest development as equal citizens within society.

Knowing that rehabilitation for people with disabilities is seldom a priority in Africa, Vanneste (2000) states that it is unrealistic to expect countries to invest scarce resources in solving the problems of the weakest amongst them, rather than investing in health (e.g. vaccinations, basic health services), survival (e.g. prevention against AIDS and malaria) and education (e. g. primary school education and basic training) for the 'stronger' people who are considered more likely to repay such investment. He further says that theoretically and ideally rehabilitation for PWD is a matter of human rights, for which all people are responsible. Yet, practically, in Africa it is a humanitarian, welfare target. Given the very gloomy socioeconomic circumstances, it is sometimes a luxury.

Mitchell (1999) reports that, most disabled people in Nepal have little or no access to rehabilitation. Since little financial assistance is available for rehabilitation in Nepal, many persons with disabilities have come to rely on CBR programmes to provide rehabilitation services and advocate public services (Mitchell, 1999). According to Marincek (1987), the rehabilitation system in Europe is generally too institutionalised, based on equipment and highly trained staff, but results in terms of integration of the disabled into the community are rather poor. Services belonging to health, social or vocational authorities do not have coordinated programmes and use rather different approaches growing out of different individual policies. As always when the network of bureaucracy is too long people try to find solutions outside the official system. More and more clubs, associations, special interest groups, etc. for PWD are being organised in order to make the public aware of the problems of PWD and establish rehabilitation services.

There is a danger in these programmes, which can be geared too much towards getting financial support and social assistance for their members without taking rehabilitation integration principles, such as opportunities for education, work, social, vocational, economic and political participation, into account (Mitchell, 1999; Marincek, 1987). Rehabilitation services therefore need to be regarded as a process in which PWD are intimately involved, rather than a product to be dispensed (Stewart & Bhagwanjee, 1999).

Unlike Europe, African communities have been the centre of all activities, also for PWD. Communities form a cohesive group of people with shared needs and goals and have a sense of direction regarding the problems affecting them. Thus rehabilitation programmes initiated within the African setting will have collective responsibility just as a person with disability is a collective community responsibility. This collective responsibility enhances the integration of PWD into the community, as it is the ultimate goal of rehabilitation (McLaren, 1986; Price and Marquis, 1999).

Rehabilitation services for PWD can be provided in several ways. There are three known methods, namely institution-based rehabilitation, outreach rehabilitation services and community-based rehabilitation.

2.4.1 Institution-based rehabilitation (IBR)

Traditionally, rehabilitation for PWD has been provided within institutions, such as hospitals, rehabilitation centres and Cheshire Homes, especially in Zambia. This type of rehabilitation can take place on an outpatient or inpatient basis. Residential services are provided if the patient presents with complex or multiple problems requiring specialised services, such as surgery, physiotherapy, occupational therapy or orthopaedic appliances (WHO, 1995).

This method of rehabilitation is very costly and can be accessed by few people, normally in big cities where such sophisticated services are found. PWPD in developing countries such as Zambia might not be able to access these facilities. In Zambia, IBR is provided only in big hospitals in towns where patients are expected to contribute to their health care services using a cost-sharing health scheme. This means that many patients cannot afford hospitalisation for such services and that the majority of PWPD do not attend these institutions. Outreach rehabilitation services play a role in filling the gap.

2.4.2 Outreach rehabilitation services (ORS)

Outreach rehabilitation services are essential to meet the challenge of helping PWD who would otherwise not be reached (Rehman, 1999). WHO (1995) defines outreach rehabilitation programmes as programmes in which professionals leave the institution in teams to deliver services in organised centres within communities. This method of rehabilitation entails very little or no contact with the family and community within which PWD live. This service is regarded as being costly for most governments to run.

WHO (1994) also stresses that outreach rehabilitation services are inaccessible to most PWD/PWPD even though health care workers within these localities can be utilised to provide relevant rehabilitation services if trained and with the guidance from outreach teams.

Due to the limitations of the above two methods of providing rehabilitation services, recommendations for reform of the health care system have been loud and clear. The challenge is to shift the interventions from the structured, organised, systematic professional environment of institutions to an unstructured, unfamiliar setting in the community (Wirz, 2000). Community-based rehabilitation tries to address the needs of all PWPD in the community through a comprehensive set of interventions, such as

medical rehabilitation, education, social rehabilitation, awareness building and prevention (Wirz, 2000; Twible & Henley, 2000).

2.4.3 Community-based rehabilitation (CBR)

The concept of community-based rehabilitation was further developed by WHO in 1980. CBR was the view of attempting to address the various issues pertaining to the welfare of PWD in their own home environment with the full participation of the community. The programme was designed to meet the needs of populations that were largely rural and without access to rehabilitation services (Lundgren-Lindquist & Nordholm, 1993).

The WHO (1994, 1996) has noted that even the most basic services and equipment to assist PWD develop and strengthen their social skills are lacking. Some developing countries continue to struggle with such high infant and maternal mortality rates and alarming morbidity rates that disability issues become secondary or less pressing. Dunhill, King, Lock and Swanepoel (1995) stress that in most developing countries socioeconomic conditions are poor, resources are scarce and lack of political backing for rehabilitation services or philosophy is misunderstood.

Community-based rehabilitation (CBR) is defined as being a strategy for improving service delivery, providing more equitable opportunities and promoting and protecting human rights of PWD (Lundgren-Lindquist & Nordholm, 1996). The United Nations has defined CBR as a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities (UNESCO, WHO & ILO, 1994). The WHO (1995) indicates that CBR is implemented through the combined efforts of disabled people themselves, their families and communities within the appropriate health, education, vocational and social services. CBR attempts to utilise resources provided by the community and emphasises family involvement in rehabilitation (Boyce, Malakar, Millman & Bhattarai, 1999). Providing various rehabilitation services is not an easy task in any country. The total

rehabilitation process will require different types of services, including community-based rehabilitation, which involves community action.

Over the past few decades, the CBR approach has grown and developed in response to the needs of the 80% of disabled people who live in rural areas in poor and developing countries (Price & Marquis, 1999). There are those who suggest that community-based care of people with disabilities is as old as the family itself but more detailed study of the conditions in which countless numbers of children and adults live, with families as their only resource, has shed the light on lives of incredible suffering and poverty. Price and Marquis (1999) observe that this is not necessarily due to deliberate neglect, but to ignorance, superstition and the weight of negative, rejecting and stigmatising community attitudes, often combined with lack of services, support or expertise.

McLaren (1986) states that CBR promotes community responsibility and reliance on local resources. Family and community members are involved in the essential training for their own PWD using local technology. Additionally, Miles (1998) states that the first principle of CBR should be to “unlock” and place value upon the indigenous knowledge of community members and make full use of local professional and vocational skills. CBR workers should respect disabled people’s and families’ experience of disability as a valuable contribution to their programme and, where possible, empower them to develop and manage their own programmes.

Peat (1999) reports that CBR not only promises more equitable access to services; it also provides economic, vocational and social opportunities for persons with disabilities to contribute to their families and participate in community life. CBR has shifted the focus from expensive technologies and over-concentration of public resources in the institutional sector, to the mobilisation of resources and capacities of PWD, their caregivers and communities. CBR has also focused on providing knowledge and skills so that individuals are equipped to make choices about health and rehabilitation care.

CBR has therefore continued to facilitate the full participation of persons with disabilities in the economic, social and political life of their communities. Peat (1999) further reports that CBR promotes decentralisation, individual responsibility and accountability for health, a greater role for the community and involvement of the consumer in the design and implementation of programmes appropriate to them and their family.

Rehman (1999) reports on Pakistan, an Islamic country with its own cultural heritage. Strict purdah or seclusion of women is more critical than the activity of the women, especially those who are disabled. They believe that purdah is not just a woman's personal matter as far as going out of the house is concerned, but that it rather involves the whole society. Disabled women are in a higher poverty level than able-bodied people. They are regarded as less important in society. This cultural attitude causes a double disadvantage to the disabled women, who are not able to be rehabilitated as required. For example, in the society of the purdah strangers, including rehabilitation workers, are not allowed to enter a house. This attitude hinders the successful implementation of CBR services (Rehman, 1999).

Conventional health services, commonly found in larger centres of population, frequently do not reach beyond the edges of urban areas, and in poorer countries they reach only the urban wealthy. It has been recognised that there will never be enough resources or professionals for centre-based services to meet the needs for institutional rehabilitation of PWD throughout the world, hence the advocacy for CBR for PWP (Price & Marquis, 1999; Rehman, 1999).

The Economic and Social Commission for Asia and the Pacific (1997) comments on both the simplicity and complexity of community services in CBR. The simplicity of CBR lies in its history of initiating the delivery of primary rehabilitation therapy to PWD in the communities. The complexity of CBR is the result of the current concept that CBR programmes should be multisectoral (or multidisciplinary) so that they can

provide assistance in all of the areas which are central to improvement of the quality of life of people with disabilities. This complexity recognises the need for close coordination, collaboration and cooperation between governmental and non-governmental organisations and health professionals of all types and at all levels.

In 1976 the need for rehabilitation services for PWD prompted the World Health Organisation (WHO) to include rehabilitation in the goal of "Health for All by the Year 2000". Recognising that there is a need for rehabilitation in developing countries, and yet that populations were largely rural and without access to rehabilitation facilities, WHO developed a CBR programme designed to integrate with the PHC programme. A training manual was produced containing training packages and guides for distribution to the families of the disabled and their local communities. The goals of CBR were that a disabled person should be able to look after himself, move around the house and village, attend school, do a job, carry out household activities, enjoy family life and take part in community activities (Finnstam, Grimby, Nelson & Rashid, 1988). To further emphasise the need for rehabilitation, after the Alma Ata declaration, which lay a foundation for rehabilitation services, the UN declared 1981 the International Year for Disabled Persons. The World Programme of Action concerning Disabled Persons was adopted in 1982 and 1983-1992 was declared the Decade for Disabled Persons while the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities was developed from the experiences gained during this Decade. Standard Rule number 3 declares that governments should ensure the provision of rehabilitation services to PWD in order for them to reach and sustain their optimum level of independence and functioning (UN Centre for Human Rights, 1994).

Looking at the above literature, it could be assumed that CBR has been widely accepted as a model for the equalisation of opportunities for PWD and their families in order for them to fully participate in national development within their own environment (UN, Centre for Human Rights, 1994). Lundgren-Lindquist and Nordholm (1996) indicate that CBR calls for a full coordinated involvement of all levels of society,

including community, intermediate and national, in order to achieve the goal of full representation and empowerment of PWD both in urban and rural areas. It could therefore be said that CBR would be a recommended strategy in the rural and urban areas of developed and developing countries. In Zambia, a developing country with limited resources for health care services, CBR would be a suitable strategy for the rehabilitation and reintegration of PWP in the community.

CBR has recorded some important successes regarding its implementation. Firstly, some developed and developing countries have formulated policies and strategies for the implementation of CBR and thus political will is assumed (MoH, 1995; Zhuo & Kun, 1999; Giacaman, 2001; MRPD, 2001; MCDSS 2002).

Secondly, in some countries CBR has been incorporated in the mainstream of national development issues and PHC, thus utilising the already existing structures of communities of local and national administration (Lang, 2000).

Thirdly, CBR is concerned with problem solving and improvement at individual, community and social levels and thus seeks greater development (De Villiers, 1997; Steiner, Ryser, Huber, Uebelhart, Aeschlimann & Stucki, 2002).

Fourthly, CBR is not a consistent entity; it varies across continents, client groups, communities, geographical regions and time. Indeed, the success of CBR to date may be attributed to its adaptability to various situations and places (Lang, 2000).

Fifthly, there is an inherent commitment within CBR to making rehabilitation information and techniques available and accessible to community members so that people make their own choices on what type of service they need; for example, training and

retraining of PWPD and their families for skills development so that they are able to make informed decisions (Malcolm, 1999).

Lastly, CBR has recognised empowerment as a key objective in the rehabilitation of PWPD in the community. This has been acknowledged by various researchers who have increasingly stressed the importance of promoting empowerment in all aspects of CBR practice, especially training and retraining of PWPD and the community (Holloway, Lee & McConkey, 1999).

However, the implementation of CBR has not been without problems. Firstly, society has continued to exert negative attitudes towards PWD. This suggests that PWD live in a “disabling world”. It is these negative attitudes and the manner in which society is structured that inhibit disabled people from exercising their full rights of citizenship, thereby perpetuating the medical model (Lang, 1998).

Secondly, fragmented and uncoordinated activities in many countries, especially developing countries, have resulted in ineffective services which are not really based on peoples' needs (Lang, 1998).

Thirdly, CBR is very much dependent upon the social, economic and cultural status of each country or region, since it adapts to the particular setting and needs of each country. This leaves CBR vulnerable to being affected negatively in the event of political, social and economical instability (Zhuo & Kun, 1999).

Fourthly, some governments have not been consistent in dealing with disability issues – no national policy guidelines and unavailability of national database for expenditure planning, for example – which leads to the implementation of CBR as an ad hoc

activity (Tepper, Sutton, Beatty & De Jong, 1997; Brodsky & Habib, 1997; Stewart & Bhagwanjee, 1999; CSO, 2003).

Fifthly, in some countries that do not have a multisectoral national policy, disability issues have been left in the hands of PWD themselves and disabled people's organisations to fight and lobby for the recognition of their rights and plight (Hosain & Chatterjee, 1998).

Sixthly, there are some variations in the management of disability issues and problems have arisen in various countries regarding expenditure allocations and implementation of CBR services. In Holland and Germany, for example, it falls under the health care system, in England under the social system, in Israel and Australia under the social security system, and in South Africa disability / rehabilitation services are monitored by the Office on Status of Disabled Persons (OSDP) in the Deputy President's Office but service delivery is the Department of Health (Office of the Deputy President, 1995).

Lastly, the claim that CBR is an efficient and effective strategy for the provision of community-based services has remained largely unproven. In fact, there has been scant critical evaluation of CBR (Lang, 2000).

2.5 DESCRIPTION OF THE ZAMBIAN DISABILITY SITUATION AS REGARDS TO HEALTH REFORM SYSTEM, FINANCING, HEALTH CARE SERVICES AND DISABILITY POLICIES

2.5.1 The Zambian health reform system

Zambia is a land-locked country with a total surface area of 752 600 sq km and a population of 9 885 591 people (CSO, 2003). The national average population density is 10.8 per sq km. The annual population growth rate in the 1990 National Census was 3.2%, while the life expectancy was 55.4 for males and 57.5 for females (CSO, 1990).

The 2000 National Census indicated that the annual growth rate was 2.5%, while life expectancy at birth was 50 years for both males and females (CSO, 2003).

Zambia has 73 tribes and 72 languages. There are seven official local languages, namely Lozi, Nyanja, Bemba, Tonga, Luvale, Lunda, Kaonde, while English is the official business communication language. There are 72 districts which are the local baseline government administration in all community services, including health and social welfare services (CSO, 2003). There are 20 government ministries in Zambia – such as the Ministry of Health, Ministry of Community Development and Social Services, Ministry of Education, Ministry of Science Technology and Vocational Training and Ministry of Youth Sport and Child Development – which all function under an act of parliament. Policies which direct their operations are specifically formulated for each ministry. Both urban and rural activities are directed by the policies of these ministries.

The Ministry of Health (MoH) operates under a decentralised system using the PHC approach. The government, through the MoH, established the Central Board of Health (CBoH) and District Health Management Boards in all 72 districts in the country. The Zambian government adopted the PHC system of health delivery to conform with WHO, since Zambia is a UN member. Primary Health Care advocates for health services to be accessible, affordable, equitable and acceptable to the community it serves and that the health service delivery should be as close to the family as possible (MoH, 1992).

The World Health Organisation (WHO), being a specialised agency in health, cooperates closely with other competent bodies in the United Nations system in dealing with matters relating to the right to health, as proclaimed in article 25, paragraph 1 of the Universal Declaration of Human Rights (UN Centre for Human Rights, 1994). The UN Centre for Human Rights (1994) describes the WHO Constitution adopted in 1946, that “the enjoyment of the highest available standard of

health is one of the fundamental rights of every human being without distinction to race, religion, political belief, economic or social situation". It defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (UN Centre for Human Rights, 1994). WHO (2001) defines health state as "the level of functioning within a given health domain of ICF". The health domain denote areas of life that are interpreted to be within the "health" notion, such as those which, for health systems purposes, can be defined as the primary responsibility of the health system, such as moving, neuromusculoskeletal functioning, seeing, speaking and remembering. The health-related state is "the level of functioning within a given health-related domain of ICF, which are those areas of functioning that, while they have a strong relationship to a health condition, are not likely to be the primary responsibility of the health system, but rather other systems contributing to the overall well-being (WHO-ICF, 2001)". Zambia, being a member of the United Nations, adheres to charters related to health.

As health is a fundamental right for every person, health services provision must be guaranteed by any government. "A healthy nation is a productive nation", as the saying goes. Health provision is mainly the responsibility of the Ministry of Health of any given country, which must strive to provide quality, affordable and accessible health care services as required by its citizens, which includes PWPD.

2.5.2 Health financing

Health services provision is expensive and hence most countries fall short of adequate health care services as demanded by the people. Disparities between first and third world countries with regard to provision of health care services are a fact (Neuhauser, 1997).

According to Stricklin (1997) the social paradigm "health care is a right" is no longer an adequate framework for socioeconomic constraints for health care. The total costs and

utilisation of long-term and acute short-term care continue to grow. At 14%, health care is the largest single budget item of the United States gross national product. These economic forces continue to drive a new profile for the health care system, resulting in a mandate to control the cost and use of health care.

In contrast to USA, Hosain and Chatterjee (1998) report on the health care utilisation by the disabled persons in Bangladesh. This is the ninth most populous country in the world and is extremely poor, with a gross national product per capita of only US\$220 annually. Bangladesh has a predominantly agricultural economy and consequently 85% of its population live in rural areas, with less than 0.01 hectare of arable land per head. The overall low level of development, the poor environmental conditions and the inadequate health facilities have all contributed to the persistence of poor health in rural Bangladesh.

Penny (1999) reports on how CBR programmes have been developed in Indonesia by the Bhakti Luhur Foundation and in the Cook Islands by an NGO called the Cook Islands Society for Disabled Persons because of the conviction that government financial resources are not adequate to meet the needs of the minority disabled persons.

In Zambia, as in any other country, one of the main functions of the Ministry of Health is to provide direction for health services, to set policies and to translate these into strategies and priorities (MoH, 1992). In the last decade, real per capita government expenditure on health care declined by over 50% from a peak kwacha 39 in 1982 to kwacha 12 in 1992 and kwacha 13 in 1994. In 1994, 13.3% of the government budget was allocated to health, which increased to 14.2% in 1995 and 14.3% in 1996. In 1997, it declined to 10.9%, while in real terms the budget declined by about 20% since 1995. The budget allocation for health has only increased slightly in the past two years but is still below 25% of the national budget (MoH, 1992). The Economic Report (Ministry of Finance and National Planning, 2003) alludes to the fact that health expenditure for the

period 2003 has declined to around US\$63 million compared to US\$65 million in 2002. These figures indicate US\$18 per capita, which is not consistent with the WHO Commission on Macroeconomics estimates of US\$34 per capita for Zambia (Ministry of Finance and National Planning, 2003). The fall in the gross national budget has been influenced to a larger extent by the shift from total dependence on the mining industry to other forms of income for the country. PWD, a minority, are most likely not to receive any of this budget allocation to the MoH.

The question arises how it can be expected that this resource reach the minority PWD in the community? Purves (2000) reports that conventional health care services are expensive, are commonly found in larger cities and frequently do not reach beyond the edges of the urban wealthy. It is recognised that poorer countries, such as Zambia, will never have adequate financial or professional resources for centre-based services to meet the needs of PWD. Thus, the decentralised health care service delivery system used in Zambia can be useful for the implementation and inclusion of community-based rehabilitation services for PWD as community structures already exist within the health care system.

2.5.3 Organisation of health care services

The MoH provides 51.2% of the health care services in the country through 44 hospitals and 1 037 health centres. Mission hospitals provide 34.5% through 29 hospitals, while the mining industry and private enterprises provide 14.3% through 11 hospitals. These services are channelled through the Central Board of Health (CBoH), Regional Directorates, District Health Boards and District Health Management Teams (DHMTs) to service delivery points, i.e. health centres (MoH, 1992).

The Zambia government's health vision is the development of a health care system which provides Zambians with equity of access to cost-effective quality health care as close to the family as possible. This means the provision of better management for

quality health care for the individual, the family and the community. In order to facilitate the attainment of this vision, the government has adopted the primary health care strategy as the most appropriate mode (MoH, 1992).

The interaction of human beings, including PWD, takes place in the home and community, which can embrace social, health, economic and emotional or psychological needs. According to Hale and Wallner (1996), satisfactory home care depends on variables such as environmental barriers, social support, family function, financial resources, intellectual and emotional adaptability, and changes in social roles and the use of time. An individual with a disability is best cared for and supported in the home by family and community members who share and understand the same interests and needs. The more reason why governments must include in their policies the developmental issues concerning the PWD in the community, taking into account their local resources, knowledge and skills within the framework of the family for better delivery of rehabilitation services for PWP.

Thus in Zambia, which has a limited resource base for health care services and strong family ties within communities, it would be appropriate to adopt community-based rehabilitation for PWP within the decentralised health system already in place.

2.5.4 Policies on disability

1981 was declared the International Year of the Disabled and the UN directed nations of the world to carry out a survey to reach disabled persons in their respective countries. PWD associations that developed in Great Britain, for example, influenced the government to recognise the needs of PWD and formulate policies on their rights (French, 1994a). These associations appealed to the National Health System to develop welfare provisions and community care policies for PWD in Great Britain.

In 1994/1995 the Botswana government, under the guidance of the Ministry of Health and through the Rehabilitation Services Division, drafted the 'National Policy on Care for People with Disabilities. Apart from the MoH, four other ministries – Education, Local Government, Lands and Housing; Labour, Home Affairs; Works, Transport and Communication – were actively involved in the drafting the policy (MoH, 1995). Hence the Botswana government has affirmed WHO's call to adopt primary health care for the attainment of health for all. The objectives of PHC are integrative, promotive, preventive, curative and rehabilitative services through the participation of the community at all levels of the health care system.

The government of Botswana further stated that the health care system would not be complete if rehabilitation weren't implemented together with the preventive, promotive and curative programmes. As a method of providing rehabilitation to PWD, including PWPD, community-based rehabilitation was recognised and adopted as the most appropriate approach to provide rehabilitation services within the system of PHC (MoH, 1995).

The government of Malawi also formulated a national policy regarding PWD. The Malawian government recognises the unavailability of up-to-date information on the population of PWD, incidence of disability, severity and distribution of age groups, geographical distribution and density patterns in the country. There has been no national disability policy in the country until 2001 (MRPD, 2001). Due to the lack of a policy on disability, many development programmes and services were designed and implemented without proper consultations with PWD and such programmes failed to respond to the needs and concerns of PWD. The government further recognises that the provisions made by government, NGOs and the community for PWD have in most cases been made in a fragmented manner. This approach was not only uneconomical but also unsustainable and had very little impact on the lives of PWD. The new policy on disability will require that all programmes and projects, in all sectors and at all levels, have a component of disability (MRPD, 2001).

In South Africa, the White Paper on an Integrated National Disability Strategy (1997) states that the International Year of Disabled Persons was not recognised by the South African government. This was nonetheless promoted by the NGO sector, whose adopted theme was "Full Participation and Equity". Following a 1986 investigation, an Interdepartmental Coordinating Committee for the Care of the Disabled (ICCD), involving state departments and the NGO sector, was established. Its role was to implement the various recommendations arising out of the 1986 investigation, and by the end of 1991 it had not succeeded in implementing a single one of its tasks. It was disbanded and a restructured South African Federal Council on Rehabilitation of the Disabled Persons (SAFOD) was given responsibility for policy development (Office of the Deputy President, 1997).

Currently, the Integrated National Disability Strategy paper is the focal point of the management of disability issues in South Africa. The Government of National Unity is committed to redress the desperate situation the majority of disabled persons in South Africa face by ensuring that the equality promised in the interim constitution becomes a reality. The government acknowledges that disability is a human rights and development issue which cuts across the responsibilities of a wide range of government institutions. It requires policy interventions in the spheres of constitutional development, economics, education, housing, environmental planning, employment, legal reform, health, welfare, gender, language, culture, social security, science and technology, sport and recreation, transport and others (MoH, 1995). The South African government has taken a step forward in formulating this strategy document so as to provide a framework from which an integrated and coherent policy can be developed to meet the needs of persons with disabilities in the country.

Though the Zambian constitution is silent on disability issues, the Zambian government has a policy on special education which caters for children with learning difficulties. It has incorporated the learning of children with disabilities in the mainstream of

education while trying to reduce as much as possible the seclusion of these children in special schools (MoE, 1996). The government has another policy on vocational skills training for youths and adults in training institutions. There are special units in most trades training institutions in the country that cater for the needs of PWD under the Ministry of Science, Technical Education and Vocational Training (MSTVT, 1996). The Ministry of Community Development and Social Services has a department on disability under which the Agency for the Disabled was established (MCDSS, 2002). It is unfortunate that the Ministry of Health has no policy on rehabilitation which can focus on disability prevention and provision of rehabilitation services, promotion of functioning and health issues relating to PWD to work in collaboration with the other ministries mentioned above. It is regrettable to note that Zambia, with 40 years of democracy, still does not have an integrated national disability policy nor a human rights and disability charter. It is for this reason that the researcher initiated this study to determine the impact of CBR programmes in the two study areas so as to advocate the enhancement of a policy on rehabilitation services for PWD.

HIV/AIDS related issues have caused a lot of suffering for the people and the economy of Zambia. Data from antenatal clinics from 1994 to 1998 show great diversity in the spread of HIV across the country, ranging from 1.6% to 31.9%. Antenatal data correlate fairly closely with other proxy indicators for the sexually active population. In 1997, the total number of people infected with HIV was estimated at 946 355, representing an infection rate of 19.9%. There is, however, a marked urban/rural differentiation in infection rates; 14.8% (433 430) in rural areas and 27.9% (512 925) in urban areas. As a result of the HIV/AIDS pandemic at community level a number of families has been forced to absorb orphaned children and to care for the chronically ill persons (MCDSS, 2003). This burden leads to increased poverty levels, as families can most likely not afford to provide for large numbers of family members, higher illiteracy, as families can most likely not afford educating a lot of children, and a larger disease burden on the families and the government, as they can most likely not afford the cost-sharing medical fees scheme currently used in the country. The government is also likely not to absorb the huge sums of medical costs brought about by the

HIV/AIDS pandemic into the national health budget. The pandemic calls for concerted efforts both by government and the community to be able to deal with issues of HIV/AIDS management, and the community is of key importance in these activities.

Zambia is in a good position to adopt CBR as a method of dealing with disability issues as the decentralised health care system is already operating for other programmes, such as immunisations, tuberculosis and malaria. As the country is faced with a high rate of HIV/AIDS infection, it is imperative that the anticipated high levels of disabilities due to AIDS is planned for and these plans implemented as the hospitals might not be able to cope. Community-based rehabilitation could be utilised as a strategy to enhance integration of PWP into the community, including those living with HIV/AIDS. The financial capacity of the country is strained and to expect the government to have enough resources to meet the needs of PWP is not realistic. It would therefore be wise to utilise existing structures and systems in the MoH.

2.6 RELEVANCE OF LITERATURE TO THE PRESENT STUDY

The review of literature on the current and earlier status of CBR serves as impetus for a critical analysis of the situation in Zambia in relation to CBR. The Zambian situation is such that there is lack of accurate and comprehensive database for planning of disability issues and CBR activities in the country (CSO, 2003). The Central Statistics Office has acknowledged the limitations of the past national censuses, since these censuses have not been able to capture all the PWD because of the inability to use the right terminology to identify the various types of disabilities (CSO, 2003).

The lack of an all encompassing national disability policy has resulted in uncoordinated disability management. CBR and disability management were in the hands of disability organisations, NGOs and international donors to a larger extent (Hosain & Chatterjee, 1998). This could have exposed CBR to abuse by the same society it intends to serve.

The lack of a deliberate policy on the inclusion of disability issues in the curriculum of health professionals and other community care providers is assumed to be perpetuating the lack of knowledge and skills and the negative attitudes prevalent in these institutions and professionals. With the advent of HIV/AIDS, which could lead to disability, all people concerned with the development of the nation should be conversant with disability issues (UN Department of Public Information, 1992; Hale & Wallner, 1996; De Villiers, 1997; Steulz, 1999; Struthers, 2001; WHO, 2001; Stuck, Ewert & Cieza, 2002; Heerkens, Brug, Napel and Ravensberg, 2003;).

Most CBR projects presently running in Zambia risk closure when donors pull out their support, with the exception of those that are people driven, such as the Chipata CBR programme, which has been transformed into an association. This is supported by Okuonzi and Macrae (1995), Khan (1996), Stuck, Ewert & Cieza, (2002), Chimedza and Kabzems (2002) who recommend caution on the issue of maintenance of CBR programmes in the event that donor support is no longer available.

The above factors are assumed to have resulted in the current fragmented and uncoordinated disability management and implementation of CBR in the country. Most of the efforts toward CBR programmes are those of disability organisations, NGOs and the church, some of whom receive funding and support from international donors – as is the case with the two CBR programmes investigated in this study. Government is recognising these efforts through the MCDSS, MoE and MSTVT but without the input at policy level from MoH, though some health professionals are involved at grassroots. Because of this disturbing situation the aim of this study is to lobby government at its highest level to create an office which will directly deal with disability issues in the country in a more coordinated and result-oriented fashion.

2.7 CHAPTER SUMMARY

This chapter highlighted and discussed the literature concerning various issues on disability. The various definitions of disability indicate an evolution of concepts from its first definition by the ICIDH in 1980 to the latest definitions by WHO in 2001. Some contentious words in the definitions have been substituted by others which are more culturally acceptable, for example. Literature has also revealed that the prevalence of disability is high, especially in developing or third world countries. Several reasons have been stated, namely, poverty, inadequate health facilities and health personnel, and inadequate health financing by governments, among others. Budgets have to cater for more urgent issues, such as HIV/AIDS, tuberculosis and malaria. These issues, however, pose a threat to the health status of communities leading to disease which bring about disabilities.

Researchers have reported on the impact of disability on people's lives, sociocultural beliefs and attitudes and the different reactions people exhibit towards disability. Studies reveal that disability has an impact on the life of a disabled person due to the limitations they have in performing certain tasks. Being different from the norm evokes reactions from the community. Research has also shown that women with disabilities are more at a disadvantage regarding personal relationships which can lead to marriage. Physical disability which causes disfigurement is negatively regarded in some cultures. Cultural beliefs and attitudes influence how people react to certain disabilities. These factors affect how people will participate or involve themselves in any given activity to better the lives of disabled persons in their community. It is therefore imperative for a health worker to understand the cultures and traditional practices of any community before planning rehabilitation services for persons with disabilities.

The Zambian situation was analysed with regard to the organisation of health services, health financing and disability policies in the country. It was found that Zambia has no policy on rehabilitation yet has potential in implementing CBR programmes because

there is an existing decentralised health system which encourages community participation in health matters. Incorporation of CBR services would not be an added burden but a relief in that it would transfer responsibility for rehabilitation services for PWPDP to the community.

It is believed that community-based rehabilitation, which emphasises the social model of service delivery, should be the preferred strategy rather than institutional-based or outreach service delivery. This is because CBR is initiated within the community, by the community and for benefit of the community as part of community development. Persons with disabilities belong to the community and must therefore be involved in the planning, implementation and evaluation of any services for them.

Participation by the community from the early stages of any CBR services will cultivate community cohesion, ownership and responsibility. All these factors enhance functional independence for persons with disabilities as they are accepted and able to function within their environment reducing dependency on others. Reduced caregiver dependency enhances the integration of PWD into the community.

An overview of disability issues indicates that disability exists in all communities. Each country should critically identify the existing resources within their communities and effectively utilise them for the benefit of persons with disability.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

This chapter outlined the study objectives, the research design, selection of the research settings and samples, method of data collection and data analysis.

3.2 AIM OF THE STUDY

The aim of this study was to determine the impact of a CBR intervention strategy aimed at improving functional independence and integration into the community of persons with physical disabilities in an urban and rural setting in Zambia.

3.3 OBJECTIVES OF THE STUDY

- 3.3.1 To describe the two study areas, Lusaka (urban) and Chipata (rural), and the two CBR programmes from those two areas used in the study;
- 3.3.2 To collect demographic data on participants from the two study areas;
- 3.3.3 To evaluate the existing CBR programmes in Lusaka and Chipata to establish the level of integration of PWPD into the community in relation to movement, functional activities, caregiver provision and dependency, and perceptions of PWPD with regard to their disability status;
- 3.3.4 To expose PWPD to a six-month CBR intervention strategy;
- 3.3.5 To re-evaluate the Lusaka and Chipata CBR programmes to establish the level of integration of PWPD into the community in relation to movement, functional activities, caregiver provision and dependency, and perceptions;

3.3.6 To determine the impact of CBR intervention on PWP in an urban and rural setting in relation to movement, functional activities, caregiver provision and dependency, perceptions and integration of PWP into the community;

3.3.7 To make recommendations to:

- the CBR programme managers
- the Ministry of Health
- the Ministry of Community Development and Social Services
- the District Health Management Teams from the two study areas
- the international donors of the two CBR programmes
- the community rehabilitation workers in the two CBR programmes
- the clients in the two CBR programmes
- UN agencies (WHO, ILO, UNESCO, UNICEF)
- the researcher

3.4 STUDY DESIGN

The study adopted the quasi-experimental before-and-after approach, and descriptive and comparative methods were used. See Figure 3.2 for a diagrammatic presentation of the stages of the study.

Here follows a representation of the study design followed in this study:

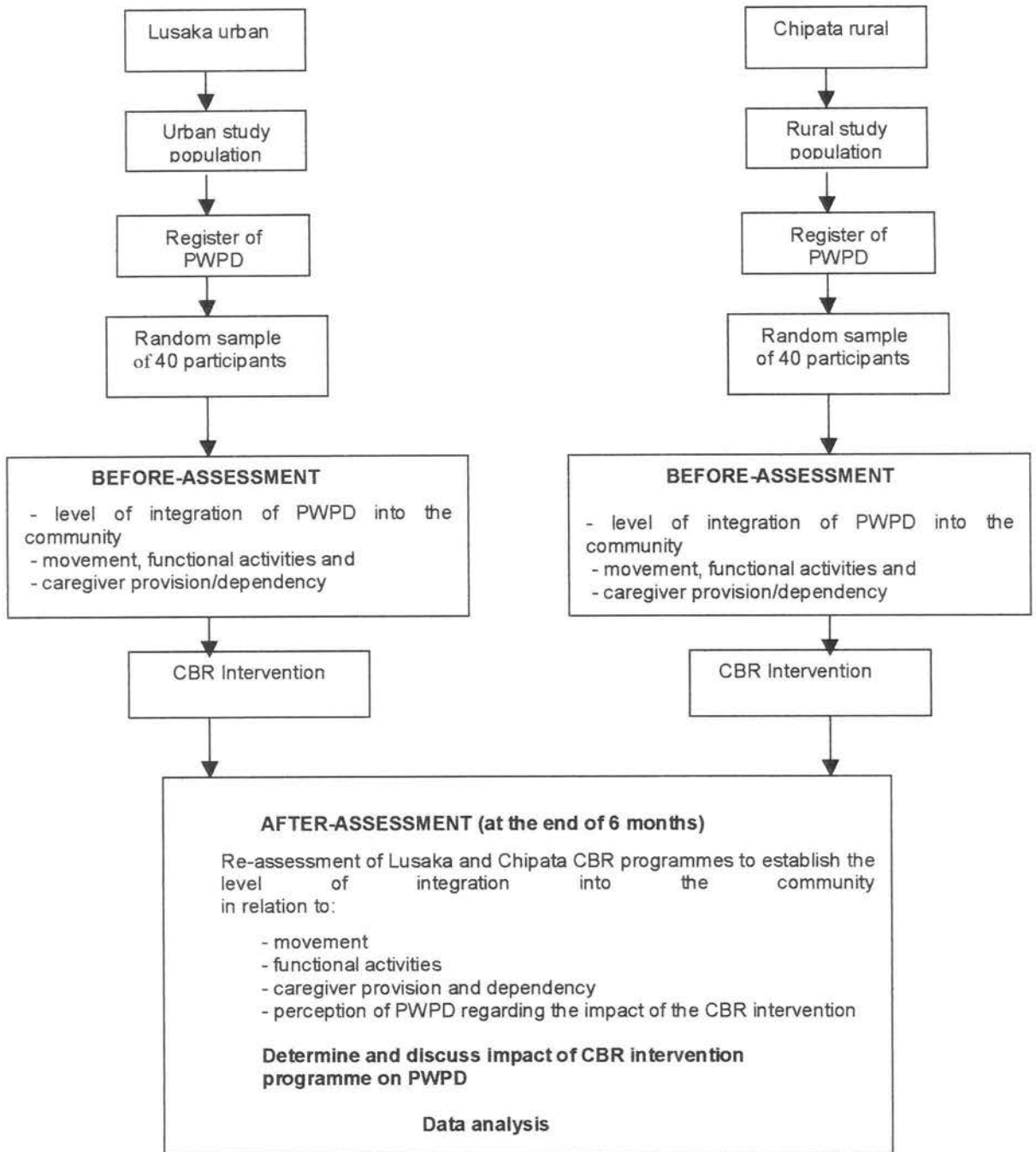


Figure 3.2: Diagrammatic representation of the stages of the study

The before-and-after study design falls in the category of experimental studies aimed at assessing the outcome of interest in a particular situation. Armstrong and Grace (2000) define the before-and-after study design as an experimental manipulation of one of the variables from a baseline state to arrive at an outcome. This involves collection of baseline data from a questionnaire distributed before and after the intervention.

Helewa and Walker (2000) define the before-and-after study design, a study where the investigator selects a single group of people and assesses an outcome of interest. There is no control group; the outcome of interest is assessed in the same individuals before and after exposure to the clinical manoeuvre or proposed causal factor. The advantages and disadvantages of the application of the before-and-after study design are set out below:

3.4.1 Advantages of before-and-after study design

- The investigator does not have to withhold treatment from those who need it.
- A high level of participation lessens the volunteer bias.
- As observations are carried out on the same individuals, the degree of variation due to subjects is reduced.

3.4.2 Disadvantages of before-and-after study design

- Prospective (forward-in-time) data collection is often not possible where a decision to study a new intervention does not allow sufficient time for a “before” phase; this necessitates retrospective (backward-in-time) data collection. This may result in lack of standardisation of eligibility criteria and outcome assessment, as well as difficulty in assessment of intervention, contamination and compliance.
- The severity of the condition may differ between the before and after phases.
- The natural history of the condition may vary between phases.
- Co-intervention differences may exist between the phases.

- Masking intervention is as difficult as in cohort studies.
- When the before and after groups consist of different individuals, patients/participants in the before phase differ in severity of the condition from those in the after phase. For example, participants may seek health care/CBR sooner due to public education or availability of the service.
- Coexistent disease differences may exist between the before and after phases, for example an outbreak of influenza epidemic would affect survival of participants with neurological disorders.

Helewa and Walker (2000) define an experimental study design as one in which the assignment of subjects is random. According to Armstrong and Grace (2000) and Helewa and Walker (2000) descriptive study is used to establish the prevalence or extent of some problem in the community. Descriptive studies are also used in understanding a problem or establishing the need for appropriate services. These studies have no scientific rigor but explain the relationship of variables. Descriptive studies have the following advantages and disadvantages:

3.4.3 Advantages of descriptive studies

- It is simple to carry out.
- It identifies and explains relationships of variables.
- It describes at least one variable.
- It presents the opportunity to better understand a situation.
- It can be used in establishing the need for appropriate services.
- It can be utilised using whatever methods of research seem appropriate.

3.4.4 Disadvantages of descriptive studies

- It is limited in scope of the research question because it addresses only one variable.

Both quantitative and qualitative methods of data collection and analysis were used in this study. According to Armstrong and Grace (2000), qualitative research on one hand deals with an exploration of the relationship between variables, but not just in a statistical sense; it is concerned with understanding the nature of the relationship between the intervention and the individual's response. Quantitative research, on the other hand, addresses the underlying casual mechanisms that link one variable to another, for example the effectiveness of a CBR intervention method.

In this study it was appropriate to combine the methods and designs mentioned above. The descriptive method was necessary for collecting the demographic data in trying to understand the relationship of the various variables. The quantitative method was useful in establishing the effectiveness of the CBR intervention modalities which is assumed to bring about integration of PWPD into the community, namely movement, functional activities, and caregiver provision and dependency. The qualitative method was used to answer the question whether or not the CBR intervention modalities were effective.

3.5 STUDY AREAS

The study areas were the CBR Programme from Lusaka Urban District and the CBR Programme from Chipata Rural District in Zambia. There are about six CBR programmes in Zambia, namely in the Copperbelt Province (2), Northern Province (1), Lusaka Province (1), Southern Province (1) and Eastern Province (1). The Lusaka and Chipata CBR programmes were selected according to the inclusion and exclusion criteria set out in paragraph 3.7. The other CBR programmes did not meet these criteria.

3.6 STUDY POPULATION

The study population consisted of people with physical disabilities (PWPD), presenting with neuromusculoskeletal impairment, who live in the two study areas and are attending CBR programmes. In Lusaka, the study population from which the study sample was randomly selected was 79. The study population for Chipata was 74. The study sample was randomly selected by placing folded pieces of papers with the names of all the PWPD in each area into a bowl. Forty (40) pieces of paper from each area were picked from the bowl. Those pieces of paper represented the PWPD who participated in the study. Only the PWPD who met the criteria outlined below were used to draw the study sample from.

3.7 INCLUSION AND EXCLUSION CRITERIA

3.7.1 Inclusion criteria for study areas

As mentioned earlier, there are six CBR programmes in Zambia. The two study areas were selected from among the other CBR programmes in the country on the following basis:

- The community participated in the execution of the CBR programme.
- The CBR programme catered for all categories and ages of PWD.
- Integration activities were carried out in the home environment and not at a rehabilitation centre.

3.7.2 Inclusion criteria for study sample

Persons with physical disabilities were included on the basis of the following criteria:

- The primary cause of disablement was acquired or congenital neuromusculoskeletal dysfunction.
- The PWD was between 7 and 60 years of age at the time of the study.
- The PWD resided in one of the two selected study areas.
- The PWD or his/her proxy had given written consent to participate in the study (See Appendix 1A and 1B).

3.7.3 Exclusion criteria for study areas

Other areas where CBR is provided were excluded from the study on the basis of the following:

- They catered for specific disability groups.
- They catered for specific age groups only.
- They have adopted the outreach approach to rehabilitation.

3.7.4 Exclusion criteria for the study sample

Persons were excluded from the study samples on the basis of the following criteria:

- The disablement was not primarily due to causes other than neuromusculoskeletal dysfunction, e.g. impaired sight, impaired hearing, mental/psychiatric disorders.
- The PWD were younger than 7 years or older than 60 years at the time of the study.
- The PWD refused to consent to participate in the study.
- The PWD missed the first assessment after being visited three times at their home.
- The PWD moved to other residential areas during the study period.

3.8 INSTRUMENTATION

3.8.1 Questionnaire

Data was collected by means of completion of a self-compiled structured questionnaire which was partly completed by the researcher and partly by the participant/proxy. The questionnaire was in English (Appendix 2). The researcher interpreted each question to the participants. The questionnaire was not written in any local language because participants preferred interpretation instead of reading themselves due to the low educational level of most of the participants.

The questionnaire consisted of six sections:

- Section A comprised 20 questions on demographic information.

- Section B, which assessed movement, comprised 10 questions. In Section B and C the questionnaire provided three alternative responses. The participants indicated the response according to their situation and the researcher entered the responses on the questionnaire. The responses were: 1 for 'not at all'; 2 for 'with help' and 3 for 'alone'. Three (3) was the highest score indicating that the participant was able to move or perform functional activities alone.
- Section C comprised 10 questions which assessed functional activities.
- Section D comprised 14 questions which assessed caregiver dependency and provision. The questionnaire provided more than one answer. As the participant responded to the question, the researcher entered the appropriate answer in the answer box provided.
- Section E comprised 11 questions which assessed integration into the community. This section consisted of two parts. One part contained questions which the researcher read to the participant/proxy. The second part was the answer sheet with the Integration into the Community Index linear lines for all the 11 questions. The participant/proxy had to mark the answer on the linear line according to the participant's situation. The Integration into the Community Index is illustrated in Figure 3.3.
- Section F comprised 2 open-ended questions which assessed the perception of participants regarding changes that occurred in the disability since starting CBR and their experiences concerning the disability before and after starting CBR. The researcher entered the responses on the questionnaire.

Does not describe my situation Fully describes my situation

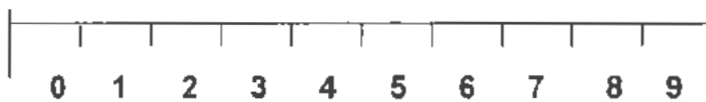


Figure 3.3: Integration into the Community Index (Modified from Halewa & Walker, 2000; Nissen, & Newman, 1992; Perenboom & Chorus, 2003)

3.8.1.1 Advantages of a self-administered questionnaire

- The information gained is available immediately.
- Any uncertainties can be clarified with the participant/proxy.
- The researcher can ensure that all the participants/proxy who consented to participate in the study complete the questionnaire

3.8.1.2 Disadvantages of a self-administered questionnaire

- Time constraints.
- The participants could feel influenced by the presence of the researcher (obsequiousness bias).

3.8.2 Qualitative data collection

Data was collected from the participants/proxy by responding to Section F of the questionnaire. This section consisted of two open-ended questions. The first asked participants/proxy to state the changes which had occurred to the PWPD's disability status since starting CBR. Question 2 asked the participants/proxy to express themselves concerning the disability experiences before and after starting CBR. The responses were entered in the questionnaire by the researcher.

3.8.3 Sources of data

- Data was collected from the following sources:
- Persons with Physical Disability (PWPD)
- Their proxy
- Community rehabilitation workers (CRWs)
- CBR programme managers
- Files at the programme offices
- Family members and the community

3.8.4 Identification of community rehabilitation workers (CRWs)

Before the commencement of data collection, eight (8) CRWs were identified in each study area to make a total of 16. These CRWs had already been trained in community survey, client assessment, basic physiotherapy exercises, functional skills, ADL, counselling, vocational rehabilitation, home-based education, referrals and provision of assistive or supportive devices/appliances. A one day revision with emphasis on the main aim of the study and areas in the questionnaire was provided for the CRWs of both the Lusaka and Chipata CBR programmes. The CRWs were provided with a clear explanation on their tasks and the responsibilities of participants/proxy during the study. These responsibilities were also explained to the participants/proxy by the CRWs as they visited the participants to inform them of the study. Details of the training and tasks of the CRW and the responsibilities of the participants/proxy are provided in Appendix 5.

3.8.5 Training of CRWs

Training of the CRWs who acted as research assistants in this study was carried out before the first assessment of PWP in the Lusaka and Chipata CBR programmes. The training was done in one day as these CRWs were already trained in CBR and were working for the two programmes. The CRWs in Lusaka are employed and receive a salary, while those in Chipata are volunteers.

3.9 PILOT STUDY

After obtaining written permission from the management of the two CBR programmes (Appendix 6A-H), the researcher conducted a pilot study on eight PWP, four from each study area. This was done in order to assess the wording and the clarity of the questions/statements in the questionnaire. The pilot study took place in April 2000 in Chipata and in June 2000 in Lusaka. It took the researcher and the participants between 30 and 45 minutes to complete the questionnaire.

The following changes were made to the questionnaire (Appendix 2):

- Separation of the spaces on the consent and declaration forms for signature of the participant and their proxy (Appendix 1B and 1C).
- Inclusion of an open-ended question for the participant/proxy to state changes that had occurred in the participant's disability status since starting CBR (Appendix 2, Section F).
- Inclusion of an open-ended question for the participant/proxy to state experiences concerning disability before and after the participant started CBR (Appendix 2, Section F).
- Inclusion of an item asking whether the participant received physiotherapy before starting CBR (Appendix 2, Section A).
- Inclusion of N/A as response 4 on item 41 because other clients were children who were not expected to be working or employed (Appendix 2, Section C).
- Item 41 to read "go to work/field" to cater for Chipata participants who go to the field or garden and do not work in an office (Appendix 2, Section C).
- Due to the vast areas cover by the study areas, the appropriate number of CRWs for each study area was increased to 16, eight (8) from each study area, to adequately cover the areas where the participants resided (Appendix 2, Section C). Initially, the researcher had selected 8 CRWs, four (4) from each study area.
- The lower age limit for participants was lowered to 7 years because it became clear that there would not be an adequate population sample in the study areas if the age limit was higher (Appendix 2).

3.10 PROCEDURE

Written permission was obtained from the Ministry of Health, Ministry of Community Development, Ministry of Education, Agency for the Disabled, District Health Management Teams for Lusaka Urban District and Chipata District, management of the two study CBR programmes in Lusaka and Chipata (Appendix 6A-H), before administering the questionnaire. The researcher made appointments with the management of the two CBR programmes, the 16 CRWs who were to be the research

assistants, the PWPD and the community, for example the headmen and the political leaders of the villages to be visited. The procedure of the study was explained to them and written permission (Appendix 1B) was obtained from all the PWPD and their proxy between April and June 2001.

The questionnaires were completed both by the researcher and the participant/proxy (in case of the child participant) at the time of the interview. The two assessments in the Lusaka area, covering the Chaisa, Chipata (this is a township in Lusaka urban district), Garden and Mandevu compounds, took two weeks each. The two assessments in Chipata rural area, covering 29 villages in the Jelusalemu and Kamulaza areas, took three weeks. The Chipata assessments took longer because of the distances between the villages which the researcher and the assistants had to cover.

3.10.1 Assessment of PWPD (1st interview)

When the questionnaire was first administered, an assessment of PWPD's needs was done. The first interview was done to assess the participants' status in movement, functional activities, caregiver provision and dependency and the level of integration into the community. A schedule of visits for each PWPD was then drawn up between the CRW and the participant/proxy in the presence of the researcher. The PWPD was visited by the CRW once a week; this was recorded by the researcher for verification at the second interview. After the first interview, the needs of PWPD were identified within the following means of intervention (Appendix 5);

- Movement activities
- Functional activities (Activities of Daily Living – ADL)
- Counselling to PWPD, family and community
- Information on disability rights
- Caregiver training on the handling of PWPD
- Advice on type and use of appliances

- Home health education
- Basic physiotherapy
- Fundraising activities
- Basic literacy education

3.10.2 Intervention stage

Each PWPD was visited twice a week by the CRW assigned as research assistant to that area. The rehabilitation schedule which was drawn up for each PWPD was followed by the CRW and the PWPD/proxy. The PWPD/proxy were asked by the researcher to indicate the days in which the CRW did not visit for verification at the 2nd interview and to ensure that the PWPD received the number of visits scheduled. The PWPD received one intervention visit a week for six (6) months, making it a total of 24 visits.

3.10.3 Re-assessment of PWPD (2nd interview)

After six (6) months, the second interview was conducted in both study areas. The same procedure – questionnaire and qualitative interview – was followed. The second interview was done to assess the participants' status after the CBR intervention in movement, functional activities, caregiver provision and dependency and integration into the community. The consistency of the visits by the CRWs was verified by the researcher. No CRW/research assistant missed any of the visits. If a schedule was changed due to some reason, an alternative day for the visit was set.

3.11 DATA ANALYSIS

Responses from the questionnaire were captured and coded on an Excel spreadsheet. The assistance of a statistician was used for the analysis of the data. Data analysis was done in five stages, which are outlined below. The statistician used the Statistica 6.0 package to analyse the data and made use of the box and whisker plots, indicating

the median values, the 25th and 75th percentiles, and the minimum and maximum distribution of the observations. The box and whisker plots were used to illustrate the differences in the median values and the concentration of the distribution of observations between the before and after scores. The p-values were calculated to determine the statistical differences between before and after scores of the variables of movement, functional activities, caregiver provision and dependency, and integration of PWPD into the community. The paired t-test was used to establish the mean and the p-values for all the variables tested. Since the paired t-test assumes that data is distributed normally, the Wilcoxon matched pairs test was done to confirm the p-value results obtained from the t-test. The Wilcoxon analysis assumes that the data is not distributed normally, so it is used to verify and confirm the results obtained from the t-test. A non-parametric linear regression analysis was done to determine the correlation relationship between integration of PWPD into the community and movement, functional activities, caregiver provision and dependency, and perceptions of PWPD regarding their disability status and experiences. The correlation coefficient is also given and explained. Scatterplots were used to illustrate the relationship and correlation between the variables tested. The p-value accepted as significant for this study is $p < 0.05$, while marginal values will be $p < 0.1$.

It is important to note that causal-effect inferences can not be made from the correlation of statistical calculations. The analysis helped the researcher to determine whether there was a relationship between one variable, for example movement, and integration. The correlation analysis also helped the researcher to determine the magnitude and direction of the relationship. It will not, however, enable the researcher to make causal inferences about the variables tested.

3.11.1 Qualitative Data

Qualitative analysis of the data in Section F (perceptions of PWPD / proxy regarding the disability status and experiences since starting CBR) were done and used to support the quantitative results. The responses from the before and after assessment

of perceptions were written in note form and others in direct quotations. Some actual words used by participants/proxy were included in the text as transcribed verbatim in order to express their feelings. The presentation tried as much as possible to retain the nuances. The responses were clustered and common variables were established. Tendencies and emphases were noted and information in each interview was sorted into predetermined themes. In all the analyses, comparative trends was done for Lusaka urban and Chipata rural participants. The following stages outline the themes and the process of analysis done;

Stage 1

- Themes on the changes in disability status since starting CBR:
 1. Functional skills
 2. Social skills
 3. Economic / survival skills
- Themes on the experiences regarding the disability since starting CBR
 1. Social stigma
 2. Economic stigma
 3. Superstition
 4. Family support

Stage 2

- Statistical analysis of the themes was done using the Wilcoxon matched pairs test to determine the significant changes in the participants' perceptions regarding the disability status before and after the CBR intervention.
- Regression analysis of the themes was done to determine the level of integration of PWPD into the community in relation to their perception (before and after the CBR intervention) regarding their disability experiences since starting CBR.

3.11.2 Quantitative Data

The data from the questionnaire was coded and the analysis was done in four stages, as outlined below:

Stage 1:

- Demographic data was analysed descriptively.

Stage 2:

- Responses from the before and after assessment of movement, functional activities, caregiver provision and dependency, integration and the quantitative part of perceptions were analysed, summarised and percentages calculated (Appendix 6).

Stage 3:

- Regression analysis was done to establish the relationship of integration with other variables tested.
- Box and whisker plots were used to illustrate the impact of CBR on PWPD by showing the mean and median scores for all the variables tested.

Stage 4:

- P-values were calculated to establish the significance of the change in scores in all the variables tested.

3.12 STUDY CONSTRAINTS AND LIMITATIONS

The following limitations were experienced:

- The distances that the researcher had to travel – 560 km to Chipata district and then to the villages on a bicycle, covering more than 100 km daily for three weeks. The distances covered in Lusaka were 10 sq km on foot daily for two weeks.
- The researcher was unable to obtain financial sponsorship;
- The findings of this study may not reflect the total picture of CBR for PWPD in the country, since the study was limited to two specific areas.

3.13 CHAPTER SUMMARY

This chapter covered the methodology of the study, outlining all the stages. The objectives of the study provided a guideline of what needed to be done to achieve the aim. A quasi-experimental before-and-after study design was adopted for the study evaluating the CBR strategy and determining the impact of this strategy on PWPD in an urban and rural setting in Zambia.

For a better understanding of the two study areas, a brief description of these areas was provided, including the criteria for their inclusion and exclusion of other Zambian CBR programmes from the study. A description of the two CBR programmes was also provided.

An explanation of the method used to select the study population and study sample was provided. Data collection was described in terms of the measuring instrument, methods of data collection, the first assessment of the participants, the CBR intervention and the post-intervention re-assessment. Sources of data were outlined. CRWs were introduced as research assistants.

The pilot study and the adjustments made to the measuring instrument as a result of this study were highlighted.

The method of data analysis was explained. The acceptable p-value for the study was determined as $p=0.05$. The use of instruments such as the paired t-test and linear regression analysis was explained. The level of correlation between the variables tested was used to establish the level of integration for PWPD into the community.

CHAPTER 4

PRESENTATION OF RESULTS

4.1 INTRODUCTION

The primary aim of the study was to determine the impact of a community-based rehabilitation intervention strategy on PWPD in an urban and rural setting in Zambia. This chapter will present the results of the study regarding the pre-intervention assessment, the intervention and the post-intervention assessment. The results for each section of the questionnaire will be provided under demographic profile, movement, functional activities, caregiver provision and dependency, and integration into the community, in conjunction with the objectives of the study. Results pertaining to Objectives 1 and 2 will be reported separately in a descriptive manner, while results that pertain to Objectives 3, 5 and 6 will be comparatively reported. Therefore, results pertaining to Objective 4 will be presented earlier than those pertaining to Objective 3. Qualitative results regarding the perception of the participants/proxy concerning the changes that had occurred in disability status since starting community-based rehabilitation and their experiences concerning the disability (Section F of the questionnaire) will be reported separately at the end of this chapter, even though some narrative will be included with other parts of the results. The qualitative section combines the results of all the sections and pertains to all five of the objectives. Statistical significance is accepted as $p < 0.05$, while marginal significance is accepted as $0.05 < 0.1$. This means that p-values less than 0.05 will be regarded as being significant while p-values more than 0.05 will not be significant. However, p-values between 0.05 and 0.1 will be regarded as marginal.

4.2 PRESENTATION OF RESULTS

Here follows a presentation of the results according to the six objectives set out in Chapter 3 in order to reach the primary aim of the study.

4.2.1 OBJECTIVE 1: DESCRIPTION OF THE TWO STUDY AREAS AND THE TWO CBR PROGRAMMES IN LUSAKA AND CHIPATA

Zambia has a total population of 9 885 591, of which 4 946 298 are male and 4 939 293 are female. The majority of the population, 65% or 6 416 423, live in rural areas, while 35%, or 3 469 168, live in urban areas. Zambia has a surface area of 752 614 square kilometres. Administratively, the country is divided into nine (9) provinces with 72 districts which represent central and local baseline government administration in all community services including health, social welfare services, education, science, technology and vocational training (CSO, 2003). The life expectancy of Zambian people at birth is 50 years (Ministry of Finance and National Planning, 2003).

4.2.1.1 Description of the Lusaka and Chipata study areas

Lusaka urban district is situated in the Government Republic of Zambia's Lusaka province, which has a surface area of 21 896 square kilometres and a population of 1 391 329. The population of Lusaka district is 1 084 703 and forms 78% of the provincial population. Lusaka province has a population density of 63.5 persons per square kilometre and an annual growth rate of 3.6%. (CSO, 2003). The Lusaka urban district CBR programme covers six townships/compounds, namely Garden, Matero, Chaisa, Mandevu, Chipata, Marapodi and N'gombe (Lusaka CBR Programme, 2002). Several languages are spoken in Lusaka district, including the seven official local languages, which are Nyanja, Bemba, Lozi, Tonga, Luvale and Kaonde. English, Bemba and Nyanja are mostly spoken (CSO, 2003).

Chipata district is situated in the Eastern province of Zambia and Chipata town is the capital of the province. Eastern province has a surface area of 69 106 square

kilometres, with a population density of 18.9 per square kilometre. Eastern province has a population of 1 306 173, of which 49.7% are male and 50.3% female. Chipata district has a population of 381 207. The annual growth rate for the province is 3.5%, which is higher than the national growth rate of 2.6% (CSO, 2000). The Chipata district CBR programme covers four areas, namely Champhande, Kasamanda, Jelusalemu and Kamulaza (Chipata CBR Association, 2002). The languages mostly spoken in Chipata district are Nyanja and English (CSO, 2003).

The two study areas were selected because they met the inclusion criteria. Additionally, they represent two different sets of cultural, geographical, economic and social aspects of PWP. While Lusaka consists of a mixture of cultures because of the migration of people from all parts of the country, Chipata represents a typical ethnic population area. Since there are existing CBR programmes in these two areas, the opportunity for an evaluation of the impact of CBR on PWP through a study such as this presented itself.

4.2.1.2 Description of the Lusaka and Chipata CBR programmes

The Lusaka urban CBR programme was initiated by the Lusaka branch of Cheshire Home International and started its operations in April 1997. The initial tasks were community mobilisation, awareness campaigns and house-to-house disability surveys in the four densely populated urban townships of Chaisa, Mandevu, Chipata and N'gombe. The total number of disabled persons on the register was 1 228 active in CBR intervention and 200 for follow-up. The programme is funded by the Christofel Blinden Mission (CBM), a German donor organisation. Other donors are the Liliane Fund and the International Federation of Hydrocephalus and Spina Bifida (IFH/SB). There is no input from the government except eye and epileptic clinics which are conducted by qualified clinical officers from the government health sector. Efforts to have the programme incorporated into the MoH through PHC and DHMTs have failed, posing a threat to its sustainability.

The programme has an administration staff of four consisting of a project director, two physiotherapists and a secretary. The other employees are thirteen trained community rehabilitation workers (CRWs), selected from the community within which they live. The CRWs go to clients' homes and assess and provide the appropriate rehabilitation intervention services according to the needs of each individual. This is done in collaboration with the physiotherapists and in consultation with the client and the family. Annual reports are prepared by the Project Director, with input from the employees, and then sent to the donors. The donors conduct an annual evaluation of the programme, without input from the government. Below is a presentation of the organisational structure of the programme.

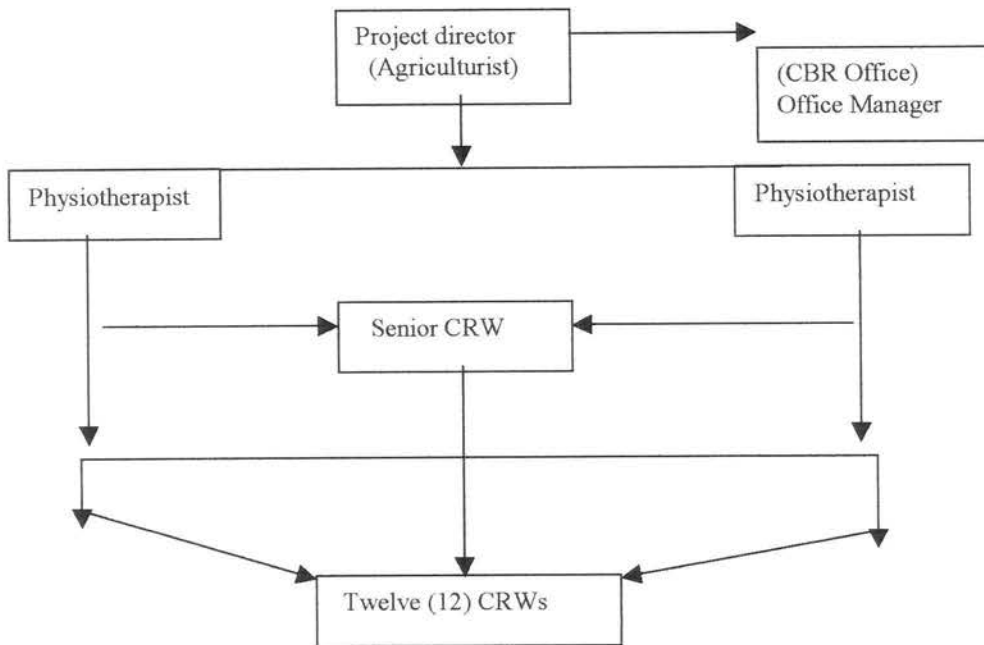


Figure 4.4: Organisational structure of the Lusaka CBR programme
(Lusaka CBR Programme, 2002)

The Chipata District CBR Programme was started in January 1996 with the help of international donors KEPA-Zambia, a Finnish centre for development cooperation, and

FIDIDA, the Finnish Disabled People's International Development Association. The programme covers four areas within 612 square kilometres from Chipata town, namely Jelusalemu, Kamulaza, Kasamanda and Champhande. In 1997, 749 PWD in these four areas were identified by means of a survey. Of this number, 197 (26.3%) were PWPD. The programme is administered by three officers at the district office. They are the programme coordinator, who is a qualified physiotherapist, a project officer, who is in charge of fundraising ventures, and a cashier. The CBR programme is run by a provincial executive board representing all four CBR areas. The board members are elected from community committees established by the community. The Chipata District Health Management Board, Chipata General Hospital, the Ministry of Community Development and Social Services, the Ministry of Education and rural health centres are all involved in the Chipata rehabilitation programme. In 2000, the Chipata District CBR Programme was transformed into an association called the Chipata Community-Based Rehabilitation Association.

The Chipata CBR programme submits annual reports to the donors, the DHMT, the management of Chipata General Hospital and the Association itself through the Executive Committee. The reports are compiled from all the reports from the smaller committees in the association and prepared by the programme coordinator. The report is tabled and discussed at the annual general meeting. This provides all the members with information on what is happening in other areas and also makes recommendations for future improvements in the running of the association. The organisational structure of Chipata CBR programme is outlined below.

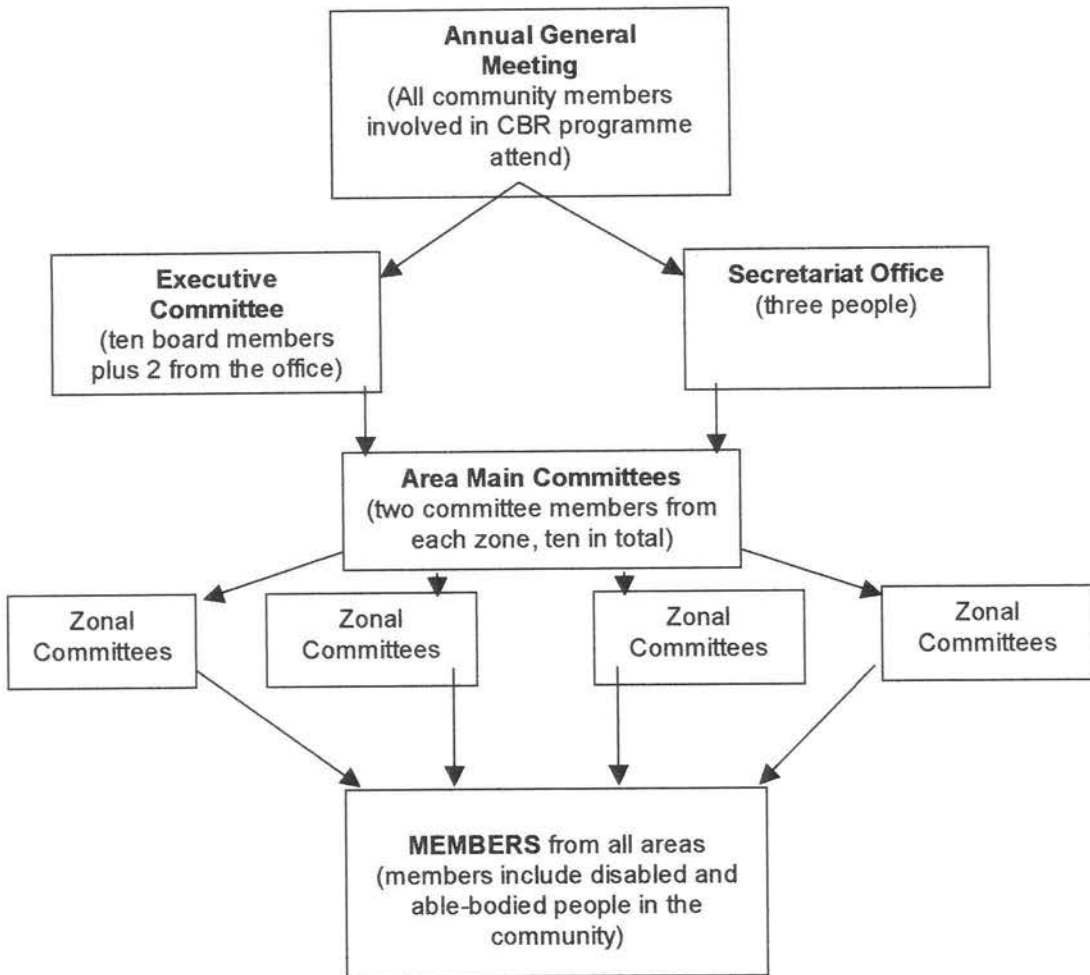


Figure 4.5: Organisational structure of the Chipata CBR programme
(Chipata CBR Association, 2002)

The two CBR programmes discussed above differ in various ways. These differences provide insight on how two approaches to CBR can function, provide rehabilitation services and meet the needs of PWD according to the environment in which the programme operates.

4.2.2 OBJECTIVE 2: DESCRIPTION OF DEMOGRAPHIC INFORMATION OF THE PARTICIPANTS FROM THE TWO STUDY AREAS OF LUSAKA AND CHIPATA

4.2.2.1 Description of the demographic information of the participants

- Section A of the questionnaire required demographic data from the participants. The following data was collected and is presented in Tables 4.1 and 4.2:
- Identity number of the participant
- Demographic location of the participant
- Language used during the interviews/survey
- The participant; whether it was the participant himself/herself or his/her proxy
- Gender of the participant
- Relationship of the participant to proxy
- Age of the participant at the time of the interview
- Age of the participant when he/she became disabled
- Family status of the participant
- Highest level of education of the participant
- Highest level of education of proxy
- Whether participant was currently attending school
- Whether participant was currently employed
- Type of employment of participant
- Type of employment of proxy
- When participant started CBR
- Whether participant received physiotherapy before starting CBR
- Nature of disability
- Medical diagnosis
- Cause of impairment

Table 4.1: Demographic characteristics of participants in Lusaka urban and Chipata rural districts, April 2001- April 2004 (n=66)

Demographic characteristics	Number of participants n=66			Percentage %		
	Urban	Rural	Total	Urban	Rural	Total
<u>Location</u>	31	35	66	47	53	100
<u>Language</u>						
English	1	0	1	2	0	2
Nyanja	22	34	58	38	51	88
Bemba	6	1	7	9	2	10
<u>Respondents</u>						
Client	5	27	32	8	41	48
Proxy	18	3	21	27	3	32
Both	8	5	13	12	8	20
<u>Gender of clients with disabilities</u>						
	19	22	41	29	33	62
Male	12	13	25	18	20	38
Female						
<u>Relationship of client to proxy</u>						
Spouse	3	9	12	5	13	18
Child	4	1	5	6	2	8
Parent	18	15	33	27	23	50
Family member	7	7	14	10.5	10.5	21
Other	0	2	2	0	3	3
<u>Age of client at time of survey</u>						
7-12	15	5	20	22.5	7.5	30
13-20	9	3	12	13.5	4.5	18
21-30	2	12	14	2	18	21
31-40	0	6	6	0	9	9
41-50	2	7	9	3	11	14
51-60	3	2	5	5	3	8
<u>Age client became disabled</u>						
Before birth	4	6	10	6	9	15
0-6	18	20	38	27	31	57
7-20	4	6	10	6	9	15
21-30	0	3	3	0	5	5
31-40	0	0	0	0	0	0
41-50	2	1	3	3	2	5
51-60	2	0	2	3	0	0

Table 1 indicates that Lusaka participants represented 47% while Chipata participants constituted 53%. When asked to choose the preferred language to be used during the interview, 2% of the participants chose English, 89% Nyanja and 11% Bemba. Forty nine percent (49%) of the participants responded to the questionnaire themselves, 32% were represented by their proxy and in 20% of the cases both responded to the questions. Male participants constituted 62% while 38% were female.

The question on the relationship of the proxy to the participant showed that 50% were parents, 21% family members, 18% spouses, 8% children and 3% community members. At the time of the survey, 30% of the participants were between 7 and 12 years old, 18% were between 13 and 20 and another 18% between 21 and 30 years. Nine percent (9%) of participants were between 31 and 40, 14% between 41 and 50 and 8% between 51 and 60 years old. The age at which the participants became disabled showed a wide range. Fifteen percent (15%) had the disability since before birth, 58% since they were between 0 and 6 years old, 15% since the ages of 7 to 20 and 5% each since the ages of 21 to 30 and 41 to 50 years. Only 3% became disabled between the ages of 51 and 60. None of the participants indicated the range 31 to 40 years.

Table 4.2: Demographic characteristics of participants regarding family status and level of education (n=66)

Demographic Characteristics	Number of participants n=66			Percentage %		
	Urban	Rural	Total	Urban	Rural	Total
<u>Family status</u>						
Single	26	19	45	30	29	68
Married	5	11	16	8	16	24
Divorced	0	1	1	0	2	2
Widowed	2	0	2	0	3	3
Separated	0	2	2	0	3	3
<u>Highest level of education of client</u>						
Pre-school	4	0	4	6	0	6
Grade 1-7	13	13	26	19.5	19.5	39
Grade 8-9	2	5	7	3	8	11
Grade 10-12	1	2	3	2	3	5
None	11	15	26	16.5	22.5	39
<u>Highest level of education of proxy</u>						
Pre-school	0	0	0	0	0	0
Grade 1-7	17	15	32	26	23	48
Grade 8-9	2	1	3	3	2	5
Grade 10-12	5	1	6	7	2	9
None	7	18	25	11	27	38
<u>Client presently attending school</u>						
Yes	9	2	11	14	3	17
No	16	7	23	24	11	35
N/A	6	26	32	9	49	48

Table 4.2 shows that 68% of participants were single, 24% married, 2% divorced, 3% widowed and 3% separated. Regarding the participant's highest level of education, it was found that the same percentage, namely 39%, had a highest education level of between grade 1 to 7 and had never attended school. Those who had a highest education level of between grade 8 and 9 constituted 11%, pre-school 6% and grade 10 to 12 five percent (5%).

The highest percentage of proxies' highest level of education (49%) was between grades 1 and 7. Those who had never attended school were 38%; those who had a highest level of education from grades 10 to 12 were 9%, while 5% attained grades 8 or 9. At the time of survey, 17% of participants attended school, 35% did not and 49% were above school-going age.

Table 4.3: Demographic characteristics of participants regarding employment status and rehabilitation services received prior to CBR (n=66)

Client presently employed						
Yes	1	21	22	2	31	33
No	5	8	13	8	12	20
N/A	25	6	31	38	9	47
Type of employment of client						
Formal	1	2	3	2	3	5
Informal	0	19	19	0	29	28
N/A	30	14	44	46	21	67
Type of employment of proxy						
Formal	5	0	5	8	0	8
Informal	9	0	9	14	0	13
N/A	17	35	52	26	53	79
When client started CBR						
1-2 years	23	11	34	35	17	52
3-4 years	9	23	32	14	35	48
Whether client received						
Physiotherapy before starting CBR						
Yes	12	1	13	18	2	20
No	19	34	53	29	51	80

Figure 4.3 shows the employment status of the participants, it was found that 30% were employed and 21% were not employed. The remaining 49% did not fall under these two categories because some were children who were not of employment age while others had retired. Five percent (5%) were in formal employment, 29% in informal employment and 67% did not fall under either one of these two categories because they were children. Of the proxy, 8% were in formal employment, 14% in informal employment, while 79% were not engaged in anything.

Fifty two percent (52%) of the participants indicated that they started CBR between 1 and 2 years ago, while the remaining 49% started 2 to 4 years ago. Twenty percent (20%) indicated that they had received some physiotherapy prior to starting CBR, while 80% had not.

Table 4.4: The nature of disability, medical diagnosis and cause of impairment of participants in Lusaka urban and Chipata rural districts, April 2001-April 2004 (n=66)

<u>Nature of disability</u>	Number of participants n=66			Percentage %		
	Urban	Rural	Total	Urban	Rural	Total
Congenital	5	8	13	8	12	20
Acquired	26	27	53	39	41	80
<u>Medical diagnosis</u>						
Amputation	1	4	5	2	6	8
Cerebral palsy	21	1	22	31	2	33
Deformity (musculoskeletal)	1	28	29	2	42	44
Hemiplegia	5	1	6	7	2	9
Other	3	1	4	4	2	6
<u>Cause of impairment</u>						
Measles	1	2	3	2	3	5
Poliomyelitis	0	8	8	0	12	12
Cerebral malaria	6	2	8	9	3	12
Meningitis	3	1	4	4	2	6
Talipes equino varus	2	2	4	3	3	6
Arthritis	0	5	5	0	8	8
High blood pressure	4	0	4	6	0	6
Other*	16	14	30	25	21	45

(*For other causes of impairment see Appendix 3)

From the results of the questionnaire presented in Table 4.3 it can be seen that 20% of participants had congenital disability, while 80% had acquired disability. Forty four percent (44%) of participants had a medical diagnosis of musculoskeletal deformity, 33% cerebral palsy, 9% hemiplegia, 8% amputation and 6% other causes. The

question regarding causes of impairment indicated that 12% of the participants' disabilities were caused by poliomyelitis and cerebral malaria each, while 6% was caused by meningitis, talipes equino varus and high blood pressure each. Arthritis was the cause of 8% of these cases, while 46% were due to other causes. (For a list of the other causes of impairment see Appendix 3.)

4.2.3 OBJECTIVE 4: EXPOSURE TO A SIX-MONTH CBR INTERVENTION PROGRAMME

4.2.3.1 Quantitative results

The existing CBR programmes in Lusaka and Chipata were evaluated in relation to the participants' status in movement, functional activities, caregiver provision and dependency, and integration of PWPD into the community. After the first assessment, the PWPD were exposed to a six-month CBR intervention programme. The CBR modalities were established after the assessment of each participant according to his/her needs. The modalities of the CBR intervention programme were based on the following areas of need that were identified:

- Mobility
- Functional activities (activities of daily living – ADL)
- Counselling of PWPD, their family and community
- Information on disability rights
- Caregiver training on the handling of PWPD
- Advice on type and use of appliances
- Home health education
- Basic physiotherapy
- Basic literacy education
- Fundraising ventures

A schedule of intervention modalities was drawn up in conjunction with the researcher, the PWPDP/proxy and the CRW. Each participant was visited once a week (a total of 24 visits in six months) and a record of visits was kept by both the CRW and the PWPDP/proxy. After six months, a re-evaluation assessment of the participants was conducted by the researcher and the CRWs, who served as research assistants. The assessment was done using the same questionnaire.

4.2.3.2 Qualitative results

In addition to the other questions, the participants/proxy were asked to answer two open-ended questions. The first question requested the participants/proxy to state the changes that had occurred to the participant's disability status since starting CBR. The issues raised were grouped under the following themes: functional, social and economic survival skills (vocational skills training). They were also asked to state their experiences concerning the disability before and after starting CBR. The issues raised were grouped under the following themes: social stigma, economic stigma, superstition and family support. Participants were also requested to share their perceptions on whether CBR had impacted on their lives or not. These results will be presented together with the quantitative results according to the topic regarding which the experiences were shared. Objective 3, 5 and 6 will be combined in presentation as the results will be reported in a comparative manner.

4.2.4 OBJECTIVE 3 AND 5: EVALUATION AND RE-EVALUATION OF THE EXISTING CBR PROGRAMMES IN THE LUSAKA URBAN AND CHIPATA RURAL AREAS TO ESTABLISH THE LEVEL OF INTEGRATION OF PWPD INTO THE COMMUNITY IN RELATION TO MOVEMENT, FUNCTIONAL ACTIVITIES, CAREGIVER PROVISION AND DEPENDENCY, AND PERCEPTIONS

In answer to Objectives 3 and 5, the Lusaka and Chipata CBR programmes were evaluated by assessing the level of integration of PWPD into the community using the same questionnaire both before and after the CBR intervention. The results of the assessment will now be presented. The linear regression graphs were used to illustrate the results showing the relationship between the integration of PWPD into the community and movement, functional activities, caregiver provision and dependency, and perceptions of PWPD as regards their disability status and experiences.

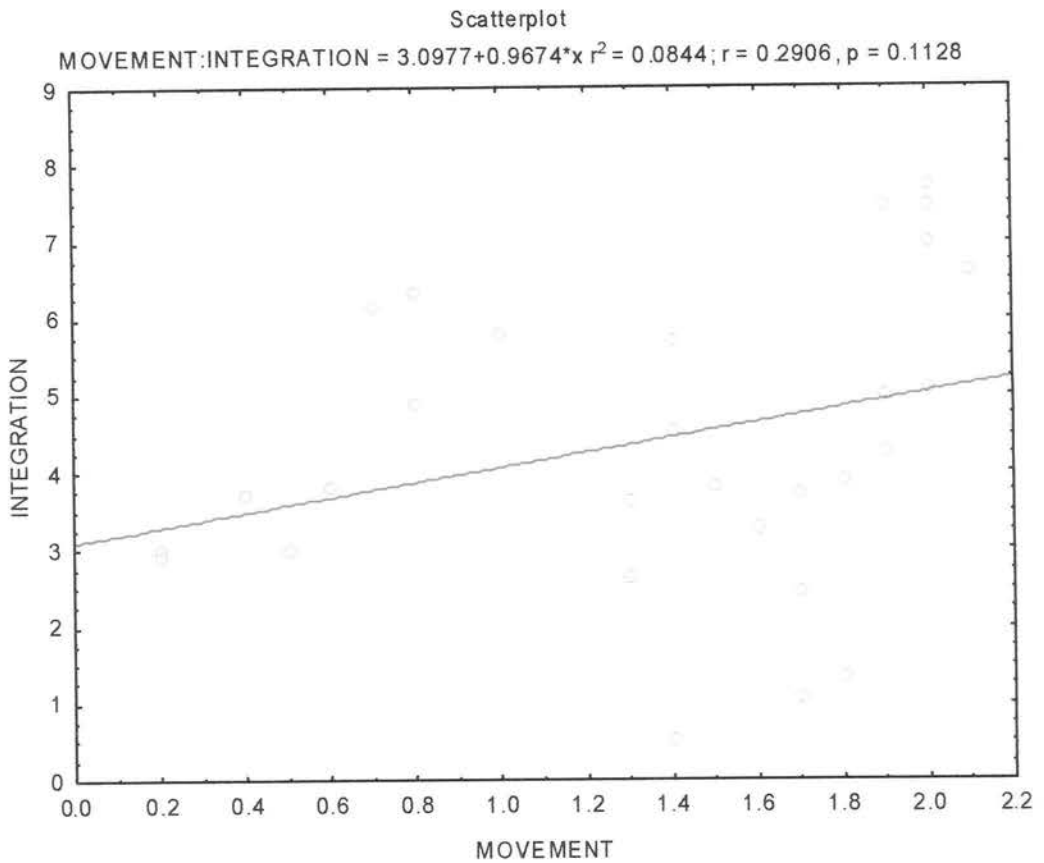


Figure 4.6: Level of integration of PWPDP into the community in relation to movement – Lusaka (before CBR intervention)

According to Figure 4.6, there was almost no relationship between movement and the level of integration before CBR intervention in Lusaka. The regression line was almost horizontal since the average level of integration was from 3.1 to 5.1 with $r=0.2906$ (correlation coefficient) and $p=0.1128$.

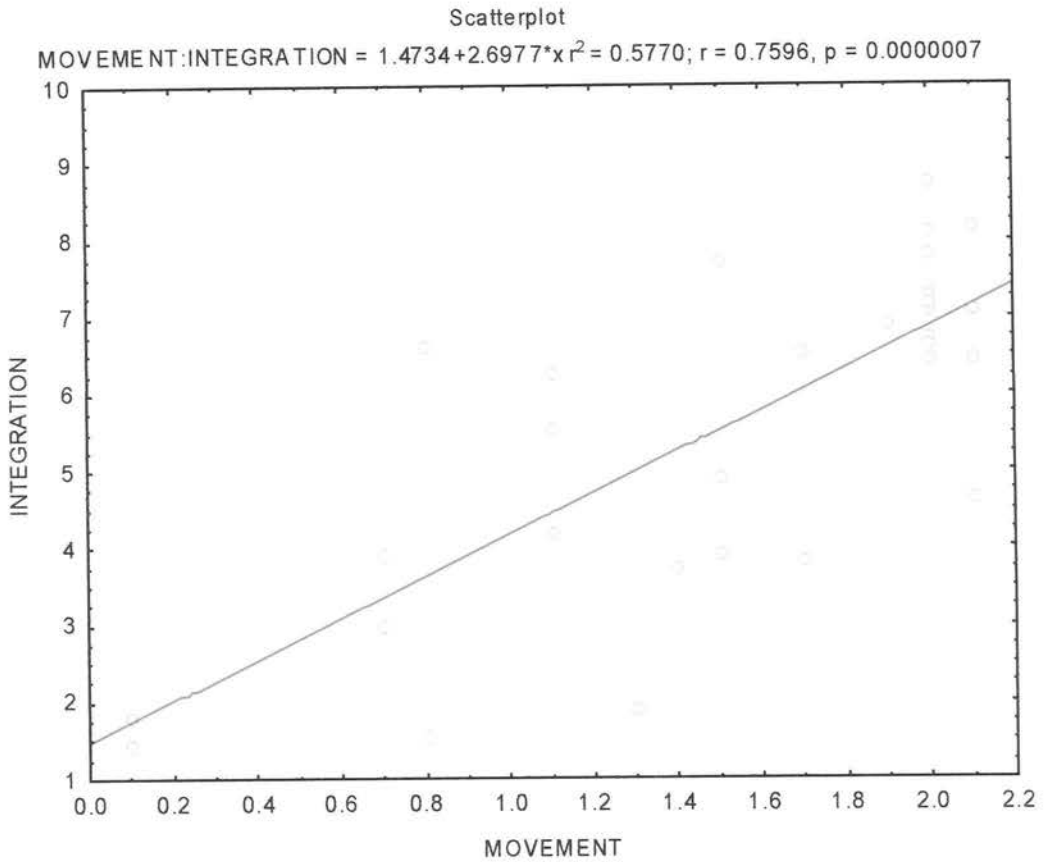


Figure 4.7: Level of integration of PWPd into the community in relation to movement – Lusaka (after CBR intervention)

Figure 4.7 shows the results after CBR intervention, indicating a strong relationship with a positive correlation between movement and the level of integration of PWPd into the community. The regression line shows an upward slope from 1.5 to 7.5 with high scores on movement associated with high scores on the level of integration, while $r=0.7596$ (correlation coefficient) and $p=0.0000$. This p -value is highly significant, indicating a high level of correlation between movement and integration of PWPd into the community.

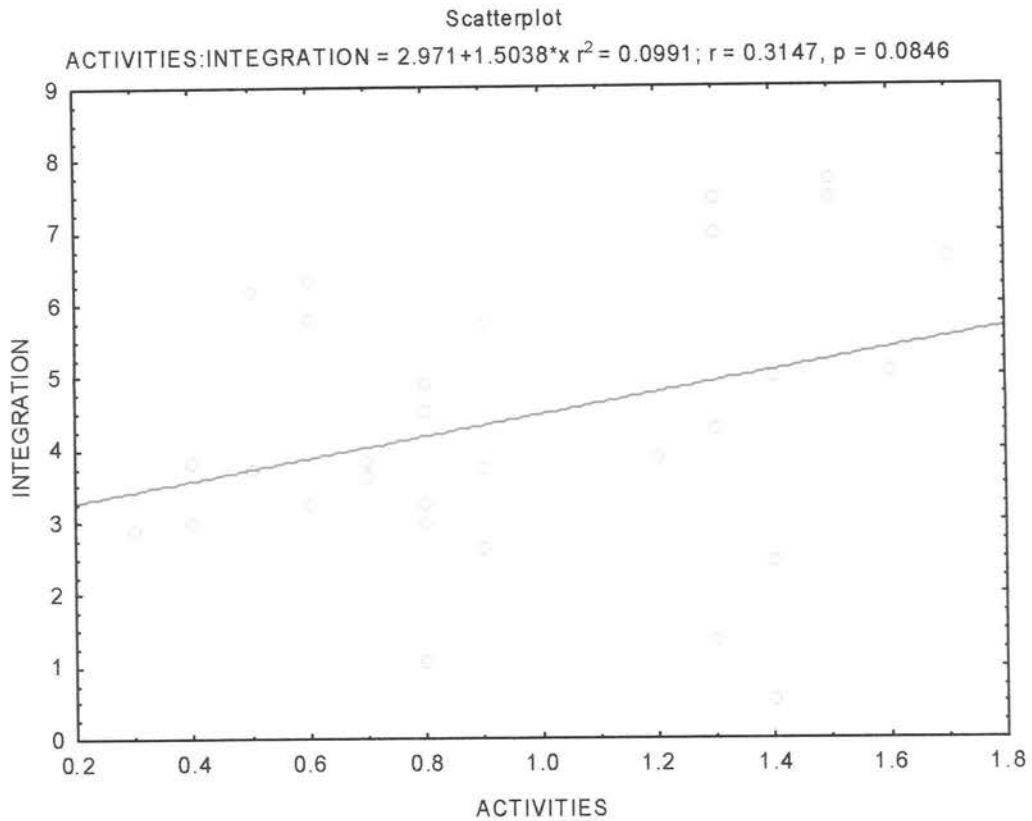


Figure 4.8: Level of integration of PWD into the community in relation to functional activities – Lusaka (before CBR intervention)

Figure 4.8 shows that there was almost no relationship between movement and the level of integration of PWD into the community before the CBR intervention. The regression line is almost horizontal, showing an average score from 3.3 to 5.7 with $r=0.3147$ and $p=0.0846$.

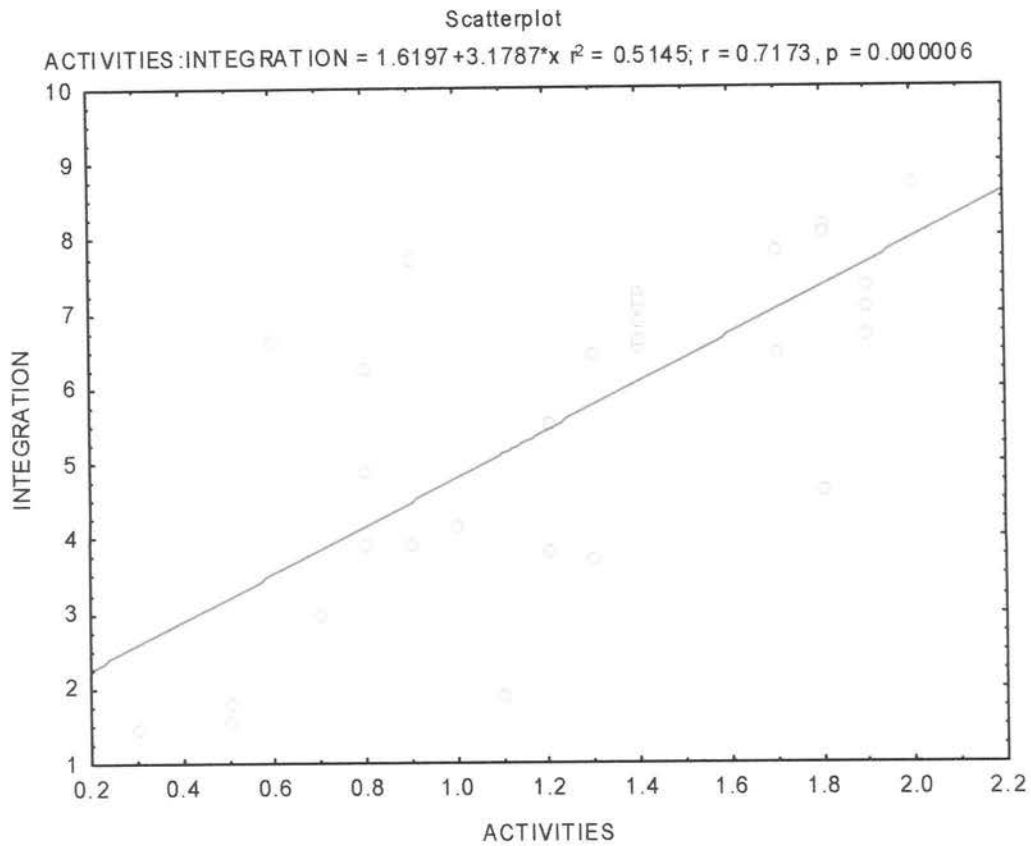


Figure 4.9: Level of integration of PWP into the community in relation to functional activities – Lusaka (after CBR intervention)

According to Figure 4.9, there was a high level of relationship between functional activities and the integration of PWP into the community, showing a positive correlation with an uphill slope regression line. The scores vary from 2.4 to 8.7 with $r=0.7173$ and $p=0000$. The p -value indicates a high level of positive correlation between functional activities and the integration of PWP into the community.

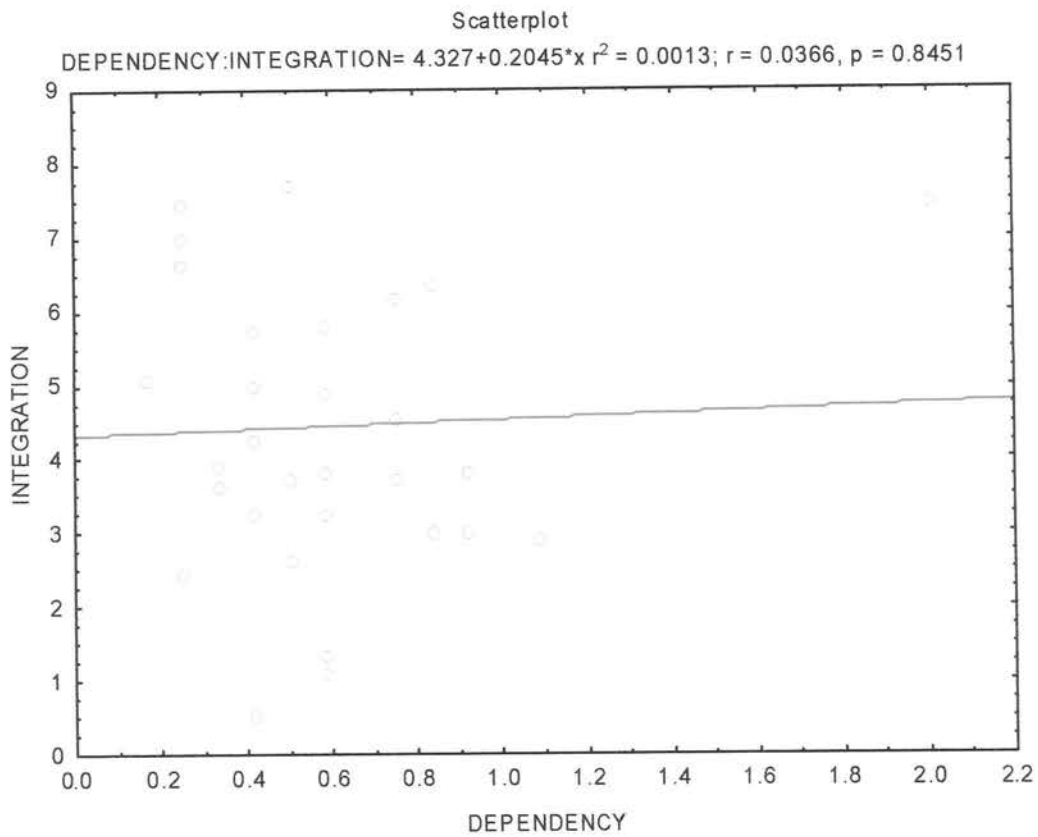


Figure 4.10: Level of integration of PWPd into the community in relation to Caregiver provision and dependency – Lusaka (before CBR intervention)

Figure 4.10 shows that there was no relationship between caregiver provision and dependency and the integration of PWPd into the community before CBR intervention. The regression line was almost horizontal, with the score averaging between 4.4 and 4.8 and $r=0.0366$ and $p=0.8451$.

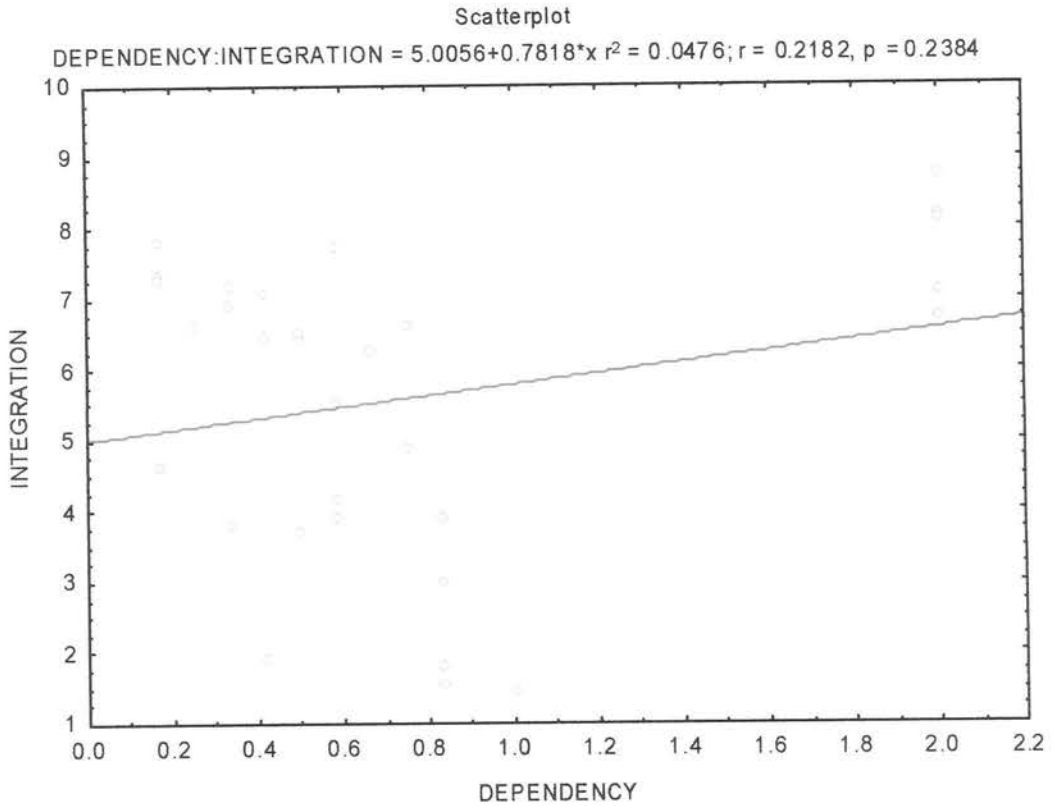


Figure 4.11: Level of integration of PWPd into the community in relation to caregiver provision and dependency – Lusaka (after CBR intervention)

According to Figure 4.11, there was a small degree of relationship between caregiver provision and dependency and integration after CBR intervention. The average scores range from 5 to 6.8, while $r=0.2182$ and $p=0.2384$. This p-value is much higher than the 0.05 accepted for this study. The results indicate that there was no significant correlation between caregiver provision and dependency and the integration of PWPd into the community.

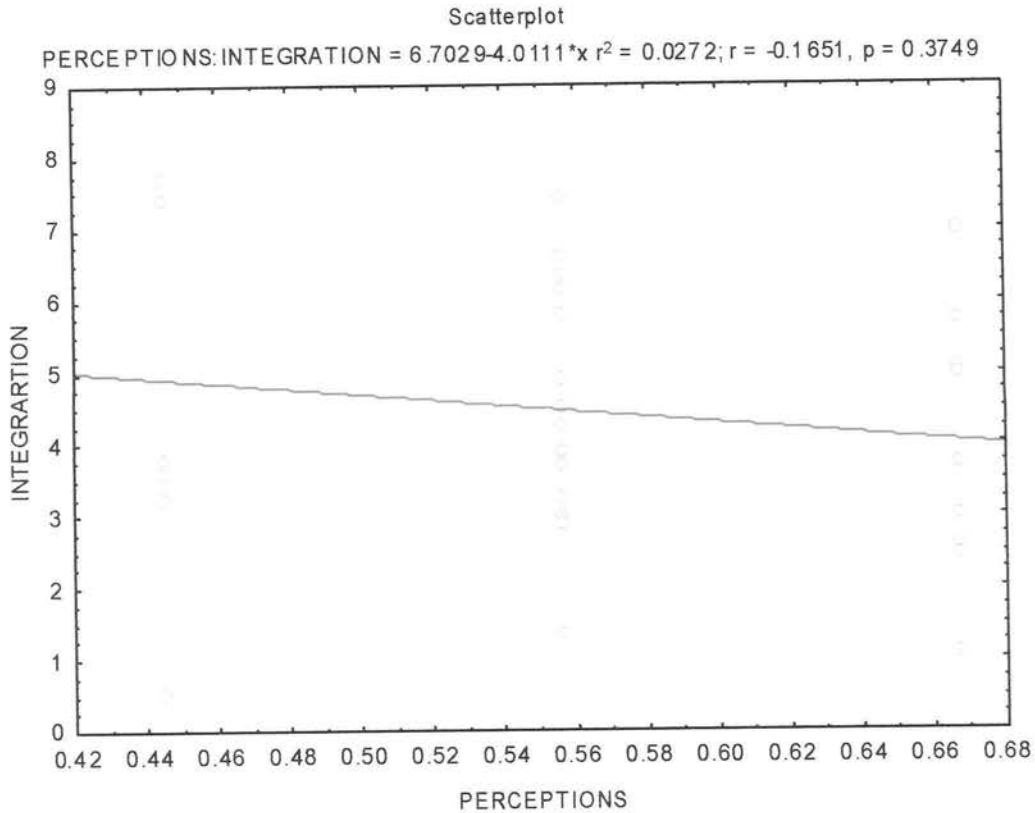


Figure 4.12: Level of integration of PWPD into the community in relation to their perceptions regarding their physical disability status and their experiences since starting CBR – Lusaka (before CBR intervention)

Figure 4.12 shows that there was no relationship between the perceptions of PWPD regarding their disability status and experiences and integration into the community before the CBR intervention. The linear regression line shows a slight downward slope from 5 to 4 with $r = -0.1651$ and $p = 0.3749$.

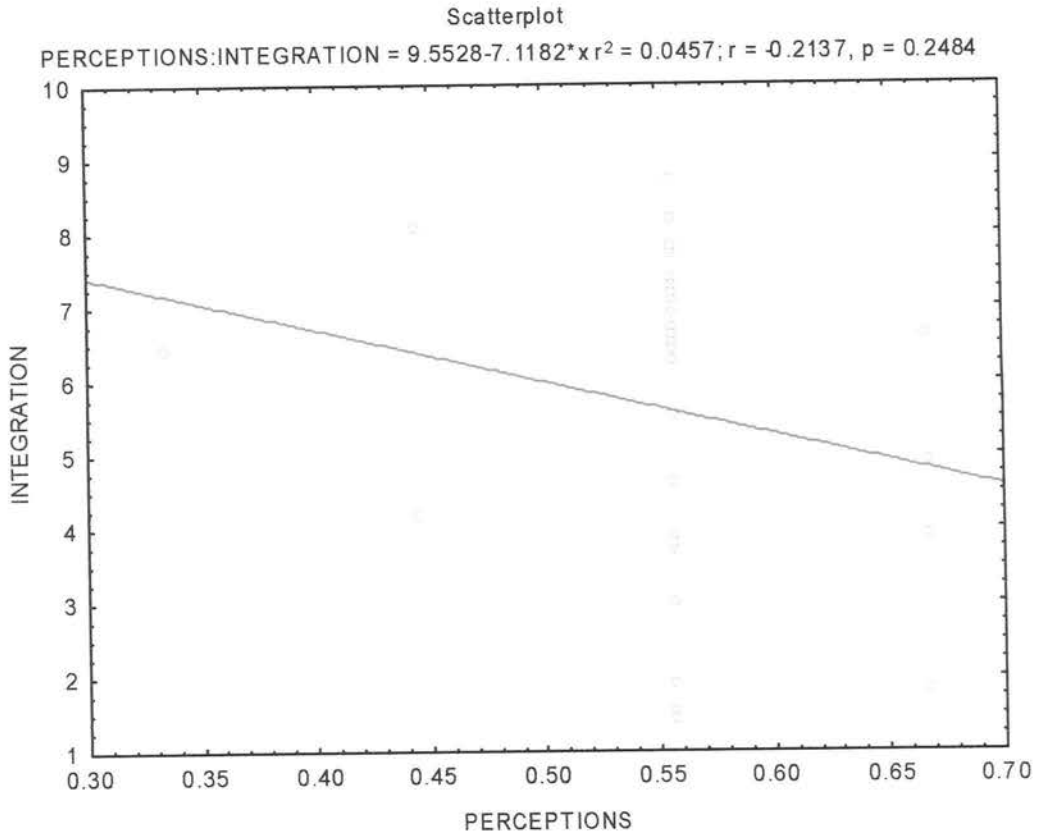


Figure 4.13: Level of integration of PWPD into the community in relation to their perceptions regarding their physical disability status and experiences since starting CBR – Lusaka (after CBR intervention)

Figure 4.13 shows the results after CBR intervention: a higher linear regression downward slope from 7.4 to 4.6 with $r = -0.2137$ and $p = 0.2484$. As can be seen from the p -value and the regression score, there was a negative correlation between perceptions and integration of PWPD into the community.

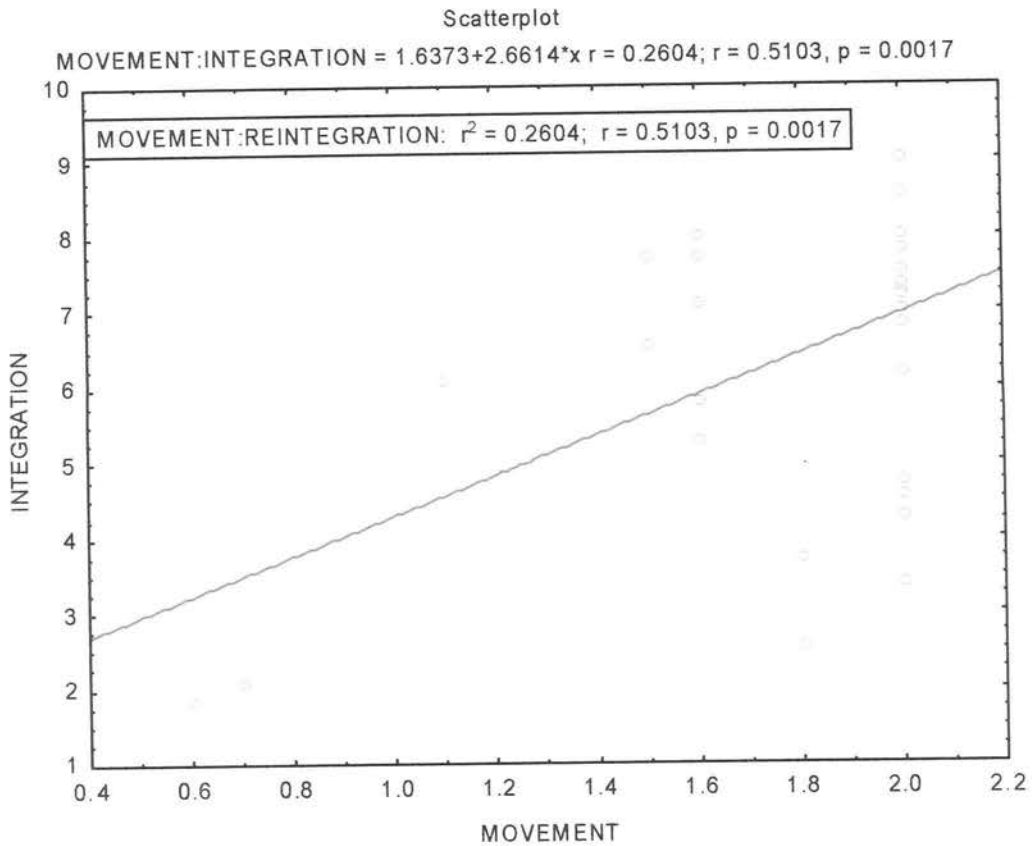


Figure 4.14: Level of integration of PWPD into the community in relation to movement – Chipata (before CBR intervention)

Figure 4.14 indicates that there was a relationship between movement and the integration of PWPD into the community before CBR intervention. The regression line showed an upward slope from 2.8 to 8.7 with $r=0.5103$ and $p=0.0017$.

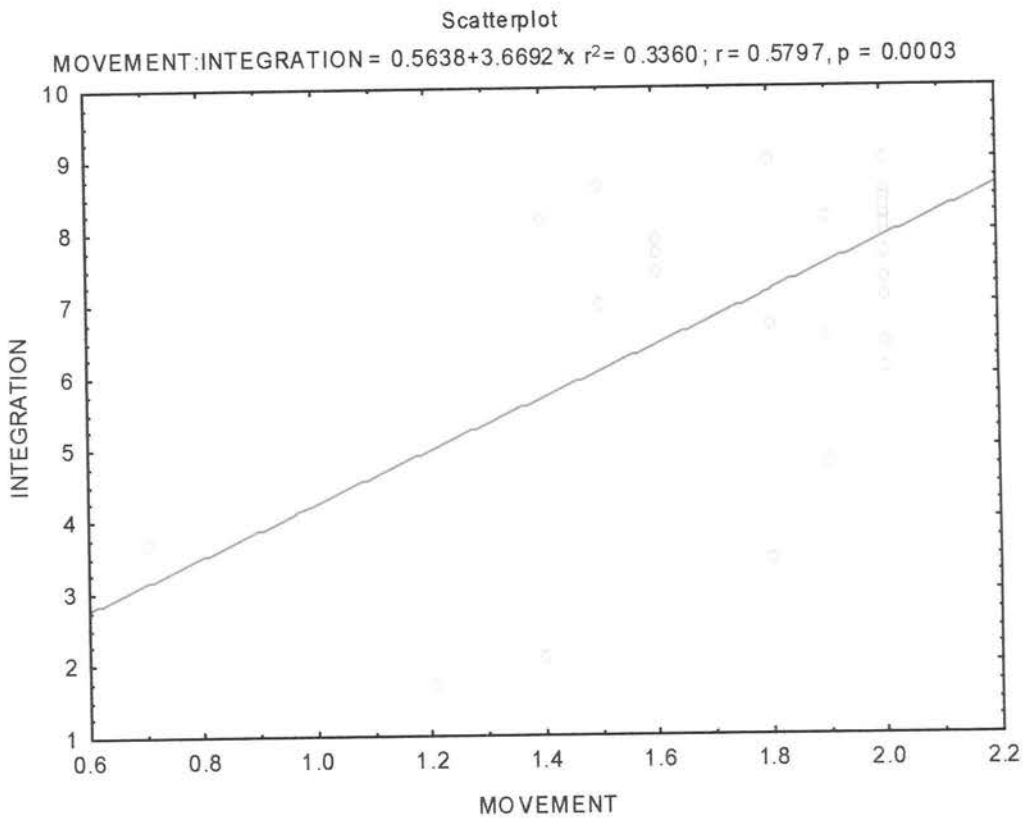


Figure 4.15: Level of integration of PWPD into the community in relation to movement – Chipata (after CBR intervention)

Figure 4.15 shows that after the CBR intervention the regression line with a high upward slope from 2.8 to 8.7. The regression score was $r=0.5797$ and $p=0.0003$. This p-value indicates a highly significant level of correlation between movement and the integration of PWPD into the community.

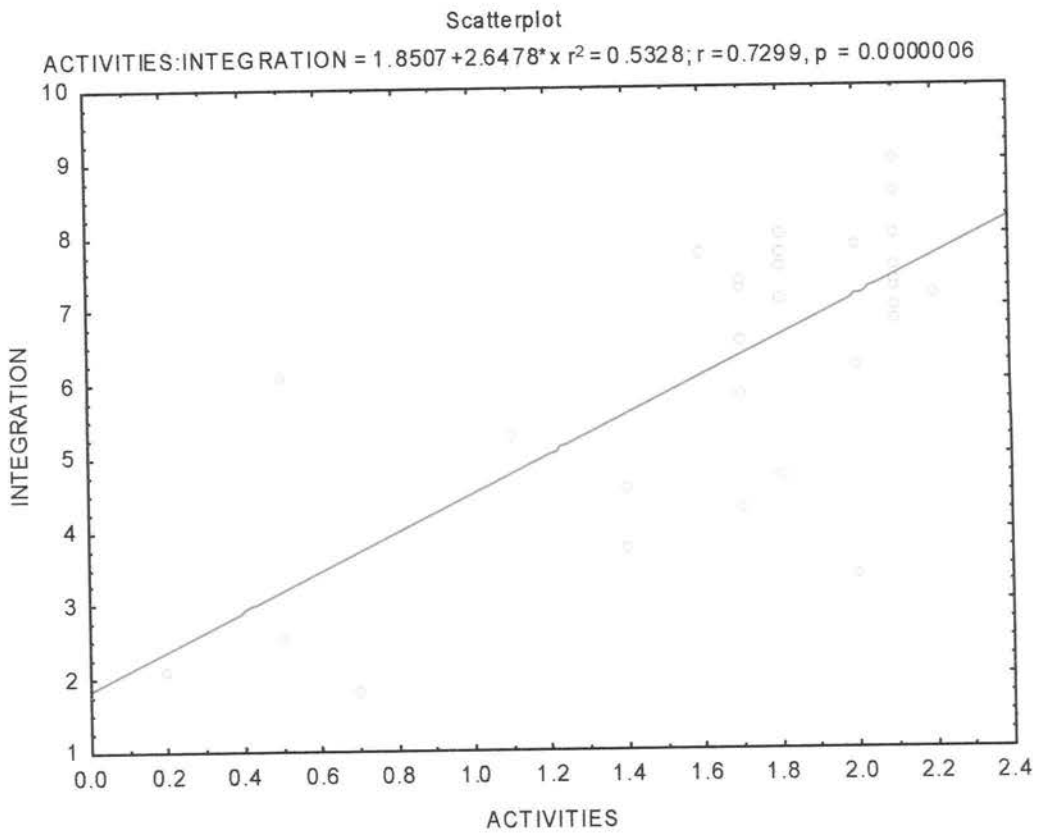


Figure 4.16: Integration of PWPD into the community in relation to functional activities – Chipata (before CBR intervention)

Figure 4.16 shows the regression line with a high slope upwards from 1.9 to 8.2 with $r=0.7299$ and the $p=0.0000$. This p -value indicates a relationship between functional activities and the integration of PWPD into the community.

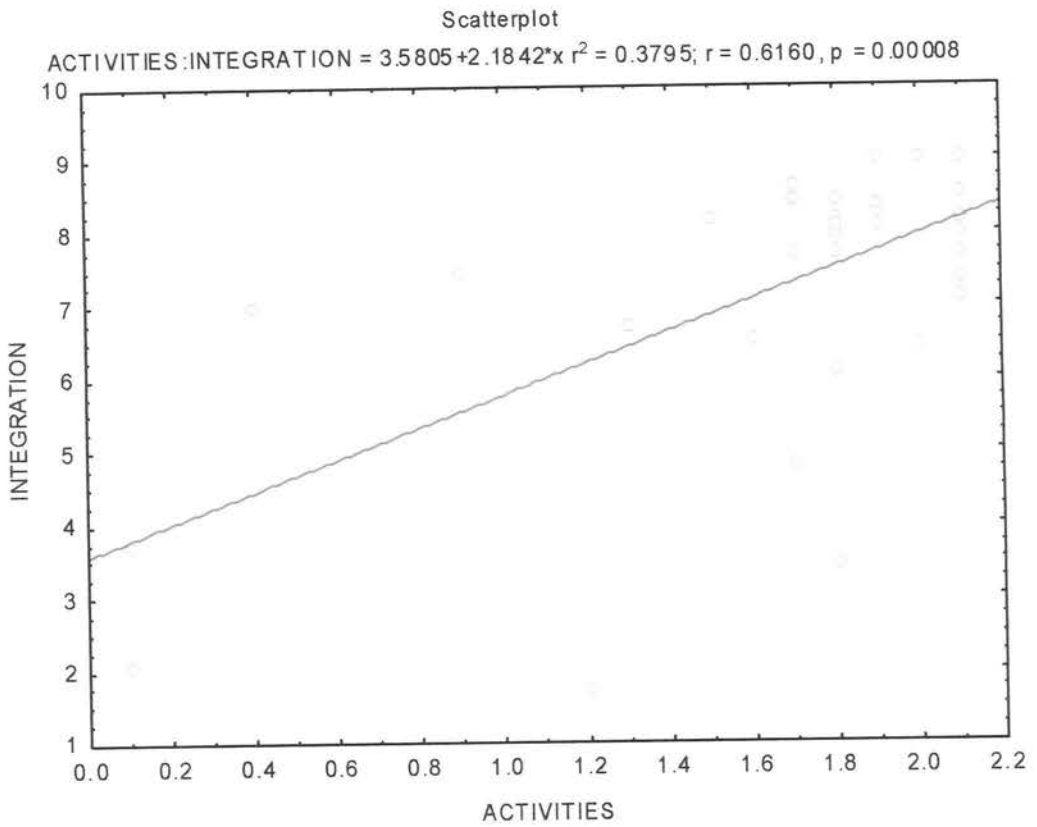


Figure 4.17: Level of integration of PWP into the community in relation to functional activities – Chipata (after CBR intervention)

Figure 4.17 shows the results after CBR intervention. The regression line runs from 3.6 to 8.4 with $r=0.6160$ and $p=0.0000$. The results show a high level of correlation between functional activities and the integration of PWP into the community, with high scores in functional activities associated with high scores in integration. This indicates a highly significant correlation between functional activities and integration.

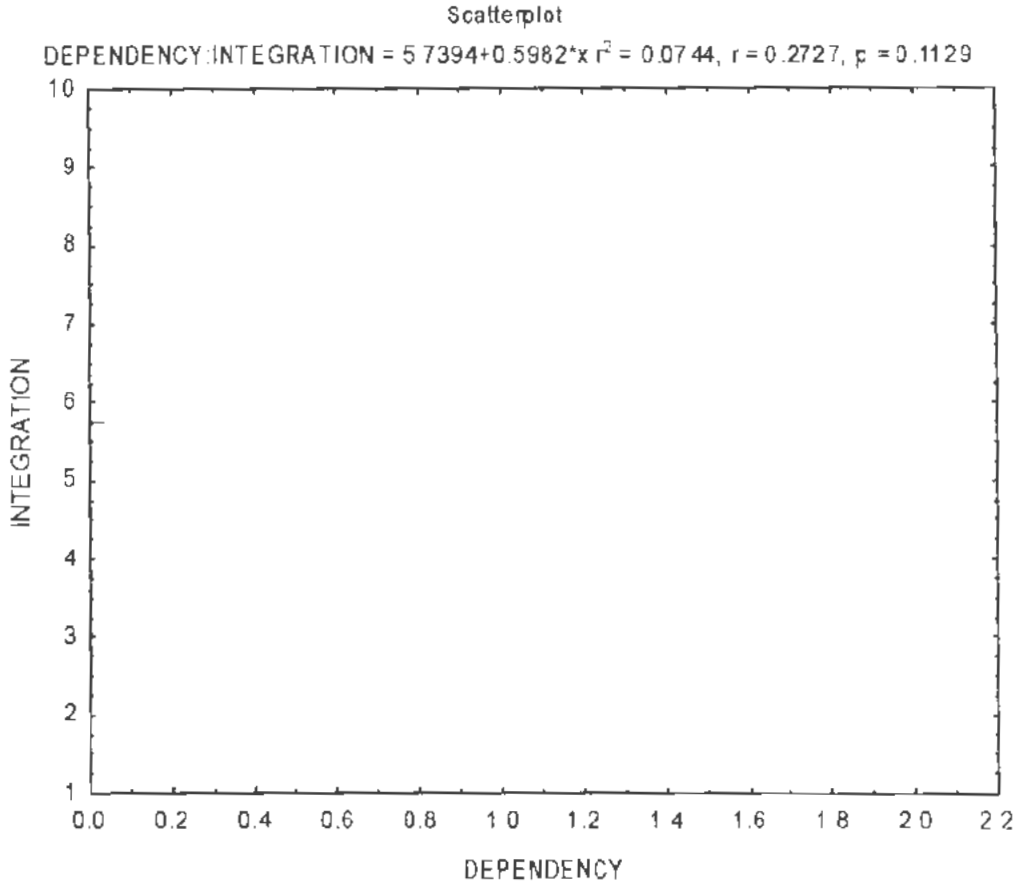


Figure 4.18: Level of integration of PWP into the community in relation caregiver provision and dependency – Chipata (before CBR intervention)

Figure 4.18 shows an almost horizontal regression line from 5.8 to 7 and a regression score of $r=0.2727$ and $p=0.1129$. This shows no relationship between caregiver provision and dependency and the integration of PWP into the community before CBR intervention.

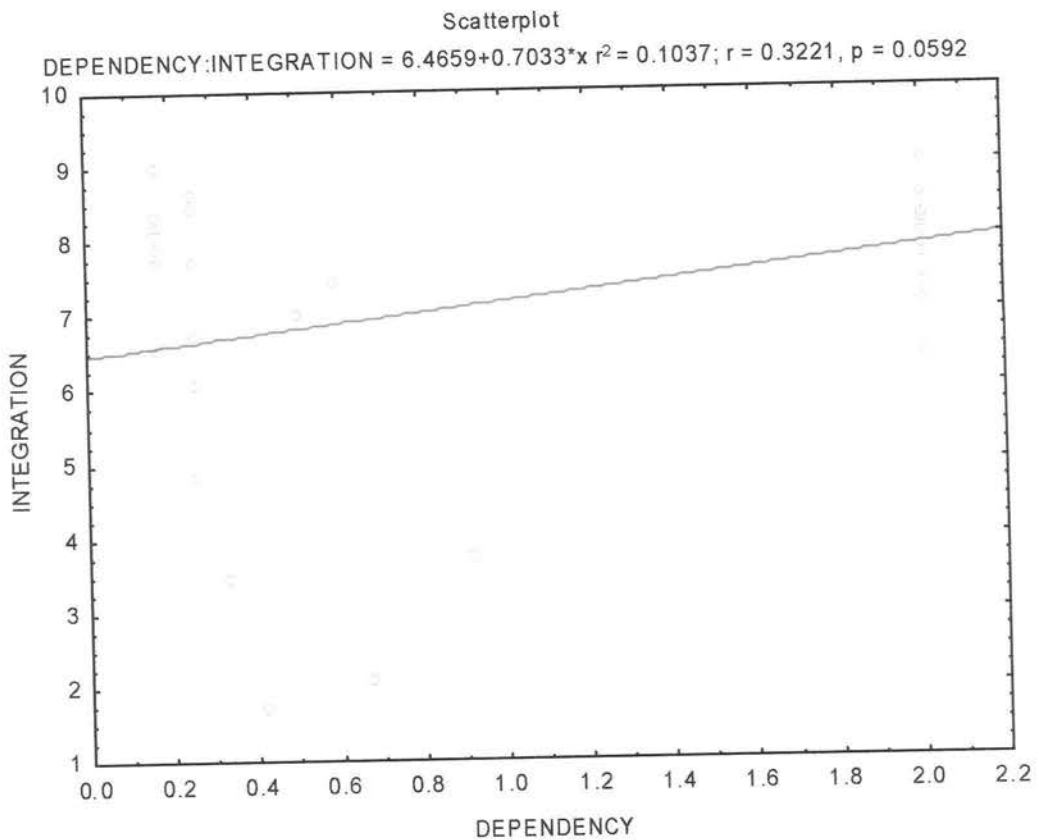


Figure 4.19: Level of integration of PWP into the community in relation to caregiver provision and dependency – Chipata (after CBR intervention)

Figure 4.19 shows the results after CBR intervention. The regression line runs from 6.5 to 8 with a regression score of $r=0.3221$ and $p=0.0592$. These results indicate a slight but not significant correlation between caregiver provision and dependency and the integration of PWP into the community.

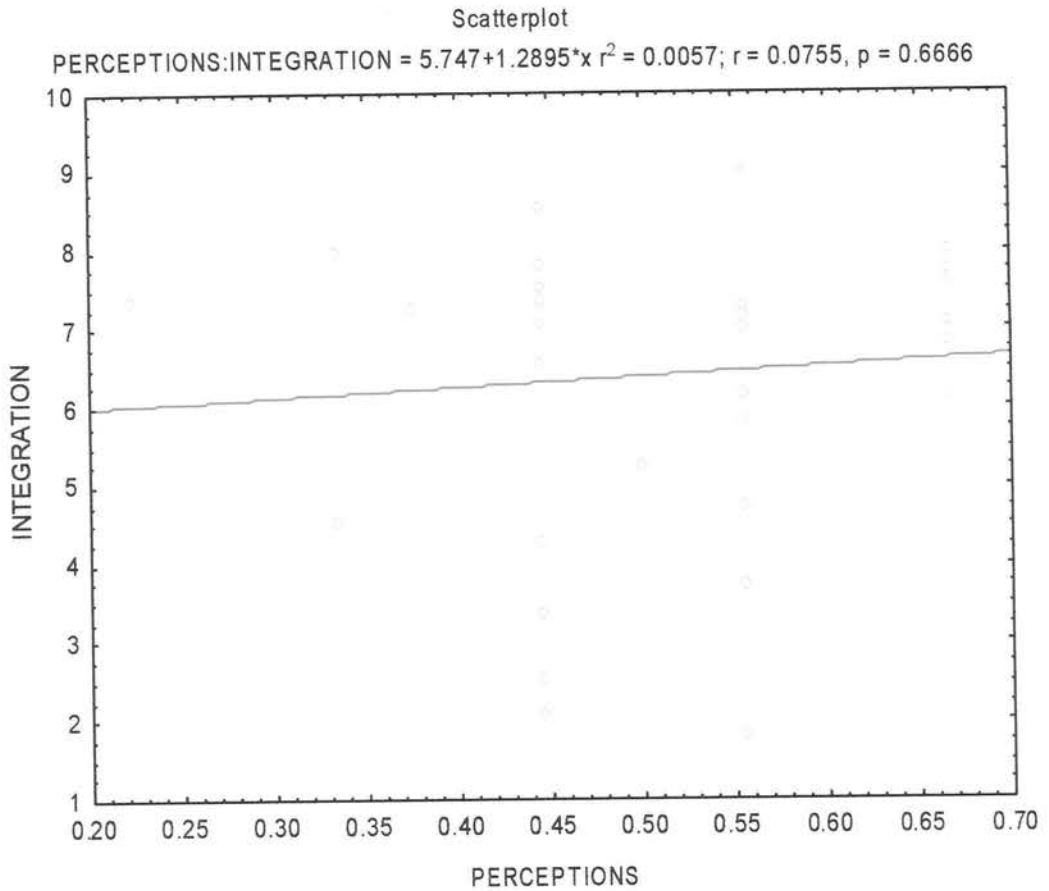


Figure 4. 20: Level of integration of PWPd into the community in relation to their perceptions regarding their physical disability status and their experiences since starting CBR – Chipata (before CBR intervention)

Figure 4.20 shows that there was no relationship between the perceptions of PWPd and their integration into the community before CBR intervention. The regression line was almost horizontal from 6 to 6.6 with a regression score of $r=0.0755$ and $p=0.6666$.

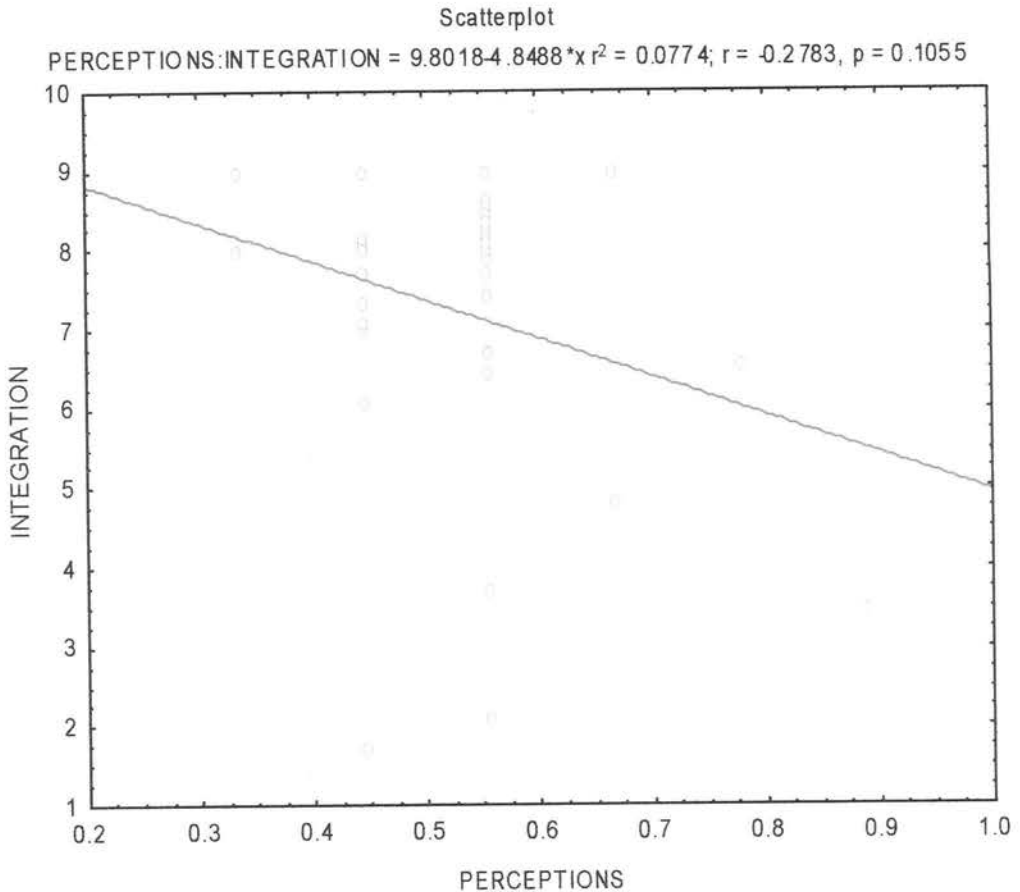


Figure 4.21: Level of integration of PWPD into the community in relation to their perceptions regarding their physical disability status and their experiences since starting CBR – Chipata (after CBR intervention)

The results after CBR intervention are shown in Figure 4.21. The regression line has a high downward slope from 8.9 to 5, the regression score is $r=-0.2783$ and $p=0.1055$. These results indicate there was a negative correlation between the perceptions of PWPD and their integration into the community. This means that participants still had negative perceptions and experiences regarding their disability after CBR intervention.

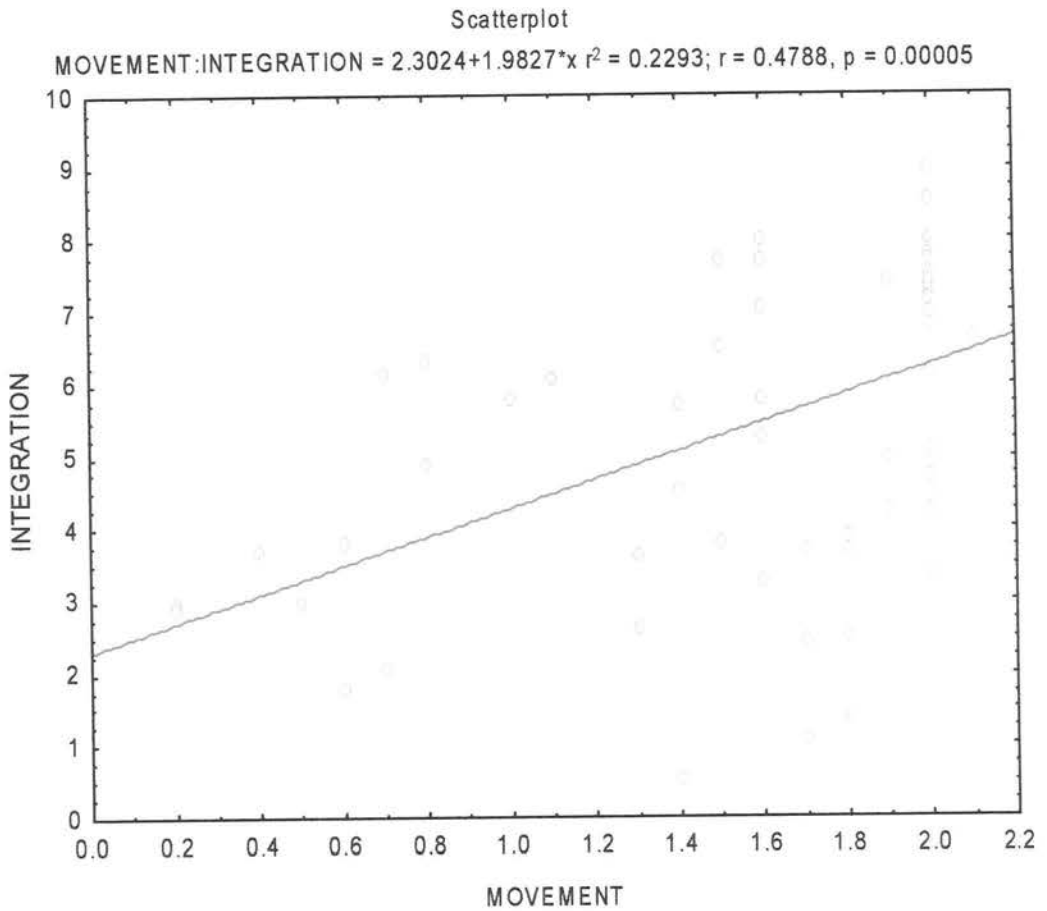


Figure 4. 22: Level of integration of PWPDP into the community in relation to movement – Lusaka and Chipata (before CBR intervention)

Figure 4.22 shows a regression line with an upward slope from 2.3 to 6.8, a regression score of $r=0.4788$ and $p=0.0005$. These results indicate that there was a significant relationship between movement and integration of PWPDP into the community in Lusaka and Chipata.

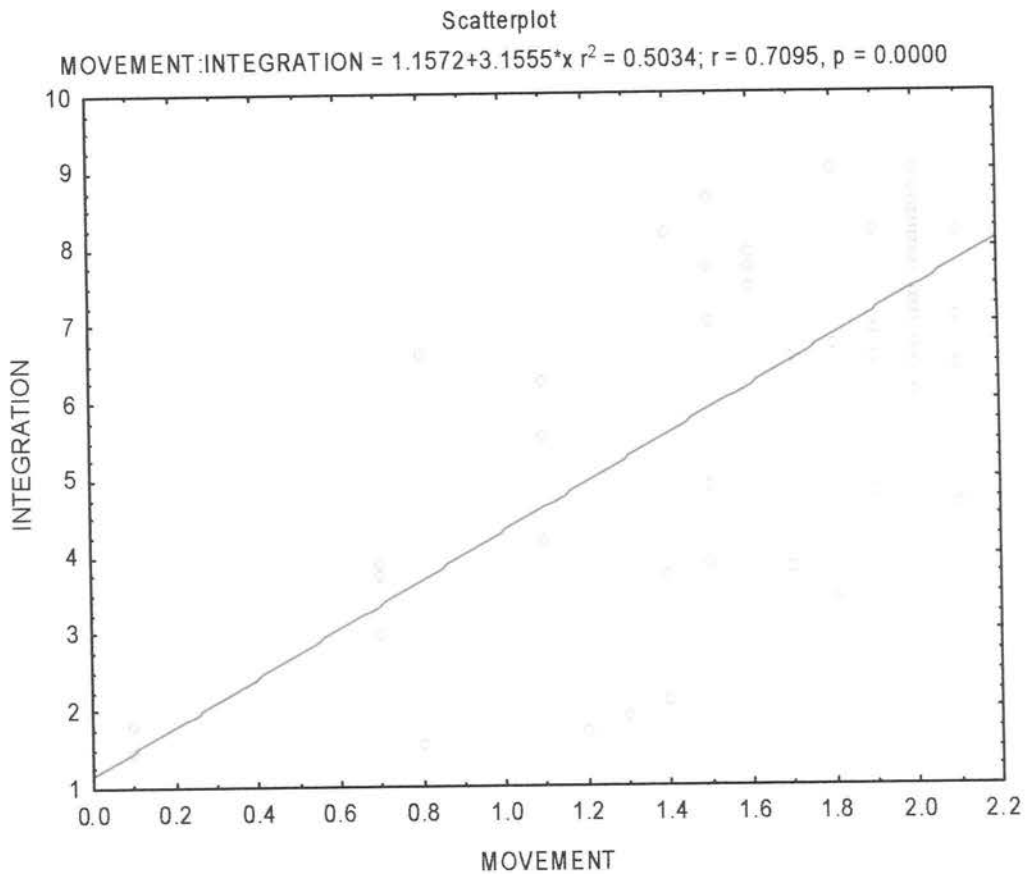


Figure 4.23: Level of integration of PWPd into the community in relation to movement – Lusaka and Chipata (after CBR intervention)

Figure 4.23 shows a regression line with a high upward slope from 1.1 to 8.1, a regression score of $r=0.7095$ and $p=0.0000$. These results indicate that there was a strong relationship between movement and the integration of PWPd into the community, with a highly significant p-value. These findings are supported by comments from parents who appreciate and acknowledge the benefits gained from CBR. Here follows an example:

“My son used to just lie in bed and had stopped school. ... I did not have anything to help him with. ... After CBR, he is now walking with a calliper and even goes to school and is in grade six, ... plays with his friends at school and here at home”.

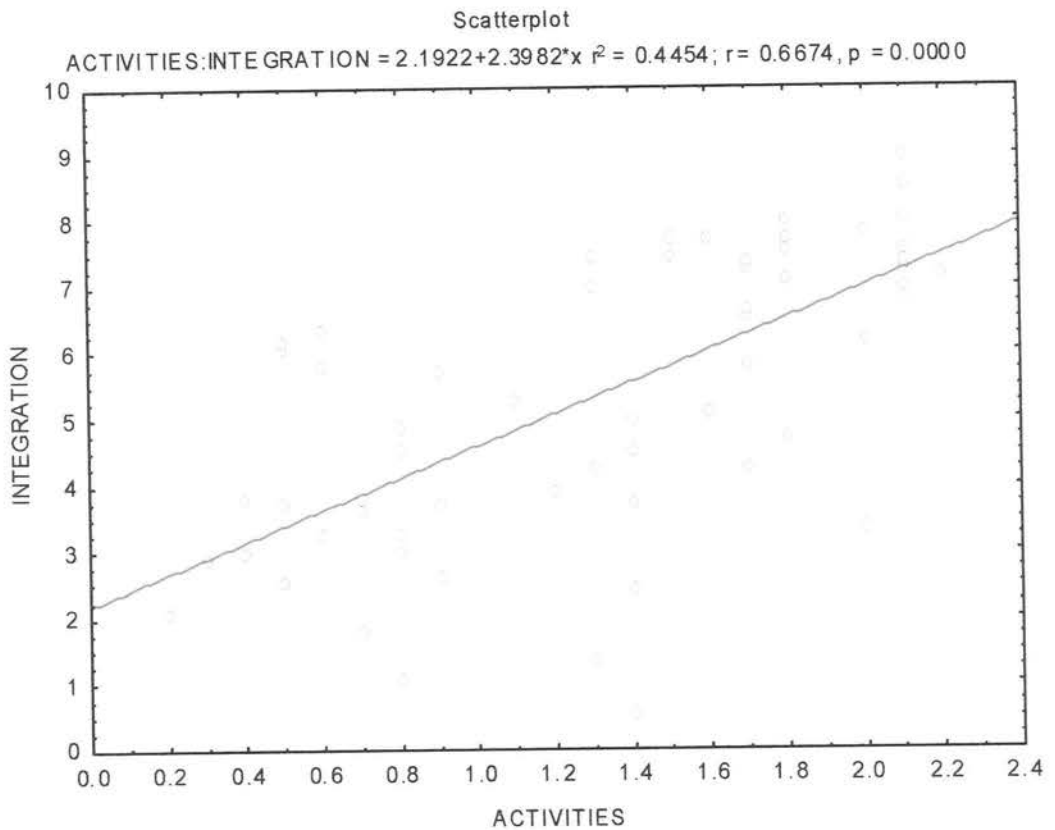


Figure 4.24: Level of integration of PwPD into the community in relation to functional activities – Lusaka and Chipata (before CBR intervention)

Figure 4.24 shows the results for functional activities and the integration of PwPD into the community before CBR intervention. The regression line runs from 2.2 to 8, the regression score is $r=0.6674$ and $p=0.0000$. These results show a significant correlation between functional activities and integration, with a highly significant p-value.

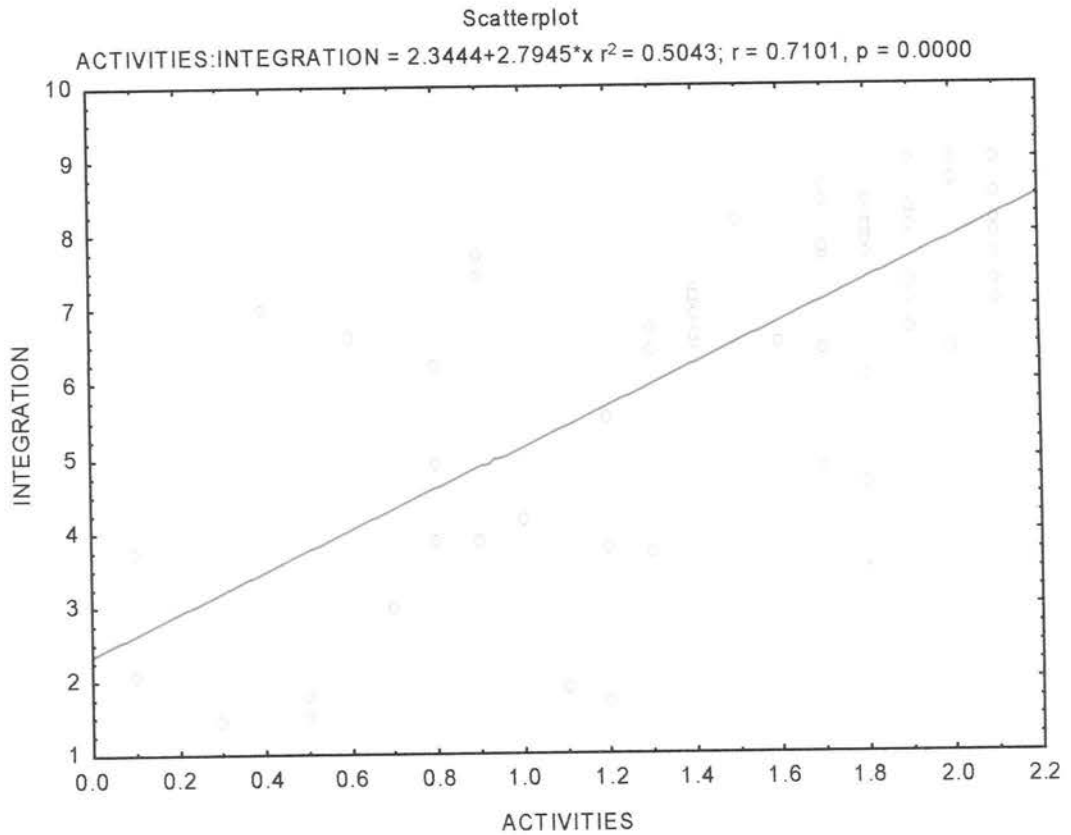


Figure 4.25: Level of integration of PwPD into the community in relation to functional activities – Lusaka and Chipata (after CBR intervention)

Figure 4.25 indicates an upward slope from 2.4 to 8.5 on the regression line. The regression score is $r=0.7101$ and $p=0.0000$. These results indicate that there is a high correlation between functional activities and the integration of PwPD into the community because high scores in functional activities were associated with high scores in integration, with a highly significant p-value.

The grandmother of a participant expressed her support of CBR intervention, since her grandson, herself and the family had benefited from CBR:

“We just used to lift my grandson but after CBR, he is able to do a lot of things for himself. CBR has provided him with a wheelchair. ... He is able to move around the village alone, he goes to the field and to church. His arm muscles were very weak but with exercise he is able to wheel himself, eats, dresses and also baths himself. ... He has grown big now so I am happy he has a wheelchair and is able to do a lot of things for himself. I have relief and the family is happy”.

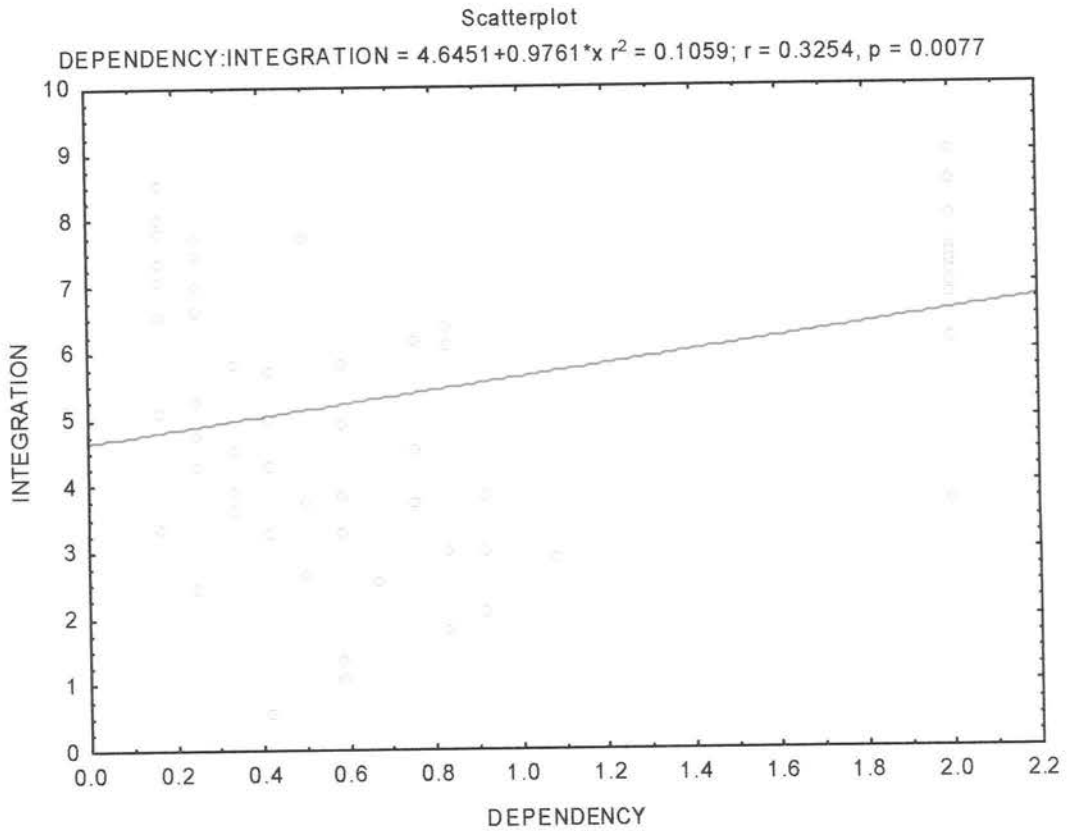


Figure 4.26: Level of integration of PWPd into the community in relation to caregiver provision and dependency – Lusaka and Chipata (before CBR intervention)

Figure 4.26 shows the regression line for integration of PWPd into the community in relation to caregiver provision and dependency before CBR intervention. The regression line was almost horizontal with a slight slope from 4.6 to 6.8 with a regression score of $r=0.3254$ and $p=0.0077$. These results show a negligible correlation between caregiver provision and dependency and the integration of PWPd into the community. Even though the p -value is less than the accepted $p<0.05$, the significance is negligible.

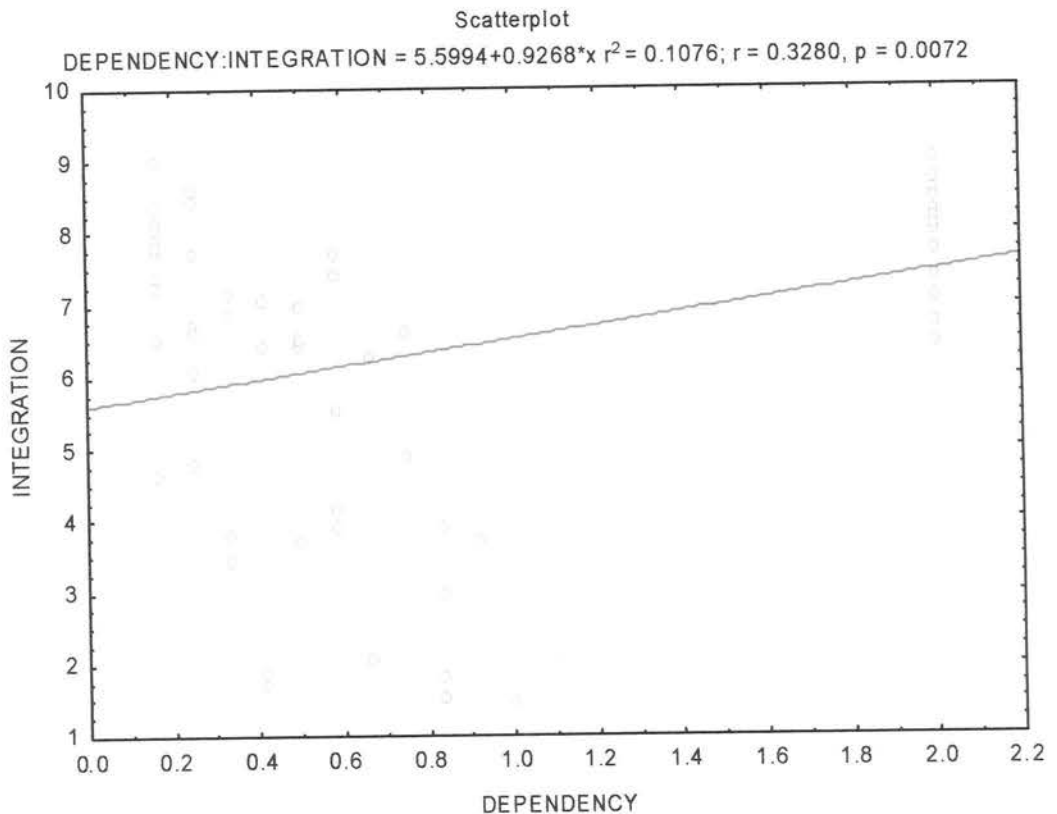


Figure 4.27: Level of integration of PWPd into the community in relation to Caregiver provision and dependency – Lusaka and Chipata (after CBR intervention)

Figure 4.27 shows the results after CBR intervention, with the regression line showing a slight slope from 5.7 to 7.7 and a regression score of $r=0.3280$ and $p=0072$. These results indicate that there is a negligible correlation between caregiver provision and dependency and the integration of PWPd into the community even though the p-value shows some significance.

On the topic of caregiver dependency, one parent commented that her son was less dependent on her because he was able to walk alone and has integrated well with his friends within the community. This is what she said:

“My son used to only move by shuffling with his buttocks but now he is walking alone with little help. ... CBR made parallel bars, a walking frame, crutches and now he has started walking without walking aids. He does not need me to be around him all the time. ... He goes alone to play with his friends and he is safe. The CBR is good, it must continue”.

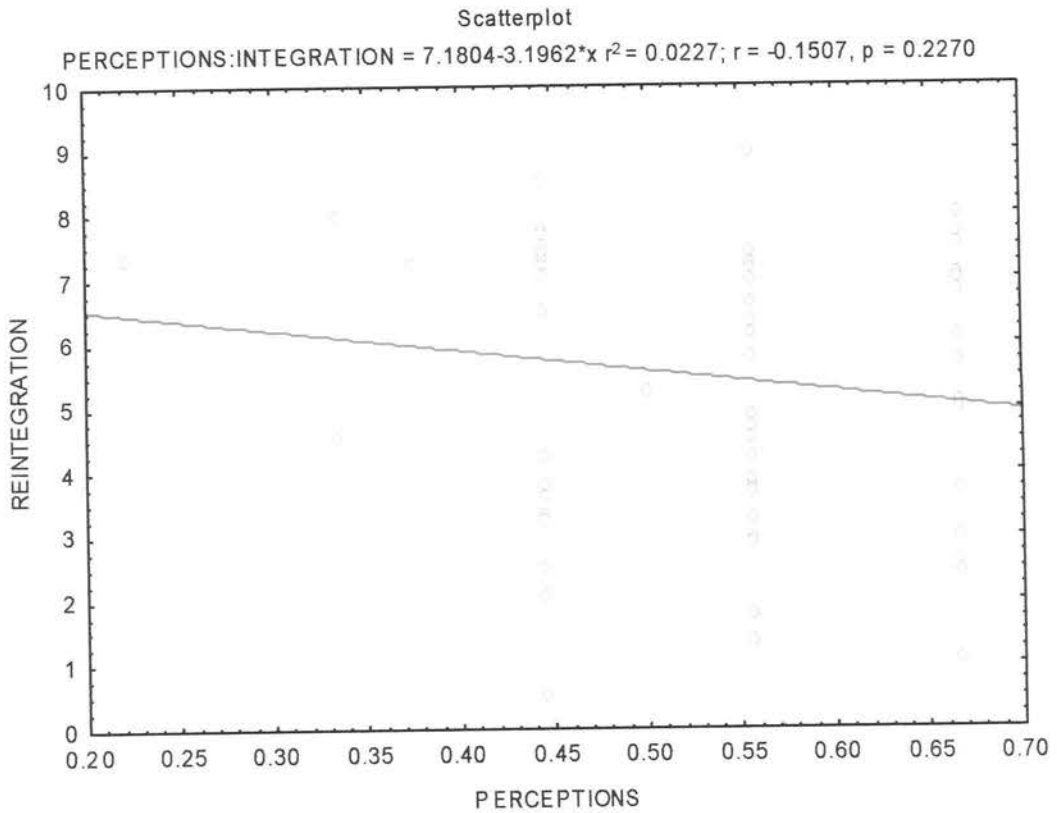


Figure 4.28: Level of integration of PWPD into the community in relation to their perceptions regarding their physical disability status and their experiences since starting CBR – Lusaka and Chipata (before CBR intervention)

Figure 4.28 indicates a negative correlation between the perception of PWPD as regards their disability and experiences and the integration of PWPD into the community before CBR intervention. The regression line shows a downward slope from 6.5 to 5 with a negative regression score of $r = -0.1507$ and $p = 0.2270$. The negative association is reflected in the high p-value which is not significant.

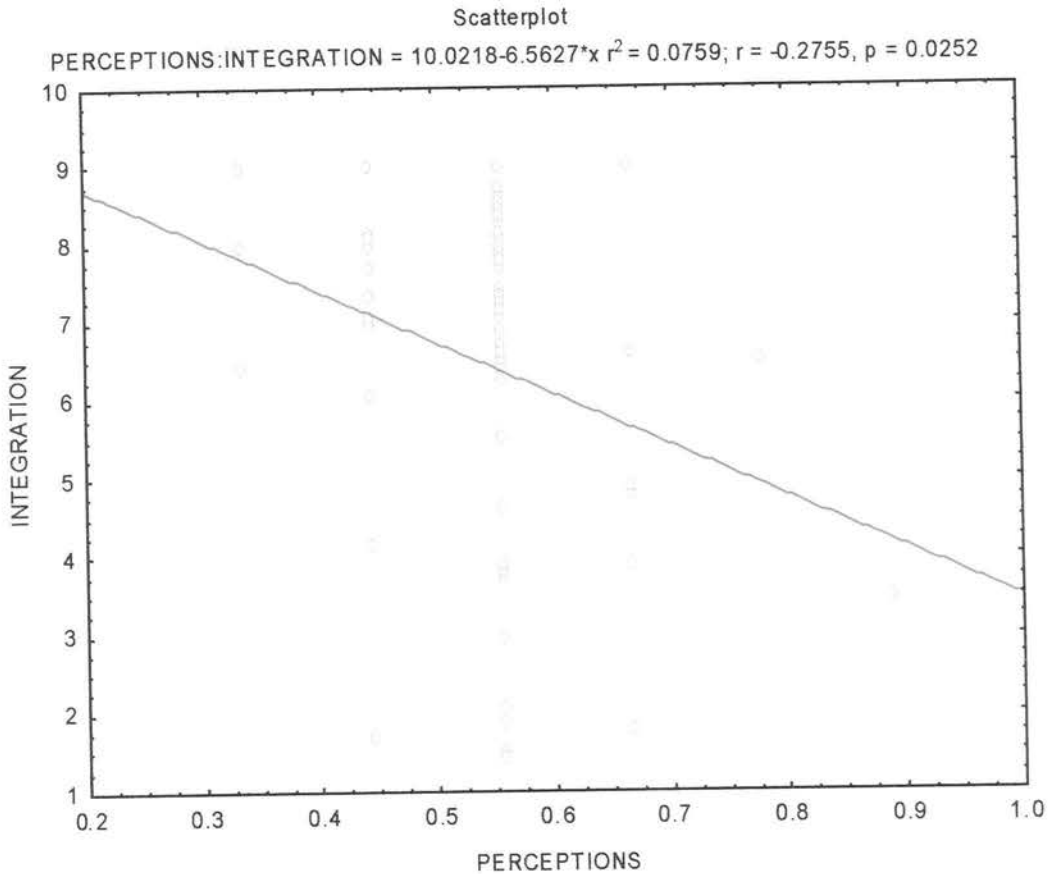


Figure 4.29: Level of integration of PWPD into the community in relation to their perceptions regarding their physical disability status and their experiences since starting CBR – Lusaka and Chipata (after CBR intervention)

Figure 4.29 shows a regression line with a much higher downward slope from 8.8 to 3.5, a regression score of $r=-0.2755$ and $p=0.0252$. These results indicate a negative correlation and a negligible significance between the perceptions of PWPD regarding their physical disability status and their experiences and the integration of PWPD into the community since starting CBR. The results reveal that the participants still had negative perceptions regarding their disability even after CBR intervention.

Even though the regression analysis showed a negative correlation between the integration of PWPD into the community and perceptions of PWPD regarding their disability status and experiences, some participants and parents had positive comments regarding CBR and its benefits:

“Before starting CBR, my life was with difficulty. I could not talk to people, my family and the community despised me because I could not contribute anything. When I wanted to marry, the community discouraged my fiancée and she refused to marry me. After CBR, I have been trained in tailoring, provided with a sewing machine and now I make clothes for sale. ... The money I make is enough to support my family. Some family members used to avoid me, now they like me and ask for help. My life has changed. ... I have more confidence in myself, I visit friends in the other village with my wheelchair which CBR gave me. I am happy now. Please CBR should continue”.

“I think that my child’s disability is a curse from my parents and they are both dead. ... In my family I am the only one with a disabled child. ... But the church encourages me a lot and says that my child was just sick”.

“My husband has deserted me for another woman. He says it is my fault that we have two children with disabilities. Even some of my relatives despise me, what can I do. I get some comfort from my sister who understands my situation. She helps me a lot financially, morally and comes to see me often. It is hard to have two children who are disabled. As is our African tradition, he said that these sons will not give him anything especially when he is old. He wants healthy children with another woman. CBR has helped me, they provided my elder son with a wheelchair. Instead of lifting him, now I just wheel him around. They carry out exercises, teach them how to do simple

activities and they have counselled me a lot especially about my husband.....it has helped me to carry on.....”.

However, the majority of participants had negative comments like the example below:

“Since starting CBR, my life has not changed much. ... Despite being trained in knitting and provided with knitting implements, there is no business to sell my items. So people have continued to despise me and talk a lot about my disability. ... My daughter who is in grade 10 feels very bad when she hears people talking about me. They say that maybe I was bewitched. I do not believe that but still I feel bad”.

Table 4. 5: Summary of the results establishing the level of integration of PWP into the community in relation to movement, functional activities, caregiver provision and dependency, and perceptions after CBR intervention

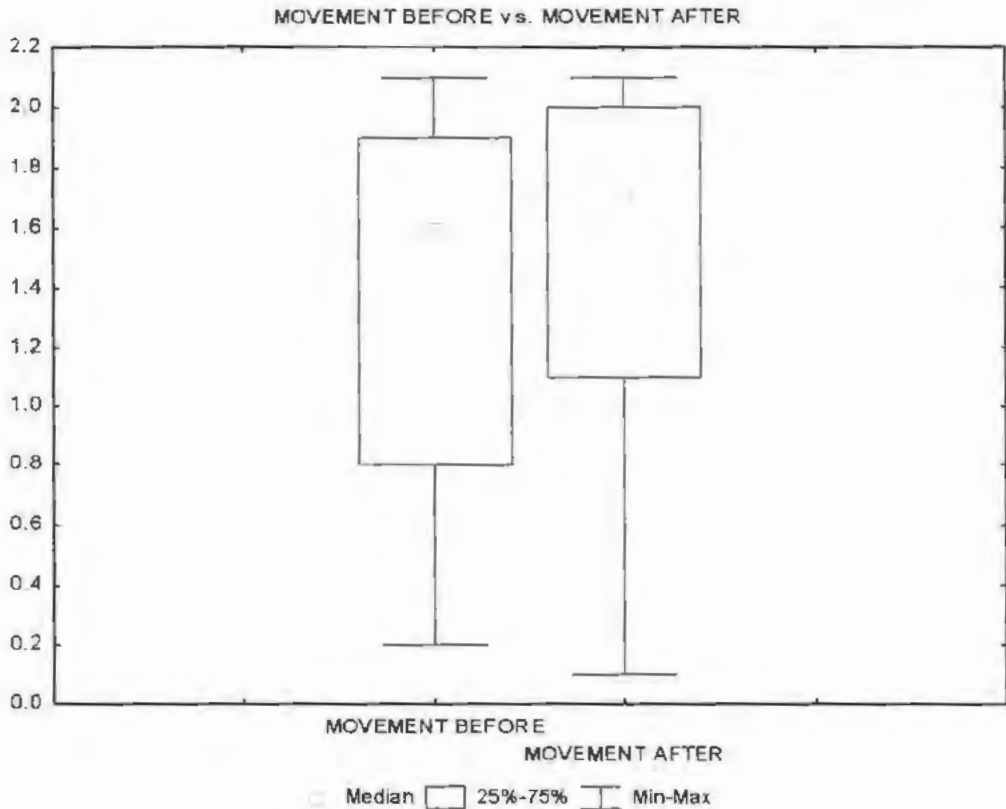
Activity	Lusaka n=31	Chipata n=35	Combined n=66
Movement vs integration	X X X	X X X	X X X
Functional activities vs integration	X X X	X X X	X X X
Caregiver provision and dependency vs integration	X X	X X	X X
Perceptions vs integration	X	X	X

Linear regression test

Positive correlation	= X X X	(high level of integration)
No correlation	= X X	(medium level of integration)
Negative correlation	= X	(no integration)

Table 4.5 illustrates the correlation between integration and movement, functional activities, caregiver provision and dependency, and perceptions. Movement and functional activities showed a high level of correlation with integration. This means that high scores of movement and functional activities were associated with a high level of integration on the linear regression line, i.e. there was positive correlation. There was no correlation between caregiver provision and dependency and integration, indicating no association between the two variables tested. Therefore much change of significance was observed in the integration level after CBR intervention. On the other hand, there was a negative correlation between the perceptions and experiences of PWP and integration. This means that CBR intervention did not influence any change in the perceptions of PWP regarding their disability status and experiences.

4.2.5 OBJECTIVE 6: DETERMINE THE IMPACT OF A CBR INTERVENTION STRATEGY ON PWPd IN AN URBAN AND RURAL SETTING IN RELATION TO MOVEMENT, FUNCTIONAL ACTIVITIES, CAREGIVER PROVISION AND DEPENDENCY, PERCEPTIONS AND INTEGRATION OF PWPd INTO THE COMMUNITY



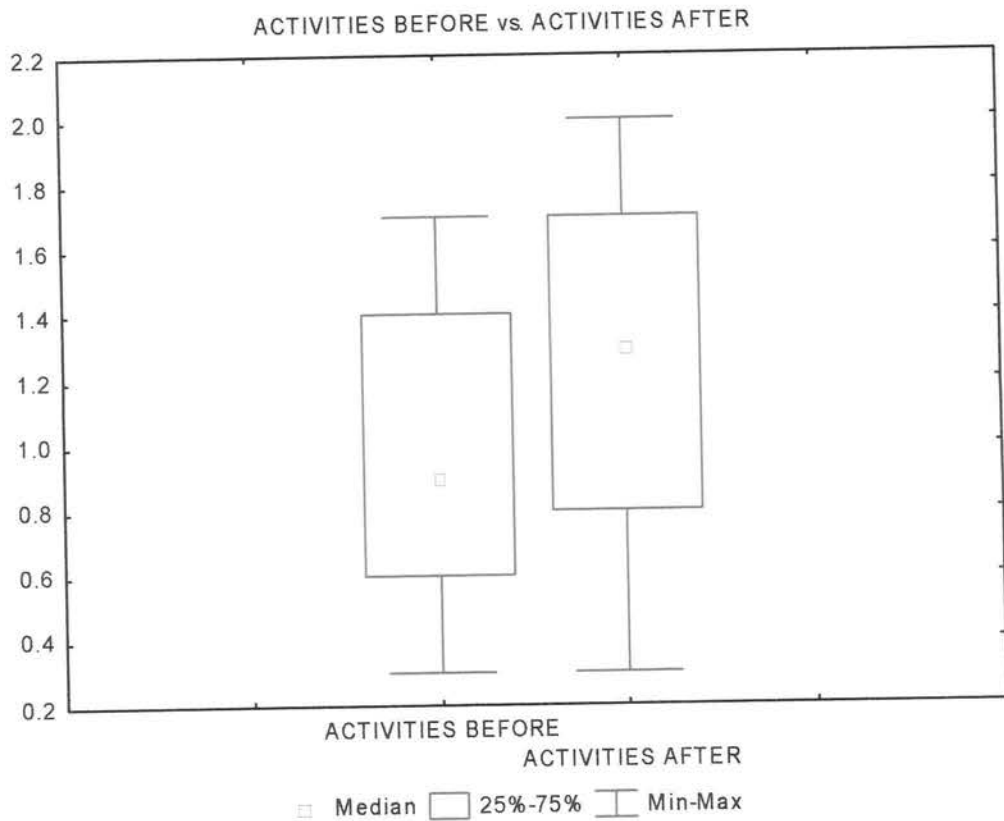
Before CBR intervention with paired t-test: Mean = 1.3935

After CBR intervention with a paired t-test: Mean = 1.5290

p=0.0229 (paired t-test); p=0.0075 (Wilcoxon matched pairs test)

Figure 4.30: Comparison between the mean and median scores for movement – Lusaka (before and after CBR intervention)

Figure 4.30 shows that the participants gained more movement after CBR intervention as the median was 1.7 after the intervention compared to the score of 1.6 before the intervention. The distribution of the scores before intervention were between 0.8 (25th percentile) and 1.9 (75th percentile) with the minimum scores being 0.2 and the maximum scores being 2.1. As the median score improved after the CBR intervention, the score distribution also improved to between 1.1 (25th percentile) and 2.0 (75th percentile), the minimum score being 0.1 and the maximum score being 2.1. The mean score for movement was 1.3935 before CBR intervention and 1.5290 after intervention, and $p=0.0229$ (t-test) and $p=0.0075$ (Wilcoxon matched pairs test). As can be seen from the difference in mean scores, the participants improved in movement after CBR intervention. The p-value showed a significant improvement at 0.0229, which is less than the accepted value for this study, namely 0.05 (5%).



Before CBR intervention with a paired t-test: Mean = 0.9806

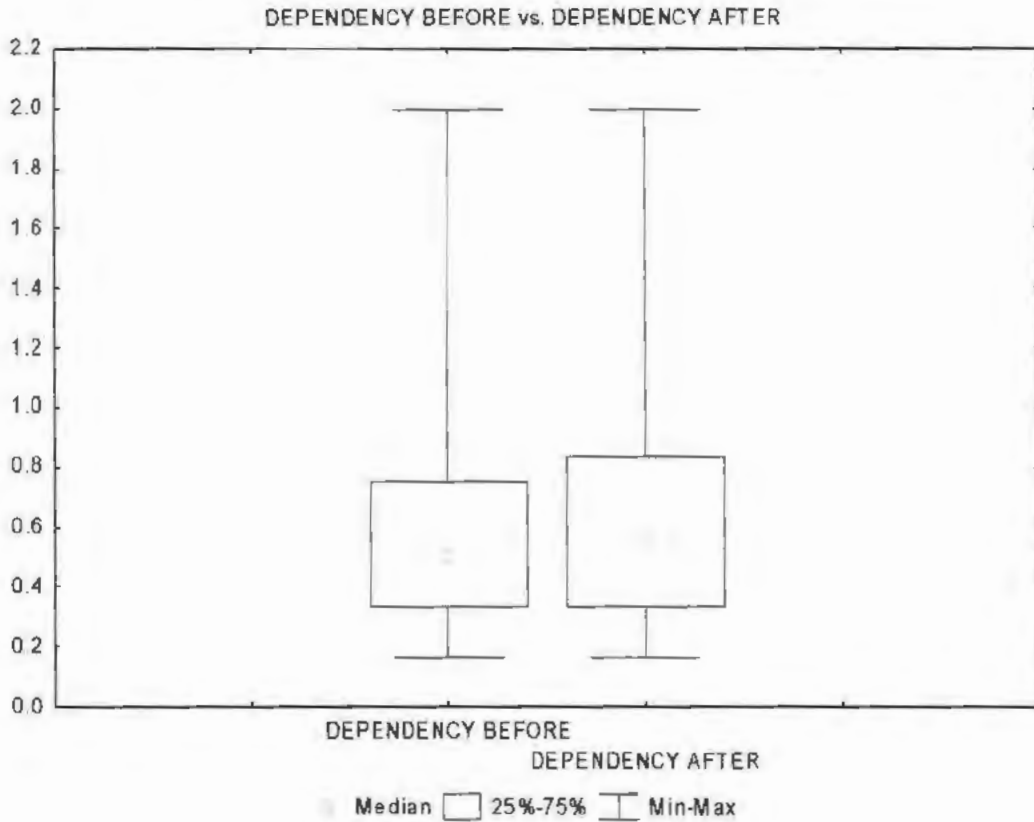
After CBR intervention with a paired t-test: Mean = 1.2516

p=0.0000 (paired t-test); p=0.0000 (Wilcoxon matched pairs test)

Figure 4.31: Comparison between the mean and median scores for functional activities – Lusaka (before and after CBR intervention)

Figure 4.31 show that participants gained more functional activities after CBR intervention as the median was 1.3 compared to 0.9 before the intervention. The score concentration and distribution was between 0.6 (25th percentile) and 1.4 (75th percentile) with the minimum score at 0.3 and maximum score at 1.7. In comparison, the median score after CBR intervention increased to 1.3 with 0.8 (25th percentile) and 1.7 (75th percentile). The minimum score was 0.3 and the maximum score 2.0. The mean score was 0.9806 before intervention and 1.2516 after CBR intervention, with a

significant $p=0.0000$ (t-test) and $p=0.0000$ (Wilcoxon matched pairs test). This p-value indicates the significant improvement experienced by participants in performing functional activity after CBR intervention.



Before CBR intervention with a paired t-test: Mean = 0.5806

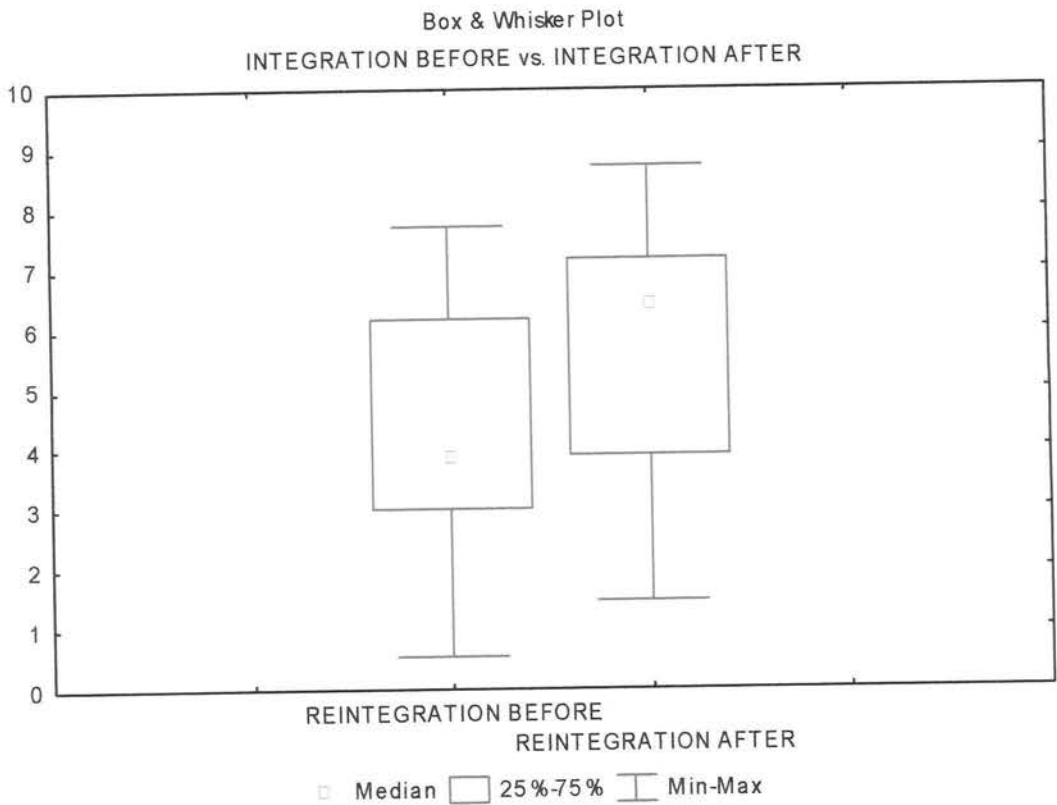
After CBR intervention with a paired t-test: Mean = 0.7580

$p=0.1127$ (paired t-test); $p=0.7823$ (Wilcoxon matched pairs test)

Figure 4.32: Comparison between the mean and the median scores for dependency – Lusaka (before and after CBR intervention)

Figure 4.32 shows that the median score before CBR intervention was 0.3 and the concentration distribution between 0.38 (25th percentile) and 0.79 (75th percentile). The

minimum score was recorded at 0.9 while the maximum score was 2.0. In comparison with the median score after CBR intervention, the median score just increased slightly to 0.6 with the 25th percentile being 0.38 and the 75th percentile being 0.81. The minimum score was 0.09 and the maximum score 2.0. The mean score for caregiver provision and dependency was 0.5806 before CBR intervention and 0.7580 after intervention, with $p=0.1127$ (t-test) and $p=0.7823$ (Wilcoxon matched pairs test). This p-value shows that there were no significant differences between the before and after scores, since the p-value was larger than 0.05 (5%), which is the accepted standard error for this study. If the accepted p-value was 10% or $p<0.1$, this p-value score would be significant.



Before CBR intervention with a paired t-test: Mean = 4.4457

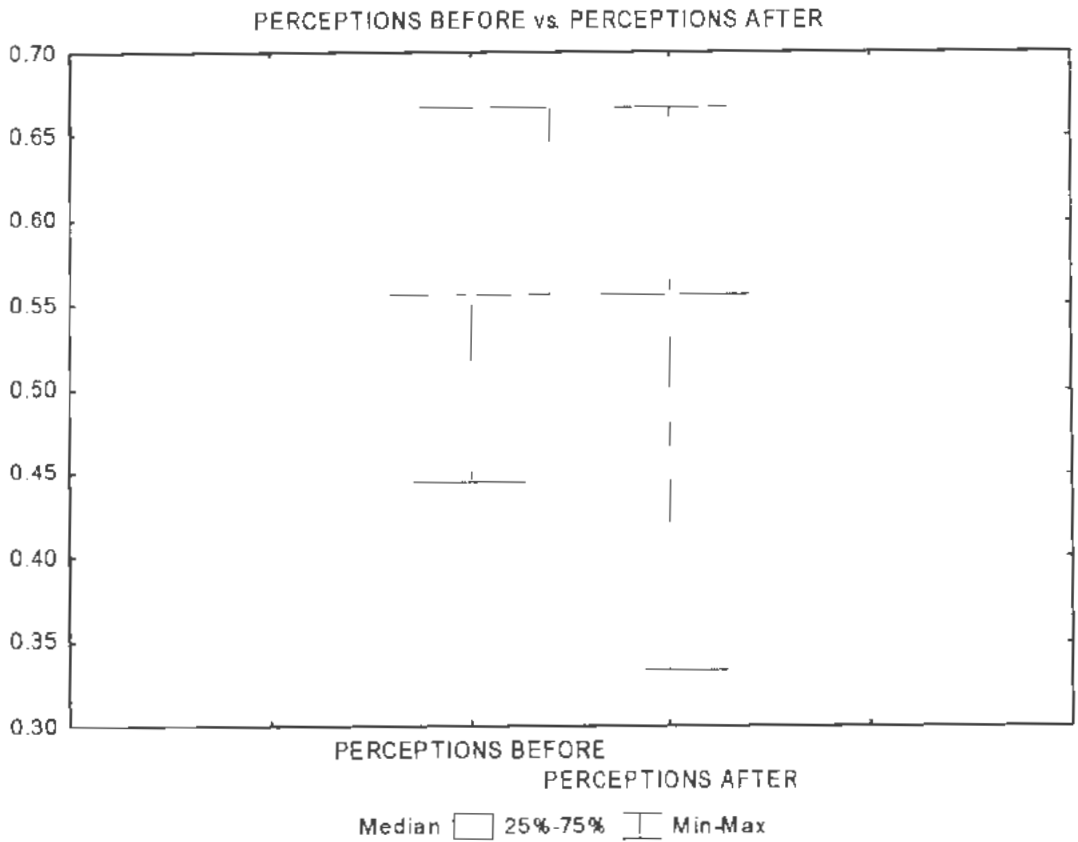
After CBR intervention with a paired t-test: Mean = 5.5982

$p=0.0103$ (paired t-test); $p=0.0168$ (Wilcoxon matched pairs test)

Figure 4. 33: Comparison between the mean and the median scores for integration of PWPd into the community– Lusaka (before and after CBR intervention)

Figure 4.33 shows that the median score for the integration of PWPd into the community before CBR intervention was 4, with the 25th percentile at value 3 and the 75th percentile value 6.1. The distribution scores recorded the minimum score at 0.5 and the maximum score at 7.8. In comparison, the median score after CBR intervention increased to 6.5, with the concentration distribution between 3.9 (25th percentile) and 7.1 (75th percentile). The minimum score was 1.5 and the maximum

was 8.88. Before CBR intervention the mean was 4.4457, while it was 5.5982 after intervention, with $p=0.01033$ (t-test) and $p=0.0168$ (Wilcoxon matched pairs test). This p -value indicates a significant difference between the before and after scores, showing that more participants were integrated into the community after CBR intervention.



Before CBR intervention with a paired t-test: Mean = 0.5627

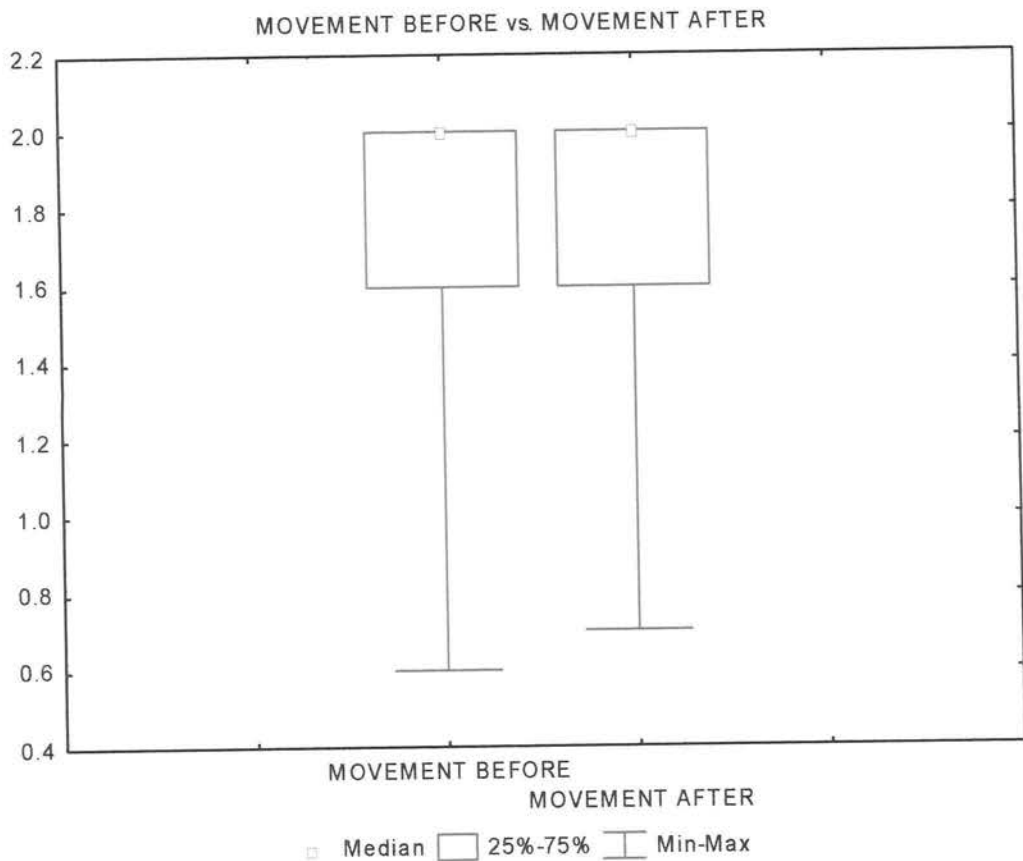
After CBR intervention with a paired t-test: Mean = 0.5555

p=0.6621 (paired t-test); p=0.5861 (Wilcoxon matched pairs test)

Figure 4.34: Comparison between the mean and median scores for perceptions – Lusaka (before and after the CBR intervention)

Figure 4.34 shows that the median scores did not change between before and after CBR intervention but remained at 0.56. Before intervention the concentration of the distribution of scores was between 0.56 (25th percentile) and 0.67 (75th percentile), which was the maximum distribution score as well. The minimum distribution score was 0.44. After CBR intervention, the minimum distribution score moved down to 0.33, while the maximum score of 0.67 stayed the same as before intervention. The mean

value was 0.5627 before CBR intervention and 0.5555 after intervention, and $p=0.6621$ (t-test) and $p=0.5861$ (Wilcoxon matched pairs test), which show no significant difference between the before and after scores. The results indicate that there were no significant changes in participants' perceptions and that they still had negative experiences as regards their perception concerning their disability status since starting CBR.



Before CBR intervention with a paired t-test: Mean = 1.7885

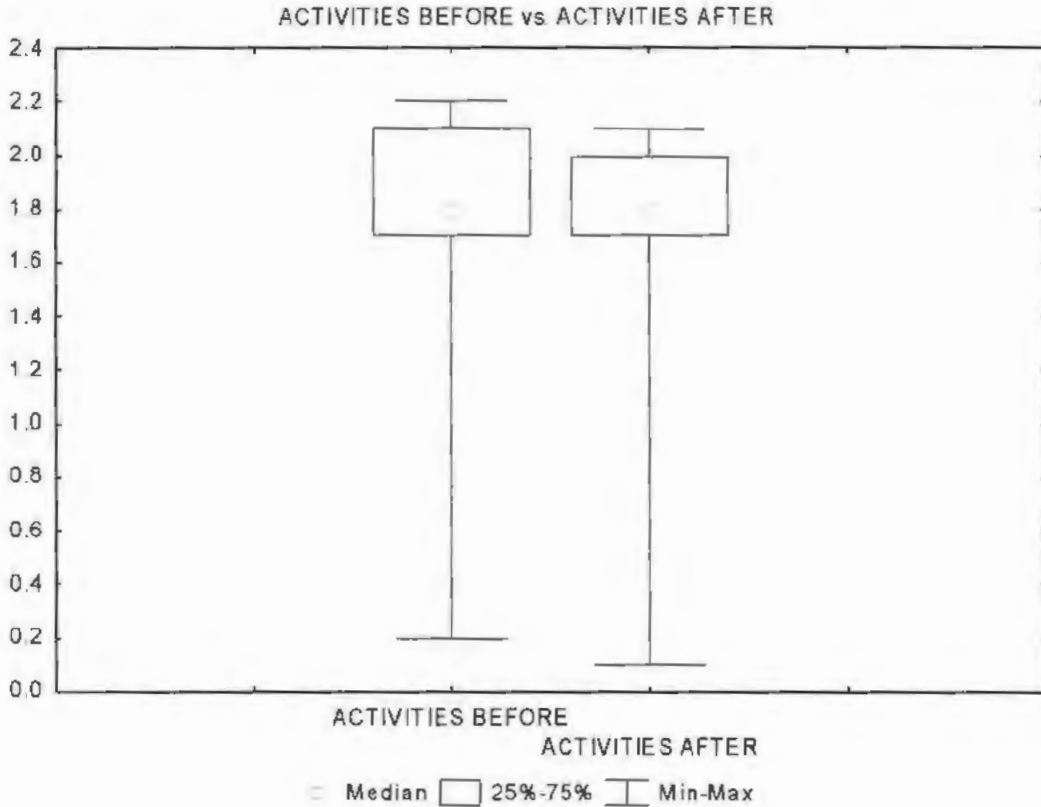
After CBR intervention with a paired t-test: Mean = 1.8171

p=0.4400 (paired t-test); p=0.4846 (Wilcoxon matched pairs test)

Figure 4.35: Comparison between the mean and median scores for movement – Chipata (before and after CBR intervention)

Figure 4.35 show that there was no difference in the median scores for movement before and after CBR intervention in Chipata. The median score is 2.0, which is also the 75th percentile for both before and after CBR intervention. The 25th percentile is 1.6 before and after intervention. The minimum score was 0.6 before intervention and 0.7 after intervention. These scores were confirmed with the t-test, which showed the mean values of 1.7885 before intervention and 1.8171 after CBR intervention, with

$p=0.4400$ (t-test) and $p=0.4846$ (Wilcoxon matched pairs test), which indicates no significant difference between the before and after scores.



Before CBR intervention with a paired t-test: Mean = 1.7171

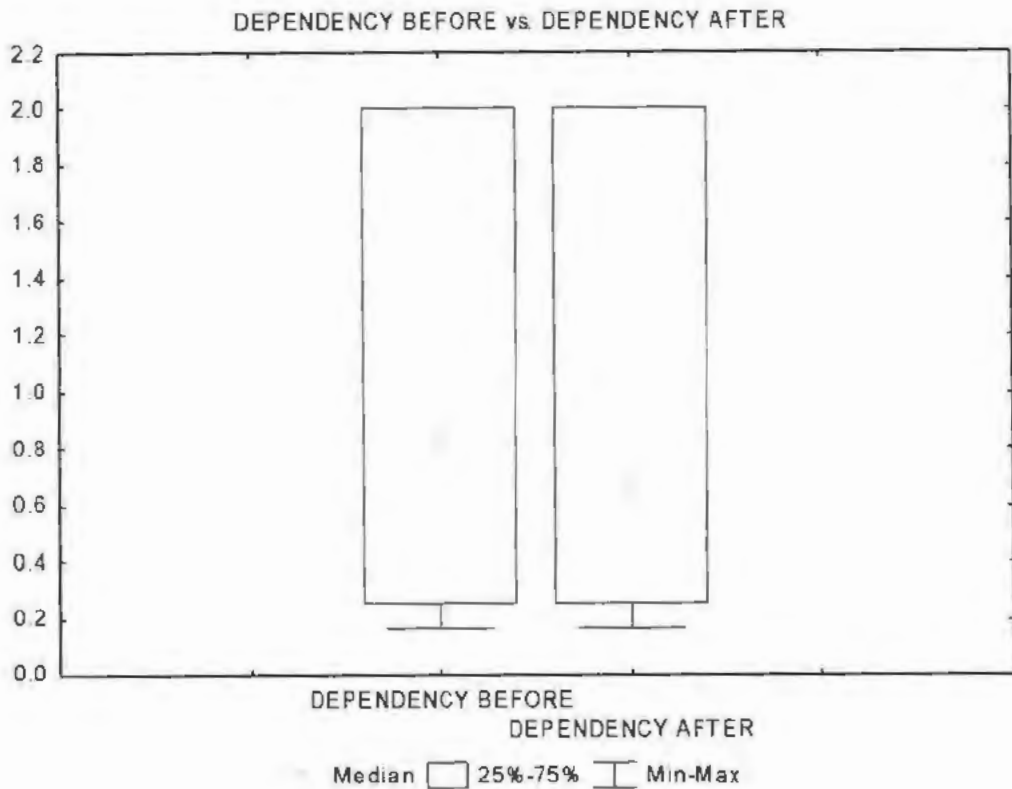
After CBR intervention with a paired t-test: Mean = 1.6714

$p=0.2757$ (paired t-test) $p=0.2940$ (Wilcoxon matched pairs test)

Figure 4.36: Comparison between the median scores for functional activities – Chipata (before and after CBR intervention)

Figure 4.36 shows that the median score before and after CBR intervention were both 1.8, with long tails indicating that the observations were not normally distributed. Before intervention, the concentration of the distribution was between 1.7 (25th

percentile) and 2.1 (75th percentile) with a minimum score of 0.2 and a maximum score of 2.2. After intervention, the minimum score was 0.1 and the maximum 2.1. The mean value was 1.7171 before intervention and 1.6714 after CBR intervention. With the paired t-test $p=0.2757$. The Wilcoxon matched pairs test was done to confirm the results and $p=0.2940$. These results indicate that there was no significant difference between the scores before and after CBR intervention in the performance of functional activities by PWPD.



Before CBR intervention with a paired t-test: Mean = 1.1000

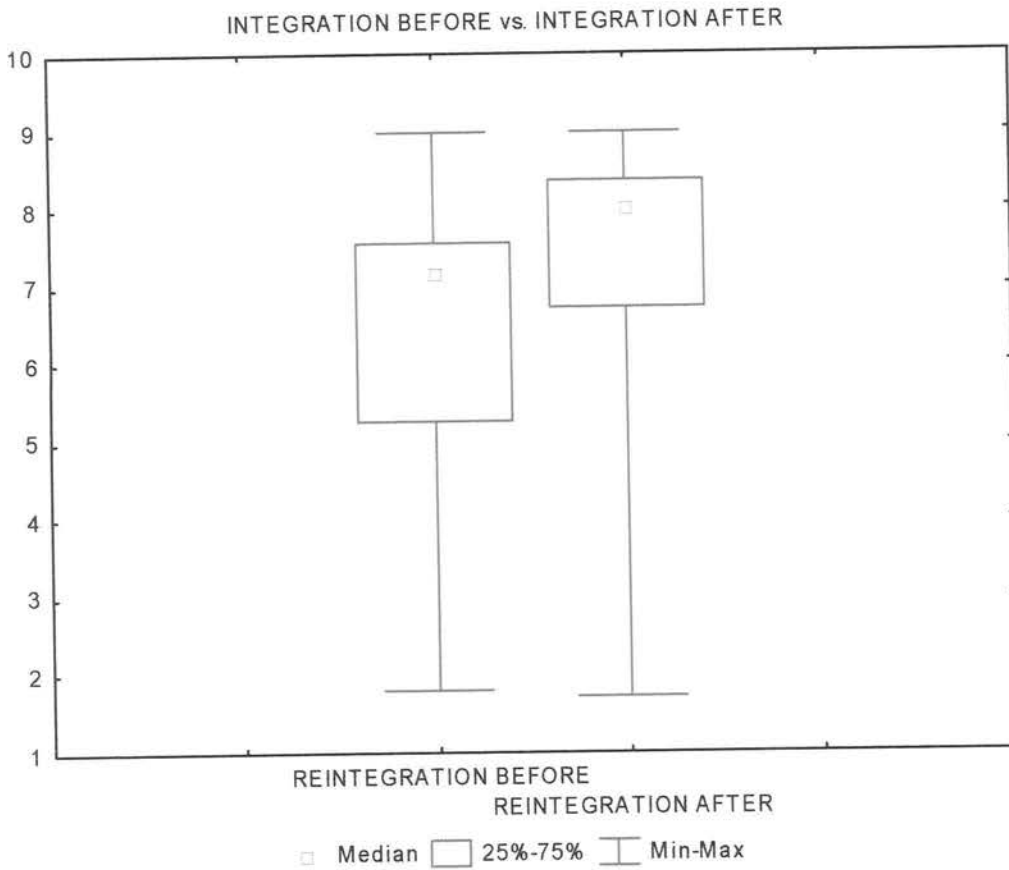
After CBR intervention with a paired t-test: Mean = 1.0880

p=0.9105 (paired t-test); p=0.6248 (Wilcoxon matched pairs test)

Figure 4.37: Comparison between the mean and median scores for dependency – Chipata (before and after CBR intervention)

Figure 4.37 shows that there was a slight difference in the median score between before and after CBR intervention. The median score declined from 0.81 before to 0.62 after CBR intervention. The concentration distribution of the 25th and 75th percentiles remained the same at 0.22 and 2 respectively. The minimum score was 0.18 both before and after CBR intervention. The mean values were 1.0000 before and 1.0880 after CBR intervention. The paired t-test result was p=0.9105, which was confirmed by a Wilcoxon matched pairs test result of p=0.6248. These results indicate that there was no difference between the scores of the observations before and after CBR

intervention. This means that the caregiver provision and dependency experienced by PWPPD before and after CBR intervention was almost the same. A slight decline in the median after intervention shows some reduction in caregiver provision and dependency but the change is not statistically significant.



Before CBR intervention with a paired t-test: Mean = 6.3974

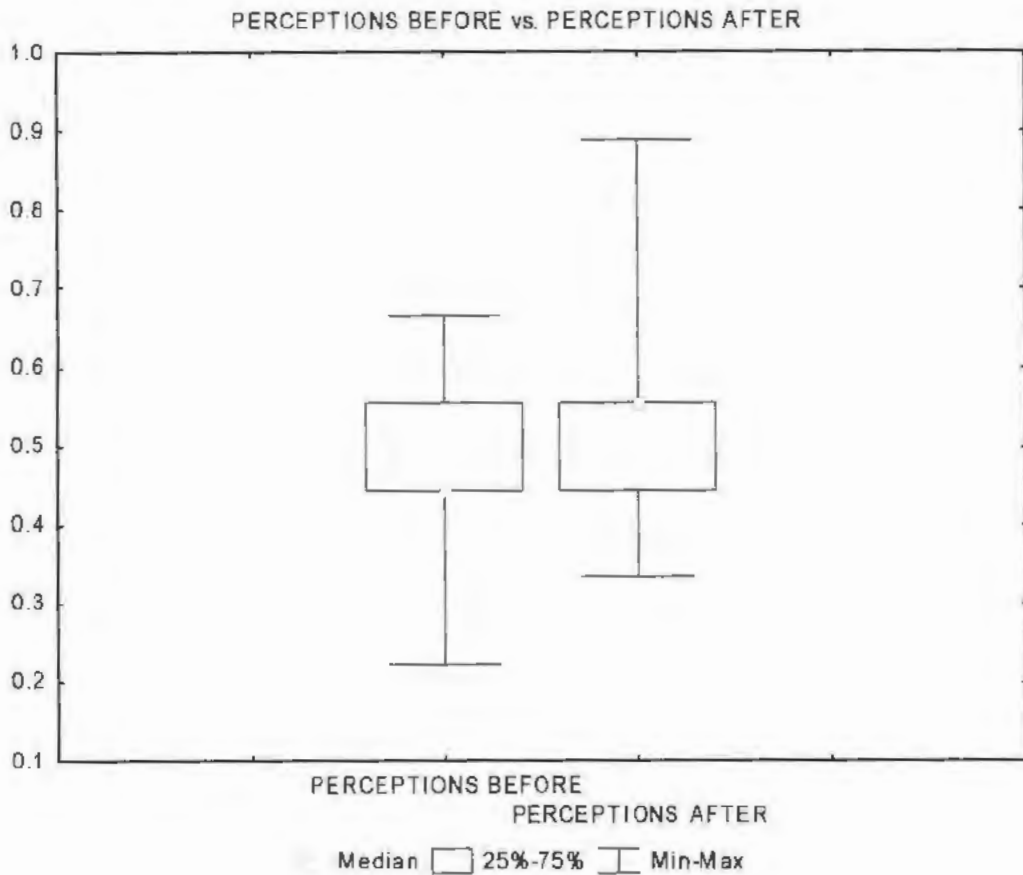
After CBR intervention with a paired t-test: Mean = 7.2311

$p=0.0046$ (paired t-test); $p=0.0001$ (Wilcoxon matched pairs test)

Figure 4.38: Comparison between the mean and median scores for integration of PWPDP into the community – Chipata (before and after CBR intervention)

Figure 4.38 shows that there was a difference between the median scores before and after CBR intervention. Before the intervention, the median score was 7.1 with the concentration distribution of observations between 5.2 (25th percentile) and 7.2 (75th percentile). The minimum score recorded was 1.8 and the maximum 9. After CBR intervention, the median score was 8 with the concentration of distribution of

observations between 6.8 and 8.4. The minimum score recorded was 1.8 and the maximum 9. The mean value was 6.3974 before intervention and 7.2311 after CBR intervention, with $p=0.0046$ using a paired t-test and $p=0.0001$ with the Wilcoxon matched paired test. These results indicate that there was a significant difference between the levels of integration of PWPD into the community before and after CBR intervention. There was a higher level of integration after CBR intervention as can be observed from the mean values and upward change in the median score. The p-values of the paired t-test and the Wilcoxon matched paired test show a significant difference between the before and after scores.



Before CBR intervention with a paired t-test: Mean = 0.5043

After CBR intervention with paired t-test: Mean = 0.5301

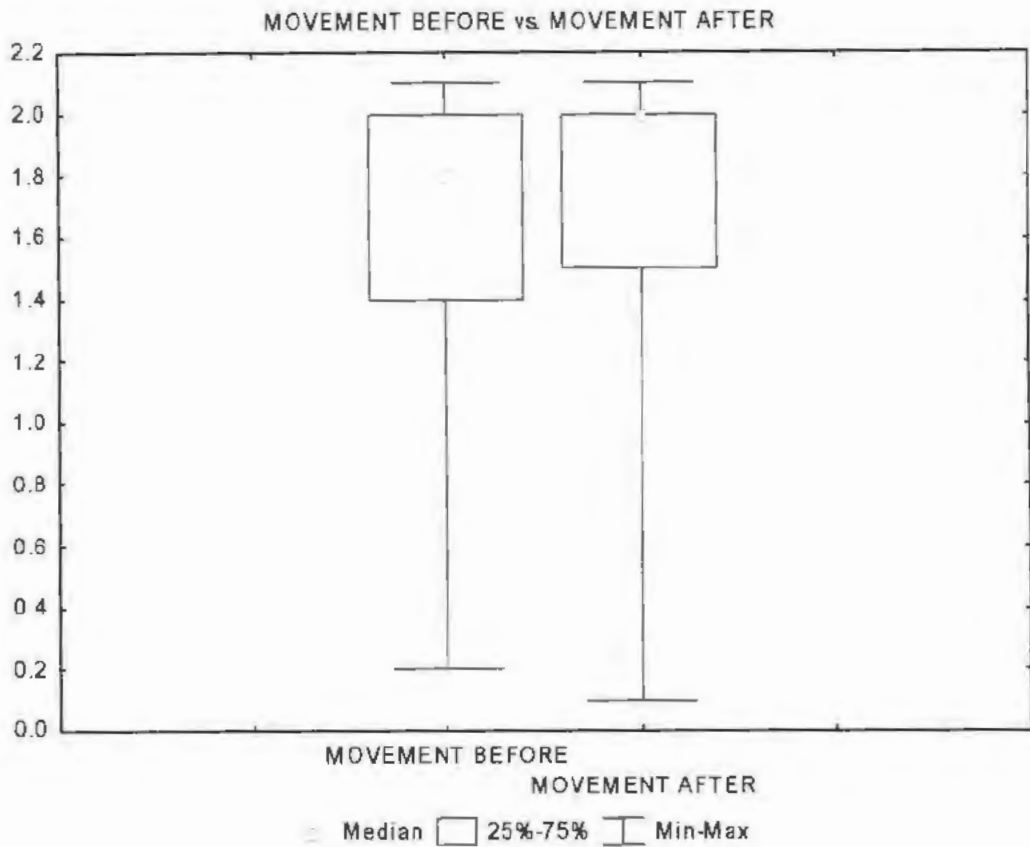
p=0.2545 (paired t-test); p=0.1215 (Wilcoxon matched pairs test)

Figure 4.39: Comparison between the median scores for perception – Chipata (before and after CBR intervention)

Figure 4.39 shows that the median score before CBR intervention was 0.44. The minimum observation recorded was 0.22 and the maximum 0.67. The scores after CBR intervention showed a median of 0.56, which was also the 75th percentile. The 25th percentile was recorded at 0.44. The minimum score was 0.33 and the maximum score 0.89. The mean value was 0.5043 before intervention and 0.5301 after intervention, with p=0.2545 using the paired t-test and p=0.1215 using the Wilcoxon

matched pairs test. These results indicate that there was no significant difference between the before and after scores. This indicates that the PWPD did not show any change in their perceptions concerning their disability status and experiences since starting CBR.

After individual scores for Lusaka and Chipata were recorded, the scores of the observations were combined. These results will be reported in the graphs which follow.



Before CBR intervention with a paired t-test: Mean = 1.6030

After CBR intervention with a paired t-test: Mean = 1.6818

p=0.0208 (paired t-test); p=0.0105 (Wilcoxon matched pairs test)

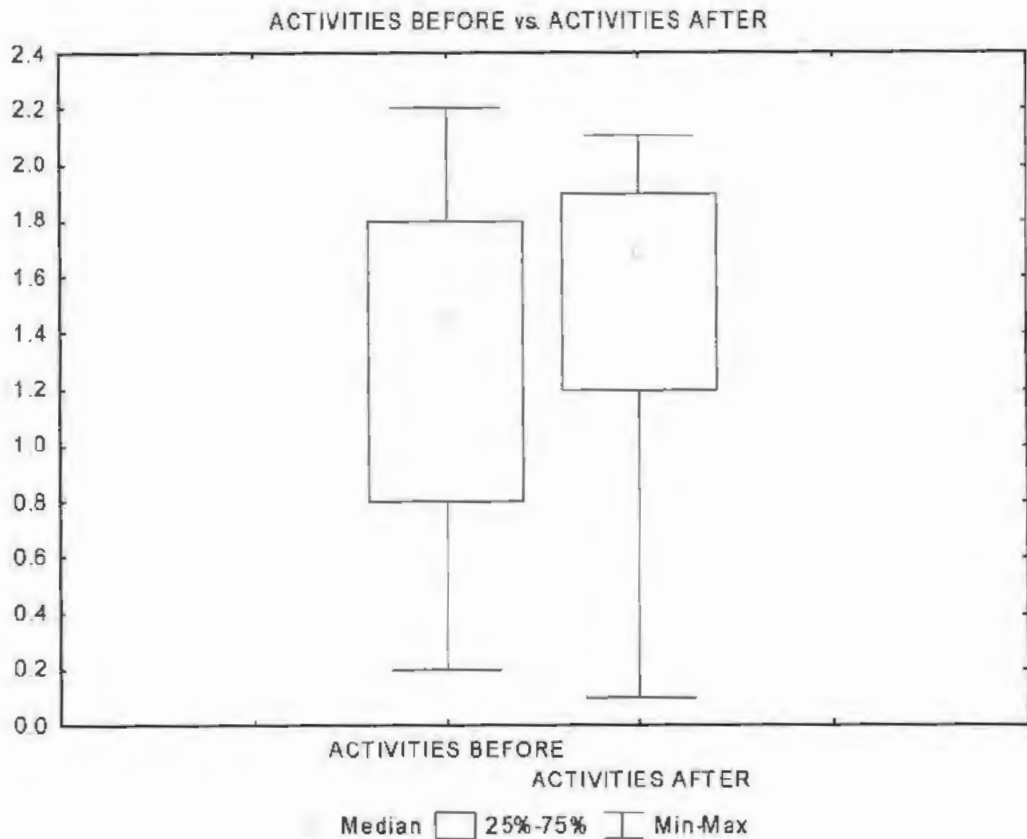
Figure 4.40: Comparison between the mean and median scores for movement – Lusaka and Chipata (before and after CBR intervention)

Figure 4.40 shows that the median score for movement before CBR intervention was 1.8 and the concentration range between 1.4 (25th percentile) and 2.0 (75th percentile). The minimum score was 0.2 and the maximum 2.5. After CBR intervention, the median score increased to 2.0 with the concentration of observations between 1.5 (25th percentile) and 2.0 (75th percentile). The minimum score then was 0.5 and the maximum 2.1. The mean value was 1.6030 before CBR intervention and 1.6818 after intervention, with p=0.0208 using the paired t-test and p=0.0105 using the Wilcoxon

matched pairs test. These results indicate a marked significance between the scores of the observations before and after CBR intervention because the p-value was less than 0.05. The Wilcoxon matched pairs test confirmed the significant difference found with the t-test. The results therefore indicate that the participants gained more movement after CBR intervention. The following comments of family members support the statistical findings:

"We used to do everything for her and you know she is a big girl. When she is having her menstrual periods, it is bad. Now she is able to move alone and baths herself, dresses herself, goes to the toilet and can help me with a few household chores. I am very happy with this CBR, it must continue".

"My husband has improved so much. Before CBR, I had to do everything for him. ... Now even if he does not talk yet, he dresses alone, walks to the sitting room and sits to watch television, he eats alone and he makes signs on what he wants and we give him. He even goes outside the house alone. ... I am very happy and relieved. I am able to do other things now because I know he is safe".



Before CBR intervention with paired t-test: Mean = 1.3712

After CBR intervention with paired t-test: Mean = 1.4742

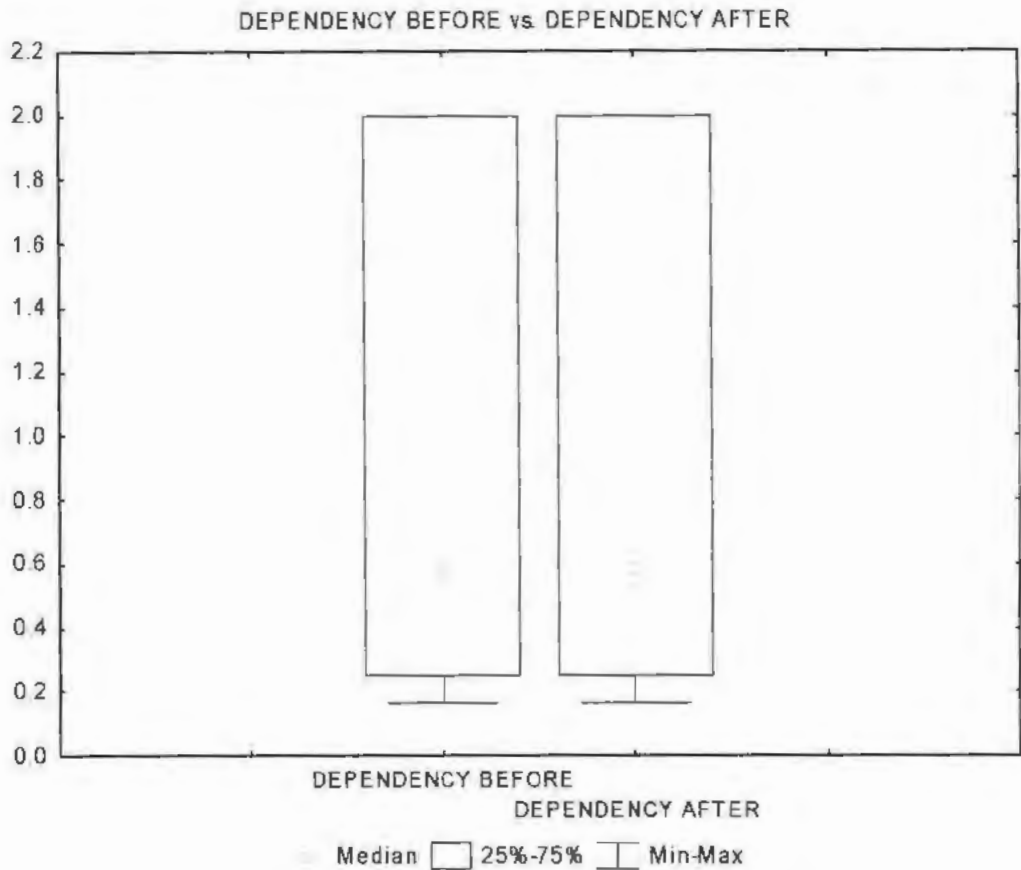
p=0.0093 (paired t-test); p=0.0128 (Wilcoxon matched pairs test)

Figure 4.41: Comparison between the mean and median scores for functional activities – Lusaka and Chipata (before and after CBR intervention)

Figure 4.41 shows that the median score before CBR intervention was 1.42, with the concentration range between 0.8 (25th percentile) and 1.8 (75th percentile). The minimum score was 0.2 and maximum score 2.2. After CBR intervention, the median score increased to 1.7, with the concentration of observations between 1.2 (25th percentile) and 1.9 (75th percentile). The minimum score was recorded at 0.1 and the maximum score at 2.1. The mean value was 1.3712 before CBR intervention and 1.4742 after CBR intervention, with p=0.0093 using the paired t-test. These results

showed a significant difference between the before and after scores. The Wilcoxon matched pairs test confirmed the result at $p=0.0128$, which was also significant. The results indicate that the participants gained more functional activities after CBR intervention compared to before the intervention. These results are also supported by the following participant's comment:

"I was unable to do a lot of household chores and look after my husband and care for my children but now I am able to do quite a lot. ... I have been trained in sewing, CBR provided me with a sewing machine and now I make clothes and school uniforms for sale and earn money for my family including my mother".



Before CBR intervention with paired t-test: Mean = 0.8560

After CBR intervention with paired t-test: Mean = 0.9330

p=0.3141 (paired t-test); p=0.5865 (Wilcoxon matched pairs test)

Figure 4. 42: Comparison between the mean and median scores for caregiver provision and dependency – Lusaka and Chipata (before and after CBR intervention)

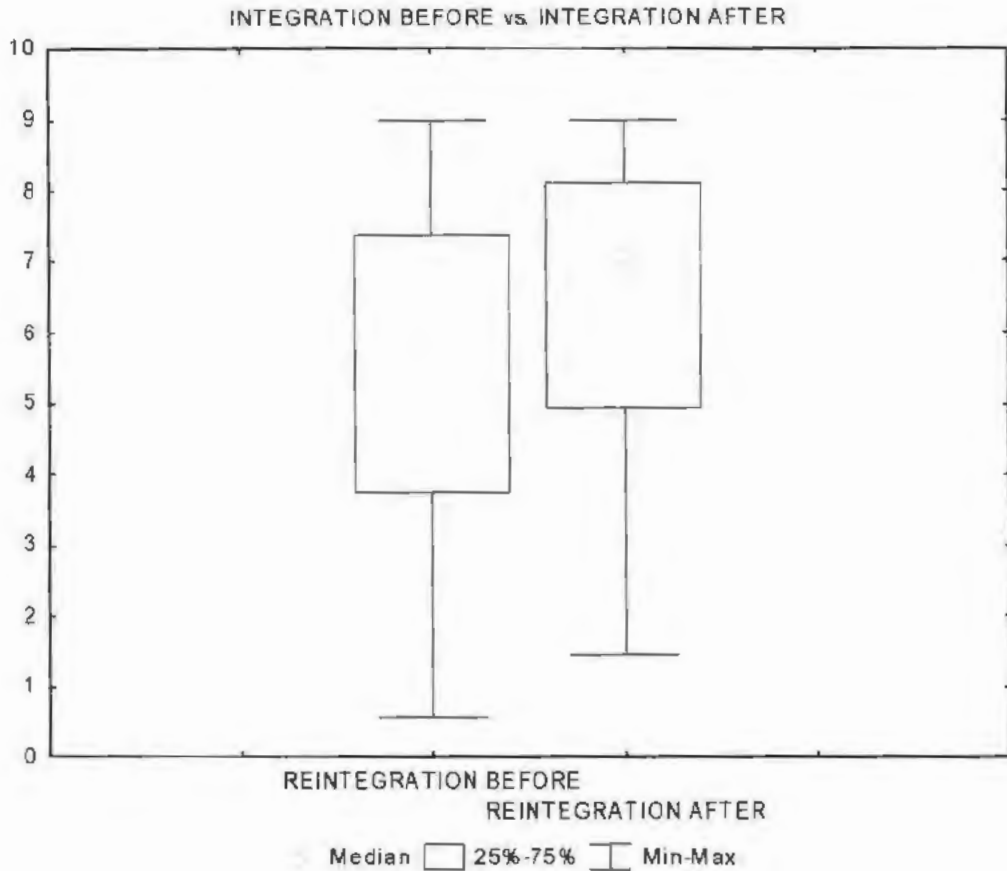
Figure 4.42 shows that the median score for caregiver provision and dependency before and after CBR intervention remained the same at 0.59. All the values of the concentration ranges for the observations before and after the CBR intervention were between 0.21 (25th percentile) and 2.0 (75th percentile), which was also the maximum score recorded. The minimum score both before and after intervention was 0.19. The

mean value was 0.8560 before CBR intervention and 0.9330 after CBR intervention, with $p=0.3141$ using the paired t-test. The Wilcoxon matched paired test was done and $p=0.5865$. The p-values in these results are more than the 0.05 accepted for this study. The findings indicate that there was no difference between the before and after scores, revealing that the participants did not change regarding caregiver provision and dependency as the comment below indicates:

"I still depend on my family, I do not need CBR, it does not work. I have pain in my leg all the time, what can you do about it? Life is not fair....."

However, there were also some positive experiences after CBR intervention as the comment below indicates:

"I used to depend on my family for everything. After starting CBR I fend for myself. CBR trained me in carpentry and I make furniture for people. The money I get is sufficient to cater for my needs. I have just got married"



Before CBR intervention with paired t-test: Mean = 5.4807

After CBR intervention with paired t-test: Mean = 6.4641

p=0.0001 (paired t-test); p=0.0000 (Wilcoxon matched pairs test)

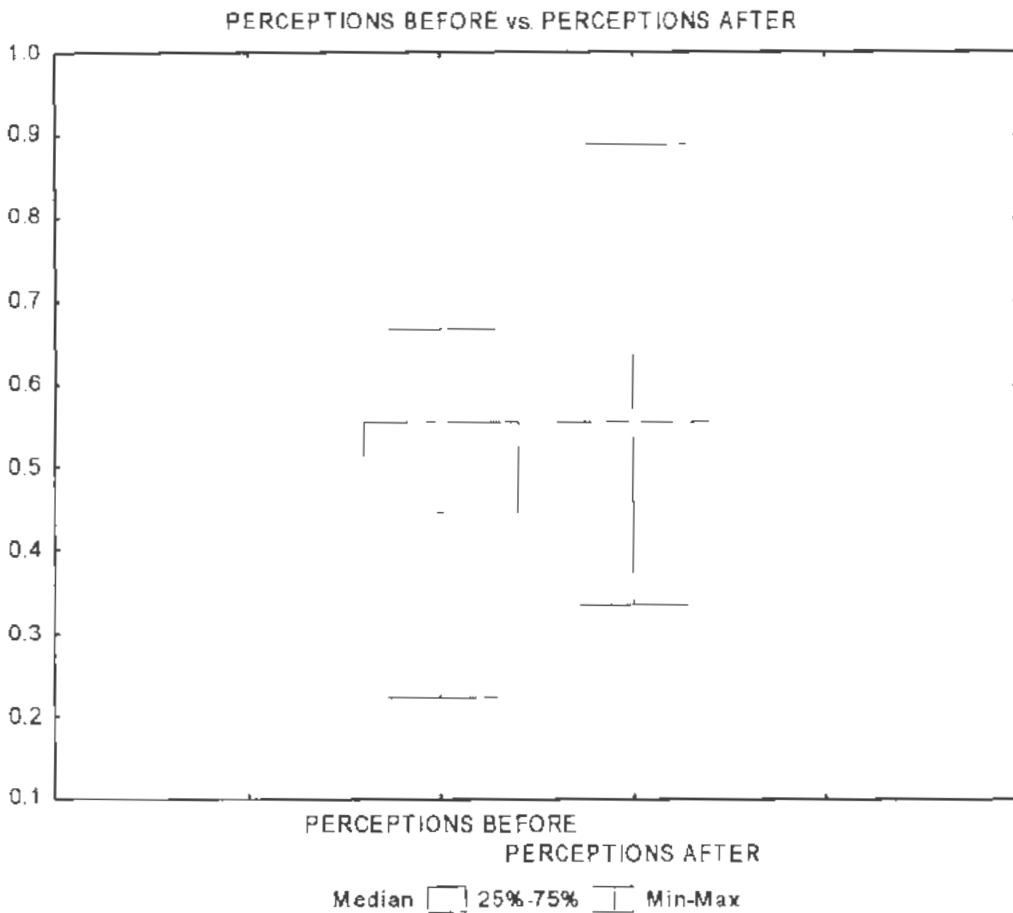
Figure 4. 43: Comparison between the mean and median scores for integration of PWPDP into the community – Lusaka and Chipata (before and after CBR intervention)

Figure 4.43 shows that the median scores changed between before and after CBR intervention. Before intervention, the median score was 6, with the concentration of observations between 3.8 (25th percentile) and 7.3 (75th percentile). The minimum score was 0.5 and the maximum score 9. After CBR intervention, the median value

increased to 7, with the concentration of observations between 4.9 (25th percentile) and 8 (75th percentile). The minimum score was 1.5 and the maximum score 9, which was the same as before intervention. The mean value was 5.4807 before CBR intervention and 6.4641 after CBR intervention, with $p=0.0001$ using the paired t-test. The Wilcoxon matched paired test was done to confirm the results and $p=0.0000$. These results indicate that there were highly significant differences in the level of integration of PWPD after CBR intervention.

One participant commented on his experiences:

“My family has been very good. They have supported me all along especially after learning about human rights and rights for persons with disabilities. In addition, CBR has trained me as a blacksmith. ... I make aluminium water buckets and pots, sell and have an income. I use the money to hire labour to cultivate my field. I have a lot of maize now in my barn. We are happy as a family”.



Before CBR intervention with paired t-test: Mean = 0.5317

After CBR intervention with paired t-test: Mean = 0.5420

p=0.4671 (paired t-test); p=0.1089 (Wilcoxon matched pairs test)

Figure 4.44: Comparison between the mean and median scores for perceptions – Lusaka and Chipata (before and after CBR intervention)

Figure 4.44 shows that the median score before and after CBR intervention did not change but remained at 0.56, which is the same value as the 75th percentile before the CBR intervention. The 25th percentile was 0.45. The minimum score recorded was 0.22 and the maximum score was 0.67. After CBR intervention, the minimum score was 0.33 and the maximum score 0.89. The mean value was 0.5317 before CBR intervention and 0.5420 after intervention, with $p=0.4671$ using the paired t-test. The

Wilcoxon matched paired test confirmed the results with $p=0.1089$. These results indicate that there was no significant difference between the perceptions of the participants regarding their disability status and experiences since starting CBR. It means that they still had negative perceptions regarding their disability. Below are some comments from participants and family members concerning their disability status and experiences:

“There is little change, I do not know whether my daughter will improve. This CBR, does it really work? ... People think my daughter is mad and so we are now using traditional medicines as well, may be they will work, I do not know”.

“People laugh at my child, because he looks different. My neighbours’ children laugh and tease my son. Even though CBR people explained to the community about the condition of my child, they have not stopped. CBR workers have explained to me about my son’s problem and now I know that he was just sick but sometimes I still think he was bewitched..... However, he plays a lot with some children who are good to him and does not like being in the house any more.....”.

“I do not want any assistance because the CBR can not do anything for me. I have pain in my hip and so I am unable to walk long distances to other villages”.

Nonetheless, there were a few positive experiences after the CBR intervention as indicated in the comment below:

“Before CBR, my life was with difficulties. My mother died when I was young, then I got disabled. My life became worse with my stepmother. She used to despise me and call me all sorts of names. ... I was helpless and hopeless. I could not even marry. ... CBR has taught me and the whole family issues concerning disability, rights and attitude change. I have been trained in tailoring, provided with a sewing machine and I make items to sell. ... I also make clothes for my family including my stepmother. ... They all now have respect for me. They used to call me Simon but now they call me Mr Soko. I am very happy with what CBR has done for me and my family. It must continue”.

Table 4.6: Summary of the results establishing the impact of the CBR intervention on PWPd in relation to movement, functional activities, caregiver provision and dependency, and perceptions after CBR intervention

Activity	Lusaka n=31	Chipata n=35	Combined n=66
Movement	X X X	X	X X X
Functional activities	X X X	X	X X X
Caregiver provision and dependency	X	X	X
Perceptions	X	X	X
Integration of PWPd into the community	X X X	X X X	X X X

Paired t-test and Wilcoxon matched pairs test

CBR Impact (improved) = X X X

CBR no impact (not improved) = X

Table 4.5 shows the impact of CBR regarding movement, functional activities, caregiver provision and dependency, perceptions of PWPd as regards their disability status and experiences, and integration into the community. Chipata participants only experienced impact on integration into the community. Lusaka experienced impact on movement, functional activities and integration but there was no impact on caregiver provision and dependency. Combined scores show impact experienced on movement, functional activities and integration and no impact on caregiver provision and dependency. This implies that the variables which had improved mean and median scores had an impact on the lives of PWPd.

4.3 LIMITATIONS

During the course of the study, some limitations were identified. One of the limitations was the distance which the researcher had to cover visiting each participant in their homes for a period of two weeks each of the two assessment periods in the Lusaka urban study area. In Chipata study area, the researcher travelled long distances of about 60 kilometres on a bicycle daily to visit the participants in their villages for three weeks of each of the two assessment periods. Secondly, the lack of financial sponsorship in the initial stages of the study made the progress of the study rather slow. Thirdly, having done the study on one urban and one rural setting might not necessarily be generalised to other areas in Zambia.

4.4 VALIDITY AND RELIABILITY

The validity and reliability of the questionnaire were tested by means of the following:

- Two lecturers in rehabilitation scrutinised the questionnaire. They indicated that the instrument appeared suitable for testing what it was meant to test (face validity).
- In comparing the scores of the pilot study and the actual study, there were no major differences in the scores obtained in the two study areas.
- Negative points influencing the validity of the questionnaire were the following:
- The use of the CRWs could have influenced the level of CBR intervention provided to PWPD since these people were already working with the PWPD in their areas.
- The presence of the researcher and her participation in entering the data on the questionnaire could have influenced the responses from participants.

4.5 CHAPTER SUMMARY

This chapter presented the statistical results of the study. The aim of the study was to determine the impact of a CBR strategy on PWPD in an urban and rural setting in Zambia. The data from the questionnaire was reported in three parts. Section A was descriptive, answering Objectives 1 and 2. Sections B, C, D, E and part of F were

statistically tested using the paired t-test to establish the p-values, mean and median scores of the variables tested, namely movement, functional activities, caregiver provision and dependency, perceptions of PWPD as regards their physical disability and experiences, and integration of PWPD into the community. The Wilcoxon matched pairs test was also used to confirm the p-value results of the t-test. Linear regression analysis was done to determine the correlation of relationship between integration of PWPD into the community and the other variables. Part of Section F was qualitative data regarding participants' physical disability status and experiences, which was reported through out the chapter as narrative.

Graphs in the form of box and whisker plots were utilised to illustrate the impact of CBR intervention strategy on PWPD before and after intervention. The results showed that there was a positive correlation between integration and movement, and integration and functional activities both in Lusaka and Chipata. Combined scores showed a similar result. There was no correlation between integration and caregiver provision and dependency, and a negative correlation between integration and perceptions of PWPD as regards their physical disability and experiences. This means that no integration took place in relation to perceptions, since PWPD still had negative experiences and negative perceptions about their physical disability status. The results of these tests attempted to answer Objectives 3, 4 and 5.

The results showed that CBR had an impact on PWPD with regard to movement and functional activities. Participants in Lusaka experienced a high level of integration, while participants in Chipata only experienced an impact on integration of PWPD into the community. All the other variables did not show any change after CBR intervention. Combined scores for Lusaka and Chipata showed an impact on movement, functional activities and integration and had no impact on caregiver provision and dependency, and perceptions.

The general assumption is that CBR is a community strategy which effects change in the lives of FWPDD and their families, aimed at enhancing social integration of FWPDD into the community, which is the ultimate goal of CBR.

CHAPTER 5

DISCUSSION

5.1 INTRODUCTION

In order to achieve the primary aim of the study, namely to determine the impact of a CBR intervention strategy on persons with physical disabilities in an urban and rural setting in Zambia, the researcher identified seven objectives, as set out in Chapter 3 of the study.

A discussion of the results of the research will focus on the issues identified in relation to the objectives of the study. It will be presented in the same format used in Chapter 4.

5.2 OBJECTIVE 1: DESCRIPTION OF LUSAKA URBAN AND CHIPATA RURAL STUDY AREAS AND CBR PROGRAMMES

Two study areas with existing CBR programmes were identified, one in an urban and one in a rural setting. The two areas and the two CBR programmes will be described according to the findings in the study.

5.2.1 Lusaka urban and Chipata rural study areas

The results of the present study revealed high levels of poverty being widespread but more pronounced in Chipata rural. It would be assumed that high poverty levels would be a contributing factor to low educational level of both the participants and their proxy as shown in this study. Due to low educational level among participants would be assumed to have resulted to poor economic status of the participants and their proxy

The results of this study showed that Lusaka urban on one hand, is a densely populated area, Lusaka being the capital city of Zambia. The results showed that Lusaka was an area with rapid population growth, since the growth rate for was 3.6%, compared with 2.6% for the country (CSO, 2003).

Chipata on the other hand, is the provincial capital of the Eastern Province of Zambia. The results of this present study revealed that Chipata has a smaller population compared to Lusaka even though it has a larger surface area. The population growth for Chipata is 2.7% (CSO, 2003). Crowding, along with poor sanitation, unclean drinking water and a dirty environment were assumed to be a risk to people's health, as outbreaks of epidemics such as cholera has been a serious community concern.

As literature showed, in 2001, 80% of Zambians were reported to be poor (MCDSS, 2003). In addition to poverty, several causal and aggravating factors were identified: poor access to health services, since health centres in rural areas are few and far between; poor access to education facilities, such as primary schools, leading to high levels of literacy, especially among women and girls; poor access to safe drinking water, which results in poor health; poor sanitation (in some rural areas sanitary facilities do not exist), leading to poor health; a concentration of social services in urban areas, which has lead to less development in rural areas where the poorest and most deprived of the population live.

Due to high levels of poverty, people's health is at risk. It could therefore be argued that disability is linked to poverty, and that poverty can be regarded as a contributing factor to disability in Zambia, more especially in rural areas. This is an enormous challenge to the government and the people of Zambia to put measures in place to reduce poverty levels and hence reduce disability incidence in the country.

5.2.2 Lusaka urban and Chipata rural CBR programmes

The results of the current study showed that the Lusaka urban CBR programme is managed by employees. The manager of the programme was an expatriate and qualified agriculturist, and he was assisted by two (2) physiotherapists and 16 community rehabilitation workers. The Chipata CBR programme was managed by three (3) management officers and the executive committee of the Chipata CBR Association. The CRWs were volunteers.

5.2.2.1 Similarities between the Lusaka and Chipata CBR programmes

The findings of this study showed that both CBR programmes are mainly supported by international donor agencies. Less support came from the Zambian government. The United Nations Assembly for International Year of Disabled Persons established a trust fund to be used to meet the requests for assistance in developing countries and PWD organisations in rehabilitation programmes. The UN furthermore encourages developed countries with resources and expertise to assist in the establishment of these programmes for the benefit of PWD and their families (UN Department of Public Information, 1992). It is most commendable that the Christofel Blinden Mission, the Liliane Fund and KEPA-Zambia are assisting Zambia to establish and support these CBR programmes in Lusaka and Chipata.

Denhill, King and Swanepoel (2000) support the concept of the identification of community leaders in the organisation and implementation of CBR programmes. They further state that community involvement from the inception of a CBR programme enhances community participation, ownership and responsibility. Previous studies have reported that democratically elected CBR programme leaders and CRWs, as in the Chipata CBR programme, is beneficial to the community as they are given the power to put in place structures which conform to their own environment (Denhill, King & Swanepoel, 2000). The Lusaka programme utilised church and community leaders to identify CRWs who live in and will work with the community. Mitchell (1999) states that community leaders should be utilised to identify individuals in the community who

can provide input regarding a CBR programme, using their own personal and community knowledge and skill in effectively implementing the programme.

International donors and developed countries are cautioned against introducing foreign ideas to developing countries without a careful analysis of the local conditions and types of communities (Kassah, 2000). Based on the assumption that the donors analysed the Lusaka and Chipata communities, the organisation and operational structures instituted by the CBR programmes would be appropriate considering the urban and rural environments as investigated by Tungar (1999) and Wade (2003).

Another similarity between the Lusaka and Chipata CBR programmes is that their CRWs received training in disability identification, assessment of disability impairments, identification of needs of PWD and PWPD, provision of rehabilitation services, provision of counselling, effective communication, advice on disability issues and human rights. They are also trained in the identification of potential fundraising ventures and activities within the community for the benefit of all. Advice on walking aids and appliances and referrals are also areas of training that CRWs undergo in both the Lusaka and Chipata CBR programmes. Another area of training done by the two CBR programmes, is the provision of basic movement and functional activities and literacy education. They are also trained to plan individual rehabilitation programmes according to the individual's needs. This comprehensive training is supported by Malcolm (1999) and Denhill, King and Swanepoel (2000) who hold the opinion that one of the most crucial aspects of a community programme's success is continued training and retraining of health workers and community members. This is indeed true regarding CBR programmes. Steiner, Ryser, Huber, Uebelhart, Aeschlimann and Stucki (2002) support the concept of CRW and community leader training because it enhances competency in the participatory process and instils confidence in the members of the rehabilitation team. One participant commended the presence of the CBR in his area because he had been informed about the rights of PWPD, issues of attitude change, behaviour and self-reliance.

Both the Lusaka and Chipata CBR programmes provided rehabilitation services in individuals' homes. One parent of a participant expressed happiness and relief that the CRWs visited her child at home. She could not afford transport fares to and from the University Teaching Hospital, the only facility providing physiotherapy in Lusaka. Thornburn (1998) states that it is more beneficial for PWPD to receive rehabilitation services in their own homes because the local use of available resources is enhanced.

Both the Lusaka and Chipata programmes have fundraising ventures as one of their programme activities. This involves the identification of a viable fundraising activity, resources, planning and implementation of the activity. According to Mpofu (2001) and O'Donnell (1993), PWD and PWPD and their families express their concerns about fundraising activities to support their disabled family member and themselves. The two CBR programmes are therefore addressing an important aspect of the needs of PWPD and their families.

Another point of similarity between the Lusaka and Chipata CBR programmes was the utilisation of existing structures, i.e. community leaders, churches, health care clinics and centres. The study noted that the Lusaka programme has its offices at a local church; some meetings are held at local schools and clinics. In Chipata, the offices are in town but the branches of the association are in the villages. Churches, clinics and villages are used for meetings and other activities. Various researchers encourage and support the utilisation of resources and structures found within the communities (Hai & Chuong, 1999; Tungar, 1999).

5.2.2.2 Differences between the Lusaka and Chipata CBR programmes

Some differences in the organisation and operation of the Lusaka and Chipata CBR programmes were also noted. The programme manager for the Lusaka CBR programme was a qualified agriculturist and the programme coordinator for the Chipata programme was a qualified physiotherapist. The UN Centre for Human Rights (1994) encourages specialised agencies and other concerned intergovernmental

organisations to participate in the development and implementation of CBR programmes for PWD in developing nations. According to WHO (2001), the health related domain of disability functioning involves aspects of life other than health conditions which contribute to an individual's overall well-being. In this case, a trained agriculturist managing a CBR programme would be well placed regarding food security and poverty, which also contribute to the causes of disability. In the Chipata CBR programme, training and utilisation of local personnel has been achieved, since expatriates trained a physiotherapist to manage the programme. The importance of whether a CBR programme is managed by a health professional or a non-health professional still has to be investigated.

Community participation and the empowerment of PWPD is a critical aspect of CBR. It was observed during this study that the Chipata CBR was transformed into an association with membership open to both PWD and able-bodied persons. Only the chair of the association should be held by a PWD to instil ownership of the association by PWD. Members identify their own needs, identify solutions and plan how to meet those needs. The association has 90% autonomy in the operation of the programme (Chipata CBR Association, 2002). Purves (2002), in support of this system of providing CBR services, states that selected local people, including disabled people, family members and representatives of the concerned sectors, should become local community rehabilitation workers. In the Chipata CBR programme, PWPD and the community were given power to manage their own affairs. A study conducted by Sharma and Deepak (2001) indicate that giving power to PWPD and the community creates community involvement in planning, decision making and the evaluation of their services and activities.

In contrast to the Chipata CBR programme, the Lusaka CBR programme employed able-bodied CRWs who were paid a salary. Persons with Physical Disabilities were consulted regarding the operations of the programme, e.g. through mothers' support groups, but only concerning certain issues, such as the need for an appliance. The

results of this study showed that the Lusaka CBR programme has not given autonomy to the community and PWPD in the operation of the programme. As mentioned, Lusaka has various socioeconomic problems associated with poverty, and having CRWs as volunteers would not be the best if quality and efficient work is expected (Hartley, 2001). However, in support of the Chipata programme model of operation, Hartley (2001) states that CBR is a model of providing community service to PWD to develop community participation, empowerment and eventually social integration. One would assume that the rehabilitation team of the Chipata CBR programme would experience a sense of community empowerment, ownership and belonging. This would not necessarily be the case in the Lusaka CBR programme, where CRWs are employed. In such a situation as Lusaka, the spirit of ownership is likely not to exist (UN, 1992 & 1994). However, Wirz (2000) supports the system of having CRWs as employees as long as they are provided with local training geared towards the needs of the project and the community they will serve. The decision on the employment of CRWs depends on the environment, geographical location and socioeconomic situation of the area where the CBR is being implemented.

These findings regarding the operational organisation of the CBR programmes in Chipata and Lusaka correspond with the findings of Giacaman (2001) that giving the power of caring for the disabled people to the community created a caring society in which programmes were executed with equality, social justice, solidarity and integration. The assumption would therefore be that the Chipata CBR programme would yield better results regarding the operational benefits to PWPD within the community than the Lusaka CBR programme.

Another area of difference identified was that the Chipata CBR programme has well-established fundraising activities for disabled members. The aim was to enhance self-sufficiency, economic independence, reduce social stigma and poverty, to restore dignity and respect to PWPD and to ensure the sustainability of the association. This type of support to PWPD is what Mpofu (2001) and Holloway, Lee and McConkey

(1999) regard as one of the most important elements of CBR. The Chipata CBR Association has a policy of training every PWD in a vocational skill of their choice in order to cultivate a sense of responsibility. After training, each participant is provided with equipment to start their own business. As a group in an area, they are given loans to do a collective fundraising activity, after which the loan must be repaid.

This type of activity has encouraged teamwork and consolidated their purpose in the community. According to Mpofo (2001), Zimbabwean communities appreciated the contribution that PWPDP have made to the development of their respective communities. As O'Donnell (1993) reports, self-sustenance and economic situation was a critical concern to PWD, especially PWPDP. Persons with physical disabilities were mostly concerned with their unmet socioeconomic needs, which were aggravated by poverty. For this reason, fundraising activities should form part of any CBR programme (Turmusani, Vreede & Wirz, 2002).

In the Lusaka CBR programme, fundraising activities had just been introduced and only catered for mothers' support groups. The mothers were trained in knitting and sewing but not provided with equipment to start a business. All the items produced were for the group, who sold and shared the money.

Tjandrakusuma (1998) cautions the Lusaka CBR programme not to fall into the trap of the charitable approach, which convinced and satisfied donors and providers of resources with numbers, but did not really transfer skills to the local community. Sharma and Deepak (2001) and Boyce and Lysack (2000) further caution professionals managing CBR programmes that they should involve patients and PWPDP in planning, budgeting, resource allocation and utilisation, as this enhanced community ownership of the CBR programme. Great achievements have been made in the area of disability awareness, highlighting the importance of professionals working in the communities and emphasising the management of disability. The Lusaka CBR was aware that it was essential that realistic and achievable goals were set with

PWPD, given the demands that are made on PWPD and their families in carrying out their normal daily activities.

Another point of difference between the two CBR programmes was the mode of transport. The Lusaka CBR programme had three vehicles, while Chipata only had a motorbike. In the densely populated Lusaka, the vehicles were used by the programme manager and staff for referral purposes, while CRWs walk to their clients' homes daily. In Chipata, the motorbike was used by the programme coordinator and the project officer to visit the CBR areas, while the CRWs were given bicycles for their visits to the clients' homes. This seemed to be realistic, since there was a higher demand for transport in the day-to-day operations of the programme in Lusaka than in Chipata. The roads in Lusaka were fit for vehicle utilisation, while some roads and areas in Chipata weren't. Thus it could be expected that running costs of a vehicle would be more in Chipata than in Lusaka. As for the CRWs, the areas in which the Lusaka CBR programme operated were relatively near to each other, compared to Chipata, where villages would be 5 to 10 kilometres apart from each other. The Lusaka CBR programme might want to consider providing their CRWs with bicycles, as it could be tiring to always go on foot. It might also lead to added motivation.

Some writers have commented on NGOs such as the Chipata CBR Association and other grassroots organisations' performance in terms of promoting democracy. Lang (2000) reports that many NGOs have failed to adopt democratic structures and operational practices within their organisations. The failure to democratise their own structures made them less effective. Nonetheless, the Chipata CBR Association could be proud of their achievements in helping to cement human and political rights in their communities, and in democratising the informal political process by training grassroots activists and building stronger local institutions. Lang (2000) also states that there is increasing evidence that NGOs do not perform as effectively in terms of poverty alleviation, cost effectiveness, sustainability, popular participation, flexibility and innovation as had been assumed. This observation could be attributed to the Chipata

Association as some of the participants indicated that CBR did not help them alleviate poverty despite having fundraising ventures. Some participants indicated that they could not sell their products rendering them not able to improve their economic status despite having been trained in a vocational skill, provided with equipment and able to produce items for sale. This could be assumed as a negative side of CBR in Chipata rural. In terms of service provision, however, there is evidence that NGOs are able to provide some services more cost effectively than governments.

Jayasooria (1999) describes PWPDP as “active people” – not “passive citizens” – who must be given the chance to participate in all the activities that concern them. This is followed by the Chipata CBR programme, which has included all PWPDP in their decision-making processes. Community involvement and participation is evident in that the association is open to all citizens. Volunteer CRWs are from within the community, which has led to a level of advocacy and lobbying more pronounced than in Lusaka.

5.3 OBJECTIVE 2: DESCRIPTION OF THE DEMOGRAPHIC INFORMATION OF THE PARTICIPANTS FROM THE LUSAKA AND CHIPATA CBR PROGRAMMES

5.3.1 Location, gender, language and educational level

Of the initial 40 randomly selected PWPDP, nine (9) participants from Lusaka and seven (7) from Chipata were excluded from the study because of their non-availability at the start of the study. For this reason there were more participants from Chipata than Lusaka. Due to the population sample being unavailable to randomly select the study sample to replace the excluded 9 participants, replacement was not done. The population sample available did not meet the set out criteria stated in chapter 3 to be included in the study.

There were more male participants than females. This corresponds with the national figures indicating that PWD are more male than female (CSO, 2003). (The reasons for

this would be interesting to pursue at a later stage). Most participants preferred to use Nyanja and Bemba, while English was the least preferred language. This preference corresponds with the results regarding level of education. Five percent (5%) of participants and 9% of proxies had attained the highest level of education which was grade 8-9 and grade 10-12 respectively. Those who had not been to school and the school-going children who were not attending school formed the largest percentage. This could be the reason why the participants/proxy preferred to use local languages rather than English. When they were asked if they preferred to read the questionnaire themselves they gave a negative response since it would be difficult and to take them a long time to read and understanding the contents. They preferred the questionnaire to be read to them and interpreted. (The researcher read and interpreted the questionnaire to the participants/proxy as she could both speak and write all the three languages.) These results agree with the UN Department of Public Information (1992) who have stressed that PWD and PWPD would be among the less educated, with high levels of poverty, especially in developing countries such as Zambia. Hosain and Chatterjee (1998) also explain that most PWPD are less likely to be educated, especially in developing countries.

More participants responded to the questionnaire on their own. Other used a proxy, or both the participant and proxy responded. This indicates that more participants were able to understand, explain and express themselves after the researcher read and interpreted the questionnaire to the them. Those who used a proxy were mostly children and adults who were not unable to explain their own situations. This would also confirm that caregiving is essential in the rehabilitation of PWPD.

5.3.2 Age of the participant, family and employment status and relationship of participant to proxy

At the time of the survey, 30% of the participants were between the ages of 7 and 12 and 58% of the participants indicated that they became disabled before reaching seven years. These findings correspond with the statement of Turmusani, Vreede and Wirz (2002) that disability occurs mostly among children and women. This has led to advocates of human rights, including disabled people's organisations, to fight for children's rights, especially for the disabled.

It is also important to note that 14% of the participants in this study were between 41 and 50 years old while 8% were between 51 and 60 years. These results caution Zambia to prepare for the future, when the country will be faced with an increase in the disabled adult population. This has implications for the country's budget allocation for the provision of care and services to the elderly.

The study revealed that 68% of the participants were single and 24% were married. Smaller percentages were divorced, separated or widowed. Thornburn (1998) states that a single-parent household doubles the burden of disability and perpetuates poverty for PWPDP.

It was found that 30% of the participants were employed; 29% of this group were in informal employment. The results revealed that there were more participants who were employed than those who were unemployed. Those who were below and above the age of employment constituted the largest percentage. There was a considerable difference in employment status between Lusaka and Chipata, where a larger percentage of participants were employed. A reason would be that most of the participants in Lusaka were younger than those in Chipata, where participants were mostly of employment age. The study revealed that most participants in Chipata were engaged in informal employment, such as farming, carpentry, blacksmithing and sewing – the vocational skills they have received training for in the CBR programme.

The assumption can therefore be made that there would be more unemployed PWPD in the absence of CBR such as Chipata's. Pfeiffer (1999) states that most PWPD are unemployed because of race, age, gender, ethnicity and their living in rural areas and not because of a disability. However, the results of this study confirm the benefits of training PWPD within their communities using CBR. Jabbar & Chowdhury (1999), the UN Department of Public Information (1992) and Mitchell (1999) maintain that the training of PWPD for income generation helps in alleviating poverty, increases self-confidence and creates self-reliance and responsibility in the community. One participant in this study said that he had received training in carpentry through CBR and that he was now able to support his family and himself. His wife is no longer subjected to the prejudice of the community because of the poverty his family was experiencing. He had gained respect, dignity and self-confidence through CBR.

Another area of interest was the relationship between the participant and the proxy. The study showed that most proxies (50%) were parents, followed by family members and spouses. The least were children (8%) and then other members of the community (3%). This agrees with the findings of French (1994) who explains the intrinsic family dynamics of caring for PWD and especially PWPD. She states that parents, mothers in particular, often feel compelled to become carers and tend to feel guilty if they reject the role. They do not only feel that it is their duty; to care is a central, almost biological, aspect of the female character, even as a child. French further states that spouses take centre stage in caring for their disabled spouse. In reality, most PWPD have always lived within the community, as they were assisted or cared for by their families, as this study has revealed. According to Fehrsen (1995), strong support systems found within the community help the patient look within the family, home, work, school and church, where other people can provide care. It is interesting to note there was not much difference between the results of Lusaka and Chipata regarding the relationship between the participant and the proxy. The only exception was with regard to spouses, since more participants had spouses as proxies in Chipata than in Lusaka.

5.3.3 Nature of disability, medical diagnosis and cause of impairment

According to the findings of this study, there were more PWPD who suffered from cerebral palsy and musculoskeletal dysfunctions. These conditions were caused by cerebral malaria, poliomyelitis and arthritis. Other causes revealed a higher percentage, covering isolated cases of trauma, malnutrition, hydrocephalus, spina bifida, sickle cell anaemia, elephantiasis, osteomyelitis and burns. According to the CSO (2003) and the Ministry of Finance and National Planning (2003) the main cause of death in Zambia is malaria, both under and over five years, and 54.1% of disabilities are caused by diseases/illness. In this study it was shown that malaria was among the leading causes of disability, followed by poliomyelitis. These findings are consistent with the MoH (1992) which has recorded malaria as being responsible for 31.8% of hospital admissions, being the highest among others causes.

5.3.4 Period participant started CBR and if he/she had been receiving physiotherapy prior to CBR

Those who had started CBR 1 to 2 years before the study was conducted were slightly more than those that had started 3 to 4 years before the study. These periods correspond with the inception of the CBR programmes in Lusaka and Chipata. Of all the participants only 20% had been receiving physiotherapy before starting CBR. This is typical for Zambia because all the clinics in the townships/compounds do not have physiotherapy services. The services are only found at two government hospitals in the city, namely the University Teaching Hospital (UTH) and Chainama College Hospital. These health institutions are not in the communities where the majority of the citizens live. An individual has to spend a considerable amount of money on transport to reach these facilities, which is unaffordable considering the poverty levels in the country. None of the rural health centres in the country have physiotherapy services and only a few district hospitals provide these services. This begs the question where these PWPD would be if there were no CBR services. One mother remarked that if it were not for the physiotherapist from UTH, who referred her to the CBR programme so that

her child could continue physiotherapy, the condition of her child could have deteriorated.

5.4 OBJECTIVES 3, 4, 5 AND 6: EVALUATION BEFORE AND RE-EVALUATION AFTER CBR INTERVENTION OF THE LUSAKA AND CHIPATA PROGRAMMES BY ESTABLISHING THE LEVEL OF INTEGRATION OF PWPD INTO THE COMMUNITY

The participants were assessed in terms of movement, functional activities and caregiver provision and dependency to establish the level of integration of PWPD into the community. The results of the evaluation before and after intervention was discussed comparatively to answer objectives 3, 4, 5 and 6.

5.4.1 Integration of PWPD into the community in relation to movement

The findings of the present study correspond with other studies that suggest that mobility is the basis for any activity. You need movement to change positions, adjust posture or perform any functional activity (WHO, 2001). The ability to walk safely and independently, referred to as “mobility”, is a fundamental part of the basic activities of daily living and therefore preserving mobility is a critical part of maintaining and preventing further disability (Shumway-Cook, Patla, Stewart, Ferrucci, Ciol & Guralnik, 2000). If lack of movement prevents one from performing life activities, participation restriction occurs (Desrosiers, Noreau, Rochette, Bravo & Boutin, 2002). The present study revealed that after CBR intervention, increased movement was associated with increased level of integration of PWPD into the community. The results from both Lusaka and Chipata suggest that movement forms a means of interaction between individuals as well as between a person and the environment. Movement gives a holistic image of an individual as an active being who is able to change position, posture and location and thus gain health and well-being (Broberg, Aars, Beckmann, Emaus, Lehto, Lahteenmaki, Thys and Vandernberdhe, 2003).

One parent expressed how CBR had improved her child's mobility:

"My son used to just lie in bed and had stopped school, I did not have anything to help him with. ... After starting CBR, he is now walking with a calliper and even goes to school and is in grade six".

On the same subject of movement, a wife to one participant said:

"My husband has improved so much. Before CBR, I had to do everything for him, he could not move. Now, even if he does not talk yet, he dresses alone, ... walks to the sitting room to watch television. He makes signs on what he wants and we give him. He even goes outside the house alone. ... I am happy and relieved. I am ... able to do other things now because I know he is safe".

Because of this man's ability to move, he gained some functional independence (Rimmer, 1999).

McMullen and Mitchell (1999) state that one of the benefits of CBR is increasing the mobility of PWPD to live more independently. He stresses that the objective of CBR is to assist PWPD to adapt to their disability and live as independently as possible. According to WHO (2001), mobility includes changing location by moving or walking from one place to another. In this context, the results of the present study correspond with WHO's conceptual understanding that movement is a critical aspect of CBR in enabling PWPD to perform tasks such as associating with others within the house, participating in family matters by being part of the group and also interacting with the environment outside the house. It would appear therefore, that movement contributes to the integration of PWPD into the community.

5.4.2 Integration of PWPDP into the community in relation to functional activities

This study's results for both Lusaka and Chipata showed significant positive correlation between functional activities and integration after CBR intervention, suggesting a strong relationship between functional activities and integration of PWPDP into the community. The results showed that high levels of functional activities are associated with high levels of integration. Some of the functional activities assessed were self-care needs, preparing meals and participation in family and community activities. According to Mulholland, Packer, Laschinger, Olney and Panchal (1998), the performance of functional activities such as preparing meals, washing clothes, domestic or household chores, and joining in family and community activities are an essential aspect of CBR in enhancing the integration of PWPDP into the community.

The present study identified some differences in functional activities between Lusaka and Chipata. For example, the task of fetching water may not be a very difficult one in urban areas, while PWPDP in rural areas find this task very difficult because of the distance to be covered to the source of water and carrying the bucket on the head. According to Mulholland et al. (1998), the same functional activity will differ according to the environmental needs and demands placed upon the PWPDP to perform and that further will determine the functional limitations and participation restrictions. The ability to perform functional activities has levels: firstly, the type of activity itself; secondly, the capacity to perform; and thirdly, the actual performance of the activity (WHO, 2001). According to the findings of this study, the type of activity can cause an incapability to perform that task, even if you had the capacity, because of the environment you are in.

Here are a few comments by participants in relation to functional activities:

"I was unable to lift a bucket of water onto my head ... wait for someone to help me lift the bucket to my head"

"I am happy I have a wheelchair from CBR, am able to go to church and field though I cannot cultivate or plough or even visit other villages because the foot path is very small and rough, I cannot pass with my wheelchair. There is even a river just nearby, I cannot cross. I hire people and supervise. ... I grow a lot of vegetables for sale. I have money now to look after myself and my family".

"At least now my daughter is able to help me with some household chores. She can draw water from the tap over there for cleaning dishes, for bathing herself and her brother. CBR has helped her. The family appreciates it very much".

This girl in town with water on tap might not have the same level of functional activity in the village setting. She would be unable to perform the task because of the environment in which she would be, like the rural woman who needs assistance with lifting the bucket onto her head. According to Jablensky (2000), one needs to be aware of these variations and differences in the environment if you are investigating activity limitations and functional restrictions in relation to the integration of PWPD into the community. Soukup and Vollestad (2001) explore the context of activity limitations further by referring to the perspectives of body, personal and society levels. The individual has to be willing to perform the task, society has to give equal opportunity to the PWPD, and the environment has to be receptive to the needs of the PWPD to allow him/her to participate in whatever functional activity.

Giacaman (2001) holds the opinion that family and society have to create an enabling environment for PWPD to take care of themselves. This means the creation of a caring society, with equal societal justice and solidarity.

Rozario (1997) considers another dimension of integration of PWPD into the community as regards functional activities and attributes the level of integration to spiritual transformation, hope, personal control, positive social supports and meaningful engagement in life. Family, community or society can hinder or facilitate the integration of PWPD into the community by their positive or negative responses and reactions towards PWPD. A supportive family enhances an individual's independence/interdependence, productivity, community integration and satisfaction (Brown, 1997). This is confirmed by the following participant comment:

“My family has been very good and supportive all along. They encourage me to participate in whatever I want and mostly I succeed. At the end, we are all happy, I have a fulfilling life”.

5.4.3 Integration of PWPD into the community in relation to caregiver provision and dependency

The results of the present study showed that there was no correlation between caregiver provision and dependency and integration of PWPD into the community. The results for both Lusaka and Chipata indicated no relationship between caregiver provision and dependency before or after CBR intervention. This could be attributed to various factors which were revealed in this study. The results showed that despite the CBR intervention having been provided to the participants, most of them still showed the attitude of not accepting their disability status. Their negative attitude it would be assumed, resulted in the participants not to have appreciated the care given to them. It would also be assumed that because of the non-appreciativeness of the care being given, the participants perpetually depended on the caregiver than being independent. This line of thought is expressed by Thoren-Jonsson (2001) who states that the physical impairment itself may impose greater demands on the individual PWPD, so that he/she fails to appreciate the care being given. This in turn poses a risk regarding integration into the community.

The other factor which was revealed in the study was failure of PWPD to cope with difficulties and participation restrictions encountered due to the disability. This could be explained in the expression by one participant:

“What can I do, my disability is permanent. I am not able to participate in a lot of things in the family and in the village. Sometimes even when I want to participate, for example dancingpeople laugh at me the way I dance.....then I stop”.

Another factor identified was the frustrations experienced by PWPD and sometimes the proxy due to unmet needs and expectations. One participant expressed the following:

“I cannot marry because of my disability. People despise me..... What can I do? I need a wife, but”.

Yet another factor identified was the need for financial resources, family honour and prestige of having a child especially a son. A mother of one participant said:

“What can I do to help my two disabled sons? My husband has deserted me. ... He wants healthy children from another woman. ... The eldest boy is growing older and his condition is getting worse. I am failing to lift him, my back aches sometimes ... and I am growing older too. ... I do not know what to do. ... I do not have any income to support these children and myself. No food sometimes ...”.

It seemed in her anguish, this mother expressed her frustrations for having two disabled sons. She had no financial resources and the husband who was the bread winner and provider, left her for another woman presumably in the hope of having normal children. The disability of her two sons caused pain which made her feel

helpless and hopeless. This situation could be assumed to have been as a result of the unmet needs and expectations of family honour and prestige caused by the disability of these two sons as expressed by Anderson and Venter (1997).

In support of these findings from the research, Chan, Lee and Lieh-Mak (2000) highlight issues which can contribute to non-integration as regards caregiver provision and dependency. Firstly, they site acceptance of the physical status by the individual; secondly, unrealistic appraisal of stressful situations; thirdly, failure to cope with difficulties; and fourthly, frustrations due to unmet expectations. Jones, Charlesworth and Hendra (2000) state that physical burden and emotional stress on the part of the PWPD reduce the level of their integration into the community. CBR therefore needs to identify and address the neuropsychological needs of PWPD and the social functioning of their carers.

Chipchase and Lincoln (2001) observe that carers have reported being under financial strain and physical strain, experiencing feelings of tiredness, worry and pessimism about the future. This is also true in this study. These effects on the carers can affect the level of integration of PWPD into the community.

In the light of the above findings, the researcher would recommend that counselling of the participants (PWPD), the family and the community be continued and intensified to increase the understanding of disability issues in relation to cultural beliefs and values. The other area of concern especially in Lusaka where most of the participants were children, was the training of both the PWPD and the family to cope with the disability. Coping strategies and support systems for PWPD, families and community members to be more involved in the integration of PWPD into the community. Strengthening of the already existing family and community structures for example family and church communities to help the carer to cope with the disability. Intensify community awareness campaigns by the CBR programme staff including the CRWs

and the other professional staff for example physiotherapists to assist the carers have the knowledge of the existing support structures which include wings of government like The Agency for the Disabled.

Another area which could be of importance was the expertise of the CRWs. In addition to enhancing the awareness campaigns, ensuring access to existing support systems it would seem that more training of the technical staff is required to embrace all aspects of PWPD needs and this though is supported by Twible and Henley (2000). Further research could be recommended to explore the details of the deficient needs of the CRWs expertise required to provide adequate rehabilitation services to PWPD.

5.5 THE IMPACT OF CBR INTERVENTION ON PWPD

5.5.1 Perceptions of PWPD regarding their disability status and experience: effects on integration

The results of the present study indicate that there was no difference in the perceptions of PWPD as regards their disability status and experiences before and after CBR intervention. During the first interview, the expressions regarding disability status were summarised into themes which indicated that some PWPD needed to gain functional, social and economic skills. The need to gain these skills was attributed to their negative experiences of social and economic stigma, superstition and poor family support. After CBR intervention, the results indicated that nothing of significance changed in their perceptions. According to Price and Marquis (1999), ignorance, superstition, and the negative, rejecting and stigmatising attitudes of communities are assumed to contribute to the poor level of integration of PWPD into the community. They further state that CBR programmes at a village level may not yet meet the critical needs of PWPD to experience lives free from pain, poverty and hunger. This is supported by some of the participants' comments:

A mother remarked:

“There is little change. I do not know whether my daughter will improve. This CBR ... does it work? People think my daughter is mad and so we are now using traditional medicines as well, maybe they can help, I do not know”.

Another participant said:

“Since starting CBR, my life has not changed much. ... There is no business here in the village to sell these knitted items to earn some income. People still despise me and talk a lot of bad things about my disability. ... My daughter ... feels bad when she hears people talk ill about me”.

Another commented:

“Before CBR, my life was very bad and difficult. I could not marry, girls used to refuse my proposals for marriage because I had no income and looking very poor. Now because of CBR ... I have income and I am getting married soon although some people still despise me”.

Another mother said:

“I think my child’s disability is a curse from my parents. ... I am the only one in my family with a disabled child ... why? But all the same, I get encouragement from CBR and the church”.

Yet another participant remarked:

“Life has been tough for me especially when my mother died. My stepmother ... calling me all sorts of names. I was nothing to people in this village including my family. They never used to respect me because they could get nothing from me. After starting CBR ... my life has improved a little, now at least people respect me”.

One of the most important issues coming out of these comments is the importance of correct and appropriate information about the disability. Anderson and Venter (1997) report on misconceptions about the causes of disability, diagnosis and future prognosis of the conditions of PWPD. They further report unrealistic expectations and hope, for example parents of disabled children hoping that the child will look after them when they grow old. These misconceptions and expectations can lead to negative perceptions that are a hindrance to the integration of PWPD into the community. According to Devlieger (2000), disability is a cultural reality that is both time and place dependent.

All these issues contribute to PWPD being less integrated into the community. Twible and Henley (2000) therefore caution health care professionals and CBR workers to acquaint themselves with the challenges of the community to effectively deliver their services for the benefit of PWPD, their family and the community.

From the present study it has been deduced that PWPD and their families need the following:

- Appropriate and correct information and explanations on causes of disability, prognosis and other disability issues (Anderson & Venter, 1997)
- For CRWs to understand them and accept their cultural beliefs and values and work through those to achieve social integration of PWPD (Twible & Henley, 2000)

- CBR planners and implementers need to know that socio-economic survival, and not necessarily disability, may be the primary concern of the family, especially in developing countries and poor communities (Price & Marquis, 1999)
- Society and government need to learn to make efforts to reduce, if not completely eradicate, the ways in which society discriminates against PWPD

Community-based rehabilitation being a multifaced and complex issue, it requires multi-secteral approaches to deal with the complexities involved (Price & Marquis, 1999). In my understanding of disability issues after this study, is that persons with disabilities need to have their needs identified first before any strategy can be planned and implemented. In this study, it was discovered that there was some multi-secteral activities and coordination among the ministries and other NGOs. The coordination was identified among Ministries of Education, Community Development and Social Services, and Health, Agency for the Disabled and the various organisations for Persons with Disabilities. This coordination was seen in the use of schools, clinics and health centres, churches, people within the community and health professionals to mention a few. From the opinion of the researcher this coordination would be recommended to be re-enforced and improved further to ensure that all aspects of the needs of PWPD are met which will further enhance integration into the community.

Discriminatory remarks, prejudice, disrespect and injustice contribute to the low level of integration of PWPD into the community, thus restricting them to participate fully in family and community development (Kassah, 2000). There are still millions of PWD/PWPD whose human rights are infringed (or altogether denied by society) and unattended to by their own governments. The discriminatory act of placing negative labels on these categories of people has not been erased despite bold efforts by WHO to find suitable definitions.

5.5.2 Impact of CBR intervention on PWP

The impact of CBR on PWP was evaluated on the basis that the ultimate goal of CBR was the integration of PWP into the mainstream of society and thus maximising social integration (Zhuo, 1999; Georgievski, 2000; Coleridge, 2000; Chan, 2002). The results of the present study suggest that CBR intervention had an impact on PWP in that the level of integration of PWP improved in both the Lusaka and Chipata CBR programmes. In Lusaka an impact on movement, functional activities and integration was experienced, while caregiver provision and dependency remained unchanged. In Chipata there was an impact on integration, while the other variables did not change.

From the study, it would be assumed that there was no much change in the level of movement and functional activities from what had already been gained before the CBR intervention. On caregiver provision and dependency, it was also noted that presumably the participants had already gained some level of independence of which the CBR intervention had no significant impact on PWP. The other factor which could have contributed to the impact of CBR intervention not being experienced on the Lusaka and Chipata participants was the difference of the groups: Lusaka having been mostly children who almost totally depended on caregivers and Chipata mostly adults and independent .

Steiner et al. (2000) observes that the ultimate goal of CBR was to improve the quality of life of PWP, promote positive attitude in PWP and hence minimise the consequences of disability. This study has shown that after CBR intervention the perceptions of PWP as regards their disability status and experiences did not change in either Lusaka or Chipata, but remained negative. The results of this study therefore seem to show that CBR intervention did not have an impact on perception change. This scenario could be explained by the cultural beliefs and values about disability which the Zambian society upholds. This assumption could be supported by the participants/proxy comments about the cause of disability being a curse and peoples' reactions towards PWD/PWP as expressed in this study.

Hai and Chuong (1999) assert that integration of PWPD is achieved when the family is stimulated to participate in the efforts to meet the rehabilitation needs of their disabled family member. As observed in the Chipata CBR programme, families and the community have been involved and participated in the rehabilitation of PWPD. Thomas and Thomas (1998) stress active community participation as the key to achieving community integration and for CBR to have an impact on the lives of people. Tungar (1999) and Sharma and Deepak (2001) assert that rural areas' main concern is poverty alleviation. Hence, initiating income generating and vocational skills development activities, as Chipata CBR has done, and accessing resources from the programme's own efforts seem crucial for CBR to have an impact on the lives of PWPD.

However, family support and community participation to enhance social integration of PWPD in the community, could have been limited because of the negative attitude of some family and community members. Some comments and expressions of the participants/proxy noted in this study indicated that some family and community members were a hindrance to the efforts of integration of PWPD into the community. The solution to this scenario could be enhanced awareness campaigns on disability issues and rights, socio-cultural and economic issues in relation to disability. As already alluded to, ignorance was assumed to contribute to the causes of disability and its effects.

CBR intervention in Lusaka had an impact on participants with regard to movement, functional activities and integration of PWPD into the community. Kim and Jo (1999) observe that the impact of CBR is felt when therapy provided at home, enhanced mobility and functional activity participation of PWPD in turn promote the level of social integration. White and Johnstone (2000) state that parents of disabled children and PWPD look at rehabilitation as the treatment to restore functional independence. Contrary to the findings of this study, Kim and Jo (1999) state that improvements in

movement and functional activity are assumed to promote a positive attitude change in PWPD.

Negatively, the participants showed that their cultural beliefs, values and practices could have contributed to the negative perceptions about the benefits of CBR. It was noted that some participants, their families and some community members had some beliefs, for example, concerning causes of disability which could have contributed to their being unable to appreciate the CBR intervention. This could be confirmed from some expressions from participants/proxy of curses, superstition of being bewitched and belief that any intervention on the disability would not yield any positive results. Other comments from participants and members of the community concerning marriage relationships could also be attributed to the failure of the participants/proxy to appreciate the benefits of CBR looking at disability as a condition which cannot be improved no matter what is done.

The lesson learnt from this study is that PWPD, their families and the communities have deep rooted beliefs which influence their attitudes towards disability and issues concerning disability. Persons with disabilities did not necessarily need only therapy; the intrinsic critical issues of survival, poverty alleviation and sustainability of their quality of life in this cruel world of discrimination and rejection seemed also to have been issues to be addressed. As learnt from this study, societal attitudes played a critical role in building a positive construct of disability and promote the social integration of PWPD, and for CBR to have an impact on the lives of PWPD, it must work to address these issues. It was also shown in this study that community-based rehabilitation faced an enormous challenge in ensuring that attitudinal barriers were torn down in order for CBR to have an impact on the lives of PWPD.

From the results of this study, the researcher would not accept the null hypotheses regarding the level of integration of PWPD into the community and the impact of CBR intervention on PWPD. In both study areas, the results showed high level of relationship between movement, functional activities and integration of PWPD into the

community. However, there was no significant relationship showed between caregiver provision and dependency.

There was significant improvement in movement, functional activities and integration of PWPD into the community in both study areas indicating an impact of the CBR intervention strategy on PWPD. The researcher therefore would not accept the null hypothesis that the impact of a CBR intervention strategy is not related to movement, functional activities and integration of PWPD into the community. Even though, the results in the study also showed that despite the CBR intervention, the participants still held negative perceptions about their disability status and expressed negatively about their situations, there were some positive experiences expressed by participants. However, some geographical and socio-economic differences were noted between the two study areas in the lives of PWPD.

From the findings of the present study, the researcher will therefore accept the alternative hypotheses that:

1. The CBR organisation and operational structure contributes to integration level of PWPD into the community;
2. The level of integration of PWPD into the community is related to movement, functional activities, caregiver provision and dependency and perceptions of PWPD as regard to their disability status and experiences;
3. The impact of the CBR intervention strategy is related to movement, functional activities, caregiver provision and dependency, integration of PWPD into the community and perceptions of PWPD as regards their disability status and experiences.

5.6 CHAPTER SUMMARY

Chapter 5 presented a detailed discussion of the results in Chapter 4. The Lusaka and Chipata CBR programmes were discussed regarding their structural and operational management. Similarities and differences were identified, and the overall assumption is that both CBR programmes operate according to their individual environmental perspectives in delivering CBR services to PWPD.

A larger percentage (39%) of participants in this study sample are illiterate. Another 39% had not even been to school at all. The situation was the same with their proxy. These findings were consistent with statements that PWPD/PWD are most likely to be illiterate, especially in developing countries such as Zambia. Eighty percent (80%) of PWPD had acquired the disability, 44% had musculoskeletal impairments, and 33% had cerebral palsy. This technically means that 80% of these disabilities could have been prevented through concerted efforts on the part of the Zambian community. Twelve percent (12%) of PWPD's disabilities were caused by cerebral malaria and another 12% by poliomyelitis, both preventable diseases.

The study showed that CBR had an impact on PWPD in terms of movement, functional activities and integration into the community for Lusaka and Chipata only had an impact on integration into the community while there was no impact in the other variables. Combined scores showed that the CBR intervention had an impact on PWPD in movement, functional activities and integration into the community.

The study showed that PWPD seemed to have needed mobility and functional activities more in urban areas than in rural areas such as Chipata. The main concern of Chipata's PWPD seemed to have been generating income and transferring skills to PWPD and their families. This might be why the Chipata CBR programme only had an impact on integration into the community.

Based on the findings of this study, it can be assumed that community-based rehabilitation benefited PWP and their families, though at different levels and in different areas of need. Therefore CBR could be recommended as the appropriate strategy to enhance the social integration of PWP into the community.

CHAPTER 6

CONCLUSION AND RECOMMENDATIONS

6.1 INTRODUCTION

In 1976, WHO estimated that 90% of PWD in developing countries were totally neglected (WHO, 1995) and introduced a CBR strategy as part of its goal to accomplish “health for all by the year 2000”. A training manual was produced in 1980, revised in 1989 and is now widely used in many countries. It has also been translated into several languages for use at village level. In essence, the primary tenet of CBR is to provide primary care and rehabilitative assistance to persons with disabilities by using human and other resources already available in their communities. However, in many developing countries such as Zambia, much still has to be done to promote the implementation of the Standard Rules for Equalisation of Opportunities for people with disabilities in all spheres of their lives.

6.2 CONCLUSION

It is evident from literature that disability is increasing both internationally and in Zambia. It is therefore imperative for a developing country like Zambia, which has limited central budgetary resources, that disability issues are incorporated into the national agenda and that the responsibility of service provision to persons with disabilities are shared with PWD, their families and the community. With the all encompassing national policy on disability the researcher is lobbying for, PWD to be reached and their basic needs met through community-based rehabilitation. The policy would ensure guidelines and direction in the manner in which Zambian CBR programmes would be planned, implemented, managed, monitored, evaluated and supported in order to avoid the likelihood of abuse as in the slack situation prevailing now. Tailor-made rehabilitation programmes can be established based on the

individual's capacities and needs and focused directly on integration of PWPD into the family and community.

Early detection allows early intervention. Given the increase in childhood disability in Zambia, CBR programmes can assist in tracing many PWD who would never be found by institutions and, through a referral system, can make the work of other existing specialised services more effective. Community-based rehabilitation services, apart from carrying out their core work of rehabilitation, can also contribute towards the prevention of impairments and disabilities, through primary health care, vaccinations, hygiene and nutrition.

Disability is not a stable situation. Disabled children, for example, become disabled adults with different vulnerabilities and needs. Community-based rehabilitation can evolve and adapt to such situations. The family members can witness and participate in the progress of a disabled relative, thus enhancing their faith in that person's abilities and potential, and challenging their own prejudice. Above all, CBR is cost-effective if managed well. The challenge is for all stakeholders to take up the responsibility of being part of this crusade to improve the welfare of persons with disabilities in Zambia.

6.3 RECOMMENDATIONS

The researcher therefore has the following recommendations for various stakeholders.

6.3.1 PERSONS WITH PHYSICAL DISABILITIES

- Take up the challenge of knowing your rights and use the Standard Rules for Equalisation of Opportunities for People with Disabilities as a basis to demand the services. Zambia, as a member of the United Nations, signs charters, pledging to put in place policies and strategies for the implementation of the charters. Make your government accountable to the signatures.

- Ensure that the efforts of the various organisations for the disabled are efficiently coordinated to be able to deliver the intended services to the members.
- Request from government that they critically consider a national census to establish the accurate figures for disability and have a national database for disability planning, implementation, coordinating, evaluation of disability services throughout the country.
- Initiate the formulation of a Disability Rights Charter for the country which will be an all encompassing document with input from all sectors, and which will relate to the Standard Rules for the Equalisation of Opportunities for Persons with Disabilities and the World Programme of Action for Disability Issues.

6.3.2 MINISTRY OF HEALTH

- As the custodian of health care within the PHC strategy, the Ministry of Health should be obliged to be the leading ministry for CBR activities in the country. With the knowledge and expertise regarding the medical and social models of health care, the ministry is mandated to be responsible for CBR activities.
- Enhance the utilisation of PHC structures in the DHMTs in the implementation of CBR in the country.
- Within the MoH, establish a steering committee encompassing all stakeholders to coordinate and initiate the planning, implementation, monitoring and evaluation of the existing CBR programmes/projects and plan for future development.
- Establish a coordinated database and accurate documentation as a basis for planning, monitoring, evaluation and research.
- Through DHMTs, organise and coordinate referral systems and after-care services for patients and PWPD/PWD who need continued rehabilitation services at village, district, provincial and national levels of health care service delivery.
- Initiate the promotion of a multisectoral approach through the formulation of CBR committees on district, provincial and national level for the implementation of the CBR programme activities.

- Undertake the inclusion of disability issues in the curriculum of all health related training programmes in the country to ensure continued knowledge and appropriate service after completion of training.
- In liaison and consultation with the relevant ministry, revisit the national building policy to compel stakeholders to incorporate accessibility facilities for PWD/PWPD in all buildings in the country in accordance with the Standard Rules for the Equalisation of Opportunities for People with Disabilities.

6.3.3 MINISTRY OF COMMUNITY DEVELOPMENT AND SOCIAL SERVICES

- Ensure that the Zambian Agency for Persons with Disabilities is assisted in utilising its mandate to deal with disability issues more effectively, with the participation of all the stakeholders involved and under direction from the ministry, as enshrined in the Persons with Disabilities Act No. 33 of 1996.

6.3.4 FAMILIES OF PWPD AND COMMUNITIES

- Initiate the establishment of a multisectoral approach to empowering communities to ensure that all members, including PWD/PWPD, achieve equal access to all resources available to the communities and are enabled to participate fully in the social and economic life of the community.
- Initiate awareness campaigns and attitudinal change in communities to enhance social integration of PWPD into the community.
- Initiate partnership in the all the activities regarding planning, implementation, monitoring and evaluation of CBR programmes.

6.3.5 PROGRAMME MANAGERS AND CBR WORKERS

- Promote community involvement in planning, decision making and evaluation of CBR programme activities.
- Ensure transfer of knowledge about disabilities and skills in rehabilitation to people with disabilities and their families.

- Encourage counselling of the participants (PWPD), the family and the community be continued and intensified to increase the understanding of disability issues in relation to cultural beliefs and values.
- Encourage and enhance the use of appropriate technology for the production of simple orthopaedic appliances, utilising the locally available raw materials.

6.3.6 DONORS AND SUPPORTERS OF EXISTING CBR PROGRAMMES

- Ensure and encourage the involvement and participation of PWD/PWPD in the planning and evaluation of CBR programmes so that operation reports are not biased.
- Continued support should not be based only on the numbers of PWD receiving CBR service but also on the quality of the CBR and the full participation of PWD and their families. Sustainability strategies should be part of the planning from the beginning to avoid the collapse of programmes when donor funding is no longer available.
- Income-generating activities should form part of CBR activities so that PWD/PWPD can be assisted with poverty alleviation, improvement of their lives and community development.

6.3.7 INTERNATIONAL ORGANISATIONS (WHO, ILO, UNESCO, UNICEF)

- Assist government to ensure that the charters on disability issues are implemented within the country's own capabilities by providing technical support and timely advice. Charters should not simply be signed and not be utilised, as this is a waste of time and resources. The aim should be the improvement of service delivery. The Zambian government should be held accountable in implementing the disability documents which have been signed.

6.3.8 THE RESEARCHER

It is important that recommendations should not only apply to others but to the researcher as well. The following recommendations can be applied to achieve a higher level of reliability and validity in further studies:

- Include more open-ended, structured questions/statements to enable PWPD to express themselves.
- Separate the open-ended questions for the participant and those for the proxy in order to gain a wider perspective on issues pertaining to disability;
- Make use of recorded interviews as an additional method of capturing respondents' responses.
- Include a section in the questionnaire for government to express their views on the management of disabilities in the country.
- Administer questionnaires in the local languages of the areas of research in order to enable a wider participation.

CLOSING REMARKS

To stress the fact that nobody knows what tomorrow may bring, the researcher thought it important to share the following. Remember, tomorrow you might be part of the statistics – a person with a disability. So become involved in disability issues. You might just be doing it for your future!

“For my thoughts are not your thoughts, neither are your ways my ways”, declares the Lord. As the heavens are higher than the earth, so are my ways higher than your ways, and my thoughts than your thoughts.

Isaiah 55:8-9

God bless you all! Amen.

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APPENDIX 1 (A)

16th November 2000

Dear Sir / Madam

I am a post graduate student undertaking a Master of Science Degree in Medical Sciences (Rehabilitation) with the above University. I am carrying out a study to determine the impact of a community-based rehabilitation strategy for persons with physical disability in Lusaka urban and Chipata rural areas in Zambia.

You are kindly requested to assist the researcher and research assistants by taking part in the study. Participation is voluntary with no remuneration and you are free to withdraw from the study at any time with on effect on you in any way.

Upon completion, the findings of the study will help all stakeholders to be aware of the CBR strategy for people with physical disability that may subsequently be used in all parts of the country.

All information obtained will be treated in strict confidence. The results will be available on request form the Faculty of Medicine, University of Stellenbosch.

Yours Faithfully

Martha Banda-Chalwe

(Student no. 13060007)

JA Hendry (Research Supervisor)

APPENDIX 1 (B)

**PARTICIPANT INFORMATION AND CONSENT FORM
CBR IN ZAMBIA: A DESCRIPTIVE SURVEY**

REFERENCE NUMBER:

STATEMENT BY OR IN LIEU OF PARTICIPANT

I, the undersigned, (Participant and/or Proxy),
confirm that:

1. I have been invited to participate in the above-mentioned research project initiated through the University of Stellenbosch, South Africa.
2. It has been explained to me that the aim of the project is to establish the impact of a CBR intervention program in a group of persons with physical disabilities:
3. It has been explained that an interview will be conducted with me concerning demographic data, the degree of functional independence, caregiver dependency and provision and the reintegration to normal living.
4. It has also been explained that should I agree to participate, I will need to participate in a 6-month CBR program, after which an interview will again be conducted with me in respect of the degree of functional independence, caregiver dependency and provision and the reintegration to normal living.
5. It has been explained that all information will be handled confidentially. Information may be used for a thesis, publication in scientific journals, and/or presentation(s) at professional presentations.
6. I am aware that this is a once off procedure that will be implemented in 2001.
7. It has been explained that findings from this study in respect of the impact of a CBR programme may be brought to the attention of the Health authorities in the Lusaka and Chipata Districts, Zambia.
8. It has been explained that I may have full access to information regarding myself that has been gathered in the study.
9. I have been informed that I may refuse to participate in this project and that I may stop participating at any stage, and that such refusal or stoppage will not in any way negatively influence my future rehabilitation.

10. The information above has been explained to me byin English/Bemba/Nyanja and that I am proficient in that language/it has been translated to me byto my satisfaction and that my questions have been answered satisfactorily.
11. There has been no force placed on me to participate in this project and that I realize that I may stop at any time without penalty.
12. Participation in this project will not lead to additional costs for myself and that I will not benefit from it financially.

Signed at.....on.....200.....

Participant..... Witness.....

Signed at.....on.....200.....

Proxy..... Witness.....

APPENDIX 1 (C)

I HEREBY DECLARE THAT I WILL VOLUNTARILY PARTICIPATE IN THE ABOVE CBR PROJECT

Signed at.....on.....200.....

Participant signature or thumb print.....on.....200.....

Proxy signature or thumb print.....on.....200.....

STATEMENT BY RESEARCHER:

I, Martha Banda, state that:

1. I have explained the information in this document to..... and or his/her representative.
2. I have invited him/her/them to ask me questions in the case of uncertainty.
3. This conversation was held in English/Bemba/Nyanja

Signed aton.....200

.....

Researcher (M Banda)

Witness

STATEMENT BY TRANSLATOR:

I,confirm that:

1. I have translated the content of this document from.....tofor the participant and/or his/her respondent, and that I have also translated questions which were asked of me as well as the answers.
2. The information I conveyed in such a translation, was a factually correct representation of what I have been told.

APPENDIX 2

QUESTIONNAIRE

SECTION A

1. Identification number

2. Research location

1. Lusaka

2. Chipata

3. Language used for communication at the time of survey

1. English

2. Nyanja

3. Bemba

4. Respondent

1. PWPD Self

2. Proxy

3. Both

5. Gender

1. Male

2. Female

6. Relationship of proxy to the client

1. Spouse
2. Child
3. Parent
4. Family member
5. Other (specify)

7. Age of client at the time of survey

8. Nature of disability

1. Congenital
2. Acquired

9. Medical diagnosis if available (e.g. stroke, CP, amputation)

10. Cause of impairment (e.g. diabetes, high blood pressure, malaria)

11. Age when the client became disabled

12. Family status

1. Single
2. Married (including traditional custom)
3. Divorced
4. Widowed
5. Separated
6. Never married

13. Highest level of education of the client
at the time of survey

1. Pre-school
2. Grade 1-7
3. Grade 8-9
4. Grade 10-12
5. College/University
6. None

14. Highest level of education of the proxy
at the time of survey

1. Pre-school
2. Grade 1-7
3. Grade 8-9
4. Grade 10-12
5. College/University
6. None

15. Presently schooling

- 1. Yes
- 2. No
- 3. N/A

16. Presently employed

- 1. Yes
- 2. No
- 3. N/A

17. What type of employment is the client currently engaged in?

- 1. Formal
- 2. Informal
- 3. N/A

18. What type of employment is the proxy currently engaged in?

- 1. Formal
- 2. Informal
- 3. None

19. When did the client start the CBR?

20. Did the client receive any physiotherapy treatment prior to the CBR?

- 1. Yes
- 2. No

SECTION B

Disability Assessment: Movement (including any assistive devices if used)

23. Sits (including sitting up from lying down)

- 1. Not at all
- 2. With help
- 3. Alone

24. Sits upright on chair

- 1. Not at all
- 2. With help
- 3. Alone

25. Getting in and out of bed

- 1. Not at all
- 2. With help
- 3. Alone

26. Stands (including standing up from sitting)

- 1. Not at all
- 2. With help
- 3. Alone

27. Moves around inside the house

- | | | |
|----|------------|----------------------|
| 1. | Not at all | |
| 2. | With help | <input type="text"/> |
| 3. | Alone | |

28. Moves around outside the house

- | | | |
|----|------------|----------------------|
| 1. | Not at all | |
| 2. | With help | <input type="text"/> |
| 3. | Alone | |

29. Moves around the compound (including walking, crouching, crawling)

- | | | |
|----|------------|----------------------|
| 1. | Not at all | |
| 2. | With help | <input type="text"/> |
| 3. | Alone | |

30. Walks at least ten steps

- | | | |
|----|------------|----------------------|
| 1. | Not at all | |
| 2. | With help | <input type="text"/> |
| 3. | Alone | |

31. Walks to school/ work/field

- | | | |
|----|------------|----------------------|
| 1. | Not at all | |
| 2. | With help | <input type="text"/> |
| 3. | Alone | |

32. Getting into your mode of transport

- | | | |
|----|------------|----------------------|
| 1. | Not at all | |
| 2. | With help | <input type="text"/> |
| 3. | Alone | |

SECTION C

Disability Assessment: Functional Activities (including any assistive devices if used)

33. Feeds himself (including eating and drinking)

- | | | |
|----|------------|----------------------|
| 1. | Not at all | |
| 2. | With help | <input type="text"/> |
| 3. | Alone | |

34. Dresses and undresses

- | | | |
|----|------------|----------------------|
| 1. | Not at all | |
| 2. | With help | <input type="text"/> |
| 3. | Alone | |

35. Keeps himself/herself clean (including washing, bathing,
and cleaning teeth)

- 1. Not at all
- 2. With help
- 3. Alone

36. Uses latrine

- 1. Not at all
- 2. With help
- 3. Alone

37. Does household activities

- 1. None
- 2. Some
- 3. All

38. Joins in family activities

- 1. None
- 2. Some
- 3. All

39. Joins in community activities

- 1. None
- 2. Some
- 3. All

40. Goes to school

1. Not at all
2. With an escort
3. Yes

41. Goes to work

1. Not at all
2. With an escort
3. Yes

42. Has any vocational/professional training been done?

1. N/A
2. No
3. Yes

SECTION D

Caregiver dependency / provision

43. Are you able to look after yourself?

1. No never
2. No, only sometimes
3. Yes

If "Yes" to question 43, proceed to **SECTION E**.

If "No" to question 43 proceed to question 44.

If "no" to question 43 above, do you need help with?

44. Getting dressed?

1. No
2. Yes

45. Washing self

1. No
2. Yes

46. Getting out of bed

1. No
2. Yes

47. Getting into bed

- 1. No
- 2. Yes

48. Preparing meals

- 1. No
- 2. Yes

49. Feeding

- 1. No
- 2. Yes

50. Using toilet

- 1. No
- 2. Yes

51. Moving inside the house

- 1. No
- 2. Yes

52. Moving outside the house

- 1. No
- 2. Yes

53. Visiting friends

- 1. No
- 2. Yes

54. Managing own money

- 1. No
- 2. Yes

SECTION E

Identification number

Reintegration to Normal Living Index

I will read to you a list of 11 statements that describe reintegration to normal living. I would like you to rate them according to how much you agree or disagree with the statement.

EXAMPLE: I brush my teeth three times a day



Does not describe my situation

Fully describes my situation

55. I move around my house as I feel is necessary.


56. I move around my community as I feel necessary.


57. I am able to make trips out of town as I feel necessary.
58. I am comfortable with how my self-care needs are met (dressing, feeding, toileting, bathing).
59. I spend most days occupied in an activity that is necessary and important to me.
60. I am able to participate in recreational activities as I want (i.e. hobbies, crafts, sports, reading, television, computer, games).
61. I participate in social activities with family, friends, and/or business acquaintances as is necessary or desirable to me.
62. I assume a role in my family which meets my needs and those of other family members (including those you live with and/or relatives whom you do not live with but see on a regular basis)
63. In general, I feel comfortable with personal relationships.
64. In general, I am comfortable with myself when I am in the company of others.
65. I feel I can deal with life events as they happen.


Rate according to how you agree or disagree with the statement I have read to you.


Does not describe my situation


Fully describes my situation


55. 


56. 

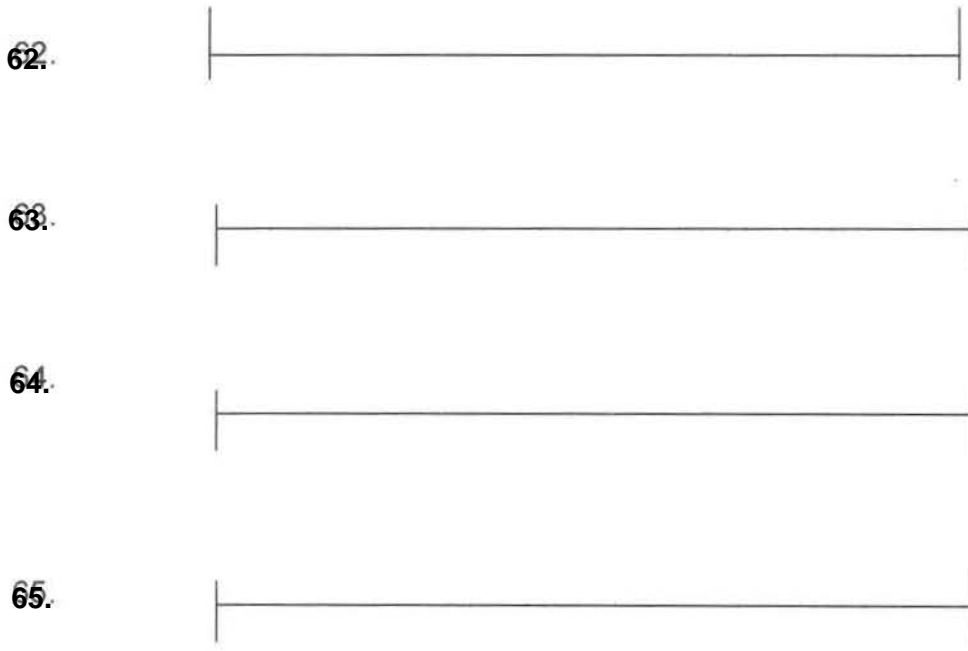
57. 

58. 

59. 

60. 

61. 



SECTION F

Perceptions of PWPD/proxy of changes in the disability status and experiences regarding the disability since starting CBR.

66. State what changes that have occurred on your/client's disability **status since starting the CBR**

- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____

67. State your experiences concerning the disability before you/the client started the CBR

- _____
- _____
- _____
- _____
- _____
- _____
- _____
- _____

APPENDIX 3

Section A of the questionnaire: Part of Question 10

Other causes of impairment

- Congenital hip dislocation
- Spinal trauma
- Comminuted fracture
- Elephantiasis
- Osteomyelitis
- Burns
- Hydrocephalus
- Prostate cancer (survivor)
- Juvenile Jaundice
- Malnutrition
- Spina Bifida
- Sickle Cell Anaemia

IDENTIFICATION REGISTER

Identification number-----

Family name: -----

First name:-----

Home address:-----

Telephone:-----

Identification number-----

Family name: -----

First name:-----

Home address:-----

Telephone:-----

Identification number-----

Family name: -----

First name:-----

Home address:-----

Telephone:-----

1. The CBR intervention for PWPD

The PWPD were assessed in movement, functional activities, caregiver provision and dependency, integration into the community and perceptions of PWPD as regards their disability status and experiences since starting CBR. After the first assessment of PWPD in Lusaka urban and Chipata rural CBR programmes, the following areas of need were identified.

- Mobility
- Functional activities
- Counselling
- Caregiver training on handling of PWPD
- Basic physiotherapy
- Disability/human rights
- Advice on type and use of appliances
- Fundraising activities
- Social skills

The CBR intervention was modified from Helander, Mendis, Nelson and Geordt (1989).

1.1 Mobility training

- Standing/sitting from bed, chair, floor and stool
- Moving inside the house

- Walking in parallel bars
- Walking in a walker
- Moving with walking aids (for example; crutches, walking stick, wheelchair)
- Getting to the latrine
- Moving around the yard
- Moving around the village
- walking to school/field/market
- Travelling by bus

1.2 Functional Activities / Self - Care Activities

- Getting in and out of bed
- Dressing and undressing
- Washing face, brushing teeth, combing hair
- Bathing
- Preparing meals
- Feeding oneself
- Cleaning dishes
- Cleaning the house and the yard
- Toileting
- Washing clothes

- Fetching/drawing water
- Fetching firewood
- Pounding maize
- Taking care of the children
- Repairing things at home especially clothes

1.3 Social Activities

- Having meals together
- Participate in family discussions
- Play with friends in the neighbourhood
- Visit friends in the village/township
- Go to watch village dances
- Participate in ploughing in the field
- Participate in school activities
- Going to the market
- Go to church and participate in religious activities
- Participate village and community activities (dances, watch football, join clubs)

1.4 Home Health Education

- Importance of brushing teeth

- Importance of bathing and keeping body clean (for example; skin, hair, nails)
- Importance of washing clothes
- Washing hands after visiting the toilet
- Toileting habits
- Safe clean water especially for drinking
- Safe storage of food
- Keeping surrounding clean
- Importance of having balanced food especially for children

1.5 Basic Literacy

- Recognizing and knowing time
- Counting skills, reading skills knowing the local currency and ability to use it
- Writing skills (for example; name, numbers, letters)
- Recognizing and knowing objects, items and the environment

1.6 Basic Physiotherapy

- Lifting arms, reaching out
- Gripping, grasping and lifting object
- Standing up and sitting down
- Transfers: wheelchair to chair, chair to bed and vice versa

- Strengthening arm and trunk muscles (lifting objects)
- Balance in sitting and standing
- Strengthening lower limbs (walking)

1.7 Type and use of walking appliances/aids

- Wheelchair
- Crutches
- Bicycle
- Walking stick
- Parallel bars
- Baby walker
- Callipers

1.8 Counselling to PWPD, family and community

- Definition of disability
- Some causes of disability; common within the community (for example; cerebral Malaria, meningitis)
- The importance of the family and the community to the PWPD/PWD
- Religious beliefs and disability
- Cultural norms and disability

- Negative and positive attitudes towards disability
- Sexuality and family life
- Family and community activities (for example; discussions, dances, creative art)

1.9 Rights of PWPD/PWD and Human rights (Equalization of opportunities)

- Right to life
- Right to health, food, clean water, education, training, shelter, clothes, clean environment
- Right to personal integrity and respect
- Right to information about disability, sexuality and family life
- Right of choice to belong to any community grouping
- Right to equal opportunities in every sphere of life
- Right to equal participation in any activity of ones choice without discrimination
- Right to receive support from the family, community and the nation

1.10 Fundraising Activities

- Organisational skills
- Business management skills
- Identification of income generating activities
- Vocational skills training

1.11 Caregiver training and handling of PWP

- Counselling on attitude change (positive caring and supportive family and community)
- Respect for PWP and equal importance
- Recognition of provision of equal opportunities for PWP
- Transfers from bed to chair vice versa
- Preparing meals and feeding
- Keeping clean and clean environment
- Clean drinking water, storage and use
- Toileting
- Self-care needs
- Effective communication (two-way)
- Mobility needs
- Social integration; family and community

1. Training of Community Rehabilitation Workers (CRWs)

- Introduction to the study
- Selection criteria for the study areas of Lusaka urban and Chipata rural CBR programmes
- Aim of the study
- Respect for PWPD and their families and the community
- Uphold human rights for PWPD
- Uphold confidentiality
- Stimulation and promotion of positive attitude towards PWPD/proxy, their families and the community

1.1 Study procedure

- The study procedure was explained to CRWs
- The assessment of participants was done by the researcher, the CRW and the PWPD/proxy during the first interview using the questionnaire. Areas of need were identified during the first assessment for each client by looking at the scores of each section of the questionnaire. Questions which the client responded negatively were considered areas of need.

1.2 Tasks of the CRW

- Prepare a schedule suitable for both himself/herself and the participant/proxy

- Make sure that the schedule is followed, if any changes to the agreed schedule, to be notified to the participant/proxy
- Carry out the rehabilitation modalities agreed upon on each visit to the participant

1.3 Responsibilities of the participant/proxy

- Be available at the time agreed for the visit by the CRW
- If any change to the time of the schedule, to notify the CRW
- Carry out the rehabilitation schedule as agreed with the CRW, participant and the family

APPENDIX 6

Table 6.7: Summary of the percentages of the scores for movement, functional activities, caregiver provision and dependency, integration and perceptions of PWPd as regards to their disability status and experiences

	Lusaka urban			Chipata rural			Combined scores		
	before	after	dif	before	after	dif	before	after	dif
Movement	80	88	8	96	100	4	90	92	2
Functional Activities	42	68	26	86	89	3	64	76	12
Caregiver provision/dependency	68	70	8	88	94	6	80	84	4
Integration	54	78	26	82	90	12	72	84	12
Perceptions	78	90	28	48	62	14	62	76	14

Table 6.5 shows the percentage scores for the responses in the first stage of the analysis data before and after assessment of movement, functional activities, caregiver provision and dependency, integration and perceptions of PWPd as regard their disability status and experiences. All the participants had been on the CBR programme for not less than one (1) year at the time of the study.

APPENDIX 7 (A)

16th November 2000

The Permanent Secretary
Ministry of Health
Ndeke House
Lusaka, Zambia

Dear Sir

**RE: REQUEST TO CONDUCT A SURVEY ON COMMUNITY-BASED
REHABILITATION IN LUSAKA URBAN AND CHIPATA DISTRICTS**

I write to request permission to use the above two districts for research. I am a Zambian Physiotherapist currently undertaking a M.Sc. Medical Sciences (Rehabilitation) degree with the University of Stellenbosch, South Africa. I am a Senior Lecturer in Physiotherapy at Evelyn Hone College.

The objective of the survey is to determine in an urban and rural setting in Zambia, the impact of a CBR intervention strategy aimed at improving functional independence and reintegration to normal living for Persons with Physical Disability. During the research process, I request that you allow me to have access to policy documents and other relevant information that might be needed.

The significance of this study is that the knowledge gained will benefit Zambian physiotherapy students, other physiotherapists the disabled people themselves and their families, and indeed the Zambian community as a whole. A personal follow-up will be made for your response although my contact phone number is 096-754576.

Thanking you in anticipation.

Yours faithfully

Martha Banda-Chalwe

Student number 13060007

JA Hendry (Research Supervisor)

APPENDIX 7 (B)

16th November 2000

The Permanent Secretary
Ministry of Education
Lusaka, Zambia

Dear Sir / Madam

**RE: REQUEST TO CONDUCT A SURVEY ON COMMUNITY-BASED
REHABILITATION IN LUSAKA URBAN AND CHIPATA DISTRICTS**

I write to request permission to use the above two districts for research. I am a Zambian Physiotherapist currently undertaking a M.Sc. Medical Sciences (Rehabilitation) degree with the University of Stellenbosch, South Africa. I am a Senior Lecturer in Physiotherapy at Evelyn Hone College.

The objective my survey is to determine in an urban and rural setting in Zambia, the impact of a CBR intervention strategy aimed at improving functional independence and reintegration to normal living for Persons with Physical Disability. During the research process, I request that you allow me to have access to policy documents and other relevant information that might be needed for the study. It is also to allow me to visit some schools where disabled pupils may be attending.

The significance of this study is that the knowledge gained will benefit Zambian physiotherapy students, other physiotherapists the disabled people themselves, their families, and indeed the Zambian community as a whole. A personal follow-up will be

made for the response and my telephone number is 096-754576 in case you need to contact me.

Thanking you in anticipation

Yours faithfully

Martha Banda-Chalwe

Student number 13060007

JA Hendry (Research Supervisor)

APPENDIX 7 (C)

16th November 2000

The Permanent Secretary
Ministry of Community Development and Social Services
Lusaka, Zambia

Dear Sir / Madam

**RE: REQUEST TO CONDUCT A SURVEY ON COMMUNITY-BASED
REHABILITATION IN LUSAKA URBAN AND CHIPATA DISTRICTS**

I write to request permission to use the above two districts for research. I am a Zambian Physiotherapist currently undertaking a M.Sc. Medical Sciences (Rehabilitation) degree with the University of Stellenbosch, South Africa. I am a Senior Lecturer in Physiotherapy at Evelyn Hone College.

The objective of my survey is to determine in an urban and rural setting in Zambia, the impact of a CBR intervention strategy aimed at improving functional independence and reintegration to normal living for Persons with Physical Disability. During the research process, I request that you allow me to have access to policy documents and other relevant information that might be needed.

The significance of this study is that the knowledge gained will benefit Zambian physiotherapy students, other physiotherapists the disabled people themselves and their families, and indeed the Zambian community as a whole. A personal follow-up

will be made for the response and my telephone number is 096-754576 in case you need to contact me.

Thanking you in anticipation.

Yours faithfully

Martha Banda-Chalwe
Student number 13060007

JA Hendry (Research Supervisor)

APPENDIX 7 (D)

16th November 2000

The CBR Manager
Lusaka CBR Programme
Lusaka, Zambia

Dear Madam

RE: REQUEST TO USE YOUR PROGRAMME FOR RESEARCH

I write to request permission to use your CBR programme for the purpose of conducting research.

I am a Zambian Physiotherapist currently undertaking a M.Sc. Medical Sciences (Rehabilitation) degree with the University of Stellenbosch, South Africa.

The objective of my survey is to determine in an urban and rural setting in Zambia, the impact of a CBR intervention strategy aimed at improving functional independence and reintegration to normal living for Persons with Physical Disabilities. During the study, I wish to request that access to clients' records and other relevant documents pertaining to the programme are made available to me as the need arises.

A personal follow-up will be made for the response and my telephone number is 096-754576 in case you need to contact me.

Thanking you in anticipation

Yours faithfully

Martha Banda-Chalwe

Student number – 13060007

JA Hendry (Research Supervisor)

APPENDIX 7 (E)

16th November 2000

The CBR Coordinator
Chipata CBR Programme
Eastern Province, Zambia

Dear Sir / Madam

RE: REQUEST TO USE YOUR PROGRAMME FOR RESEARCH

I write to request permission to use your CBR programme for the purpose of conducting research.

I am a Zambian Physiotherapist currently undertaking a M.Sc. Medical Sciences (Rehabilitation) degree with the University of Stellenbosch, South Africa.

The objective of my survey is to determine in an urban and rural setting in Zambia, the impact of a CBR intervention strategy aimed at improving functional independence and reintegration to normal living for Persons with Physical Disabilities. During the study, I wish to request that access to clients' records and other relevant documents pertaining to the programme are made available to me as the need arises.

A personal follow-up will be made for the response, and my telephone number is 096-754576 in case you need to contact me.

Thanking you in anticipation

Yours faithfully

Martha Banda-Chalwe

Student number – 13060007

JA Hendry (Research Supervisor)

APPENDIX 7 (F)

16th November 2000

The Director General
The Zambia Agency for Persons with Disabilities
Lusaka, Zambia

Dear Sir

**RE: REQUEST TO CONDUCT A SURVEY ON COMMUNITY-BASED
REHABILITATION IN LUSAKA URBAN AND CHIPATA DISTRICTS**

I write to request permission to use the above two districts for research. I am a
Zambian Physiotherapist currently undertaking a M.Sc. Medical Sciences
(Rehabilitation) degree with the University of Stellenbosch, South Africa. I am a Senior
Lecturer in Physiotherapy at Evelyn Hone College.

The objective of my survey is to determine in an urban and rural setting in Zambia, the
impact of a CBR intervention strategy aimed at improving functional independence and
reintegration to normal living for Persons with Physical Disability. During the research
process, I request to allow me to have access to policy documents and other relevant
information that might be needed.

The significance of this study is that the knowledge gained will benefit Zambian
physiotherapy students, other physiotherapists, the disabled people themselves and
their families, and indeed the Zambian community as a whole. A personal contact will

be made for the response and my telephone number is 096-754576 in case you need to contact me.

Thanking you in anticipation

Yours faithfully

Martha Banda-Chalwe
Student number 13060007

JA Hendry (Research Supervisor)

APPENDIX 7 (G)

16th November 2000

The District Director of Health
Lusaka Urban District Health Management Team
Lusaka, Zambia

Dear Sir / Madam

**RE: REQUEST TO CONDUCT A SURVEY ON COMMUNITY-BASED
REHABILITATION IN LUSAKA URBAN AND CHIPATA DISTRICTS**

I write to request permission to use the above two districts for research. I am a
Zambian Physiotherapist currently undertaking a M.Sc. Medical Sciences
(Rehabilitation) degree with the University of Stellenbosch, South Africa. I am a Senior
Lecturer in Physiotherapy at Evelyn Hone College.

The objective of my survey is to determine in an urban and rural setting in Zambia, the
impact of a CBR intervention strategy aimed at improving functional independence and
reintegration to normal living for Persons with Physical Disability. During the research
process, I request that you allow me to have access to policy documents and other
relevant information which might be needed.

The significance of this study is that the knowledge gained will benefit Zambian
physiotherapy students, other physiotherapists the disabled students themselves their

families, and indeed the Zambian community as a whole. A personal follow-up will be made and my telephone number is 096-764575 in case you need to contact me.

Thanking you in anticipation

Yours faithfully

Martha Banda-Chalwe

Student number 13060007

JA Hendry (Research Supervisor)

APPENDIX 7 (H)

16th November 2000

The District Director of Health
Chipata District Health Management Team
Chipata, Zambia

Dear Sir / Madam

**RE: REQUEST TO CONDUCT A SURVEY ON COMMUNITY-BASED
REHABILITATION IN LUSAKA URBAN AND CHIPATA DISTRICTS**

I write to request permission to use the above two districts for research. I am a Zambian Physiotherapist currently undertaking a M.Sc. Medical Sciences (Rehabilitation) degree with the University of Stellenbosch, South Africa. I am a Senior Lecturer in Physiotherapy at Evelyn Hone College.

The objective of my survey is to determine in an urban and rural setting in Zambia, the impact of a CBR intervention strategy aimed at improving functional independence and reintegration to normal living for Persons with Physical Disability. During the research process, I request you to allow me to have access to policy documents and other relevant information that might be needed.

The significance of this study is that the knowledge gained will benefit Zambian physiotherapy students, other physiotherapists, the disabled people themselves and their families, and indeed the Zambian community as a whole.

A personal follow-up will be made for the response and my telephone number is 096-754576 in case you need to contact me.

Thanking you in anticipation

Yours faithfully

Martha Banda-Chalwe

Student number 13060007

JA Hendry (Research Supervisor)