Integration of adult persons with disabilities into the workforce of developing rural villages in South Africa.

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Summary

The researcher was invited by the CSIR (formerly known as the Council for Industrial and Scientific Research in South Africa) to investigate the work opportunities for persons with disabilities (PWD) in a rural area in the Eastern Cape in which they were planning to implement their Integrated Rural Development Project (IRDP). The community development committee had requested assistance with the plight of the unemployed PWD in their community.

The aim of the study was to investigate work opportunities for PWD in rural developing communities. The study allowed the researcher to also explore possible means to maximise current services to reach into areas that are underserved in terms of professional rehabilitation services.

A participatory research approach was used for the study in which the research team consisted of the author, members from the community development committee including the sister in charge of the community clinic and three research assistants from the community.

In a two-phase disability survey in the 475 household of the area, adults with disabilities in the working age group were identified and their abilities assessed. Five development projects from nearby communities, similar to projects planned by the community were analysed. A scale had been developed that would allow a direct comparison between the abilities of the PWD and the work abilities required for the projects. The data were plotted on a spiral graphic, the Work Abilities Web (WAW), to illustrate compatibility and components for which adaptations might be needed. Taking the PWDs' level of motivation and aspirations into account job matches were made. The intellectual process of making such matches was investigated and described.

Because of a lower disability prevalence found in the area than expected from international projections the data were presented as 12 case studies.

In the feedback to the community three scenarios were provided for the employment of PWD in their midst for implementation by the community. A committee of PWD was established, which would have representation on the development committee to drive the process and to ensure that disability issues would be considered in all future community planning.

The study contributes the following innovations to the knowledge base of health and social sciences theory, in terms of disability and development issues:

■ A refinement of a participatory research model, the Mutual Benefit Research model (MBR), for research projects with communities.

■ A functional assessment format, developed for possible use by community health workers.

■ The recording and comparison method used for the WAW.

■ An analysis of the job match process used by occupational therapists in vocational rehabilitation.

In conclusion the study and the results were critically evaluated and recommendations made for the integration of PWD into the workplace in rural communities, as well as for further investigation into the methods proposed for vocational rehabilitation in underserved areas.

Key words: Employment equity, vocational rehabilitation, adults with disabilities, development projects, income generating projects, rural communities, integration of persons with disabilities, poverty alleviation, participatory research.

Acknowledgements

1 Definitions

1.1 Rural

A non-urban area whose inhabitants do not have adequate access to all the necessary services required for health, education, work and communication. (Reference page 7)

1.2 Sustainable development

"Sustainable development is positive change which does not undermine the environmental or social systems on which we depend. It requires a coordinated approach to planning and policy making that involves public participation. Its success depends on widespread understanding of the critical relationship between people and their environment and the will to make necessary changes"[25]

1.3 Person with disability

A person who experiences long-term activity limitations, which prevent him/her from performing activities successfully and safely.

1.4 Occupational performance context

Performance contexts are the temporal and environmental factors that influence an individual's engagement in desired or acquired activities or daily living, work and leisure.[130]

1.5 Occupational performance areas

Occupational performance areas are activities of daily living, work and productive activity, and play and leisure activities.[130]

1.6 Occupational performance components

Occupational performance components are sensorimotor, cognitive, psychosocial and psychological skills used to engage in daily activities. [130]

2 Abbreviations used in the thesis

CBR   Community-based rehabilitation

CHW   Community Health Worker

CRW   Community Rehabilitation Worker

CSIR   Formerly known as the Council for Industrial and Scientific
                Research in South Africa now used as in its abbreviated form

DALYs   Disability-Adjusted Life Years

DART   Disability Action Research Team

DEAFSA   Deaf Federation of South Africa

DPI   Disabled People International

DPSA   Disabled People South Africa

DPO   Disabled People's Organisation

FIM   Functional Independence Measure

GEAR   Growth, Employment and Redistribution Strategy

ICD   International Classification of Disease

ICF   International Classification of Functioning, Disability and Health

ICIDH   International Classification of Impairment, Disability and
                Handicap

ILO   International Labour Organisation

INDS   Integrated National Disability Strategy

IRDM   Integrated Rural Development Model

IRDP   Integrated Rural Development Project

MBR   Mutual Benefit Model

LDDF   Lubisi Dam Development Forum

MET   Metabolic Equivalents

NCPPDSA   National Council for Persons with Physical Disabilities of South Africa

NGO   Non-governmental organisation

OAU   Organisation of African Unity

PHC   Primary Health Care

PWD   Persons with Disabilities

RDP   Reconstruction and Development Programme

SAFCD   South African Federal Council on Disability

SAFMH   South African Federation for Mental Health

SANCB   South African National Council for the Blind

SANEL   South African National Epilepsy League (now Epilepsy SA)

SMME   Small, Medium & Micro Enterprises

TDC   Tsilitwa Development Committee

UN   United Nations

UP   University of Pretoria

UPIAS	Union of the Physically Impaired against Segregation
WAW	Work Abilities Web
WPA	World Programme of Action concerning Disabled Persons
WHO	World Health Organisation
WPA	World Programme of Action Concerning Disabled Persons
YLD	Years Lived with a Disability

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Background to the study

"Think globally, act locally." - *Anonymous*

Global trends

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- **Perspectives on local rural development**
- **Eastern Cape**
- **Socio-economic background**
- **Cultural heritage**

Local Project

- **Integrated Rural Development Model**
- **Tsilitwa**

Research question

1.1 Introduction

Globalisation and localisation – the integration of the world and the increasing demand for local autonomy – are two of the most important forces shaping development as we enter the 21st century.[1]

The World Bank, whose dream for the future is a world free of poverty, in their World Development Report for 1999/2000 explores new directions in development thinking. The two seemingly opposing forces, of globalisation and localisation, will both have to be brought into play to contain the growing disparity between the established and the developing countries.

The development efforts in underprivileged communities appear to be racing against time to catch up with the technological and economical advances that are on the one hand linking people of the world, whilst on the other hand the people who are not able to participate in this brotherhood are left out and in danger of sinking further into oblivion. Priorities and viewpoints created by the different circumstances prevailing in established and developing countries make the task of bridging the gap between them a daunting, complex undertaking.

In his budget speech for the year 2000 the Minister of Finance of the Republic of South Africa offered a more positive view on how these forces can be harnessed for development in the South African context.

"Our vision and our commitment are clear, to build a better life for all our people. This is our course. Sustainable growth and development call for on-going structural transformation of our economy so that we can take advantage of the *untapped potential in our midst* and the *opportunities presented by globalisation.*"[2]

The fact that such a viewpoint is accepted, even expected in current economic planning can largely be ascribed to continued pressure from environmental movements during the second half of the 20th century. The United Nations (UN) Conference on Environment and Development, the Earth Summit 1992, which provided the impetus for the establishment of environmental departments in governments and universities all over the world was held on the 20th anniversary of the Stockholm Conference on the Human Environment. Since the Stockholm Conference a variety of environmental agreements were concluded and the 1992 Earth Summit in Rio de Janeiro gave further momentum and direction to these efforts.

Agenda 21 of the Earth Summit called for environmental costs to be factored into every economic decision and that development and growth be measured in terms of improved human welfare and sustainable use of resources, not only in an increase of the gross national product.

The South African economy, which until recently has been exploiting the country's resources for the development of wealth, does not have the mechanisms in place for the implementation of the recommendations advocated in Rio.[3]

In South Africa, responsibility for the implementation of Agenda 21 was assigned to the decision-making structure of the National Department of Environmental Affairs and Tourism.

The Rio Earth Summit's Local Agenda 21, developed in 1992 to foster sustainable development activities at local level, has led to programmes being run from Cape Town, Johannesburg and Durban.

The South African Status Report on Implementation of Agenda 21: Review of Progress made since the UN Conference on Environment and Development 1992, declares a commitment to a bottom-up approach with a focus on people participation, which would promote conservation awareness, capacity building and rural development.[4]

Local Agenda 21 is the programme developed at the Rio Earth Summit in 1992 to foster sustainable development activities at local level. Local Government should be the chief provider of environmental services. Because of the present weak state of local government in South Africa, this challenge has not been taken up at the level where it should be implemented. There are however countless development programmes all over the country based on principles originating from the Rio Summit. The effectiveness of these programmes could be greatly increased if national and local policies were finalised and implemented in such a way that various efforts could be co-ordinated to obtain equitable access to the funds and expertise available for sustainable development.[5]

One of government's priorities is the upliftment of the poor, which in South Africa constitutes the greatest part of the population. Because of Apartheid policies of the past and the resulting lack of development in tribal areas, combating poverty in the rural areas is one of the first concerns of government. The focus of this dissertation is therefore on rural development.

To understand the rationale of *sustainable rural development* it is necessary to define and explore the various components of sustainable development, which often seems be used more as a slogan than a serious intention.

1.2 Rural Development

1.2.1 Definition of rural

According to the Oxford Dictionary, rural suggests pastoral or even agricultural settings.[6]

Conventionally the description rural applied to farmland as opposed to cities or towns. Low-density human population is implied, as opposed to wilderness. As the global population increased and cities and towns expanded, their peripheries were more commonly referred to as peri-urban. A further differentiation is made in describing small centres in rural areas as villages as opposed to small towns, implying that their existence is directly linked to the provision of agricultural services and commodities rather than being commercial and industrial growth points.[7]

These descriptions of the terms rural and human settlement in rural areas are, however, vague and in recent years strategists and developers from various backgrounds have been searching for an operational definition that describes the term rural more accurately for their purpose.

Such attempts have resulted in descriptions of rural, as for instance any area that is not classified as urban,[8] followed by a list of indicators of what constitutes rural for that specific purpose.

Reduced to basics the indicators from the various sources [9,10,11] can be summed up as:

- ■ Size of population or population density,

- ■ Distance from urban or metropolitan areas, and

■ Services available or access to emergency services.

In South Africa, as in other developing countries, these indicators are used in the process of developing an operational definition, specified for local circumstances and purposes.

The three indicators therefore are discussed briefly to determine a working definition for the purpose of this dissertation.

1.2.1.1 Size of population or population density

In South Africa the so-called Betterment Scheme of the 1960s, and its predecessors, starting in the 1940s, added a further dimension to human settlement, discussed under **1.2.1**.[12,13] This scheme resulted in the concentration of formerly dispersed farming families in rural villages. The outcome in effect was villages without any development focus (agricultural or industrial). These villages have the appearance of an urban sprawl and often are more densely populated than small towns.

The homeland policy of the Apartheid era allotted tracts of land to specific ethnic groups thereby concentrating large groups of people into specifically zoned areas.[14] The rapid population growth in most of those groups has further increased the population density in these areas. As parts of the designated tracts are inhospitable and remote, the more hospitable parts have tended to become most densely populated.

Migration of workers for the mines or other job markets has reduced the male non-urban population group and created areas populated by women, children and the aged or frail.[15]

Livelihoods in rural areas worldwide have become increasingly unsustainable because of deterioration of land, poverty and lack of services resulting in large-scale urbanisation and depopulation of some regions.[16]

South African rural communities reside in villages or in less densely populated areas of housing clusters, depending on the terrain and the style dictated by traditional rule.

Conclusion: Population density in South African non-urban areas varies greatly and no official guidelines exist at present for this indicator. Although population density should be factored into the development of an official definition it cannot be decided on without extensive surveys and consultations and will therefore not be described in the working definition.

1.2.1.2 Distance from urban or metropolitan areas

The infrastructure in most of the previous homelands is under-developed and weak, and the road and transport network poor.[13] This means that the distance from the nearest urban area does not necessarily reflect time, money or effort needed to commute there for work, education or services.

Conclusion: In the author's opinion the distance from an urban area in the previous homelands cannot be compared to distances from urban areas in other parts of the country or the world. International standards are therefore not applicable. The condition of the roads to be travelled will be taken into account as a factor in the deliberation of accessibility of services (**1.2.1.4**). This indicator will thus not be mentioned separately in the definition.

1.2.1.3 Services available or access to emergency services

In South African non-urban areas the lack of adequate services continues to impede development. A far greater percentage of the population falls in the rural category than distance would suggest, because of the difficulties entailed in reaching available services, in particular emergency services. The limited opportunities for education and work compound these problems and result in economic vulnerability and social exclusion.

Conclusion: This indicator encompasses the number of people who have to share services and the accessibility of these services as factors of accessibility and is therefore suitable for a short working definition of the term rural in the South African context.

The definition that will be used for the term rural area in this dissertation is:

> A non-urban area without a development focus and inadequate access to all the necessary services required for health, education, work and communication.

1.2.2 Definition of Development

According to the Oxford Dictionary[6], development means to unfold or realise potentialities. Other terms used to describe development in dictionaries are nourishing, evolving and promoting growth.

From these descriptions of development it becomes clear that development of communities has brought humankind to its present level of evolution and that development will take place as long as there is potential for further evolution.

Rural development could thus be defined as promoting the growth of the potential within a non-urban area. If this were to take place without external input in terms of infrastructure and services, the gap between these areas and the established world would expand because of the ever-increasing pace of technological development. One of the strategies for the promotion of growth is therefore to generate a development focus and accelerate the rate of natural development. This process requires input in the form of finances, infrastructure and manpower.

Past models of development were based on modernisation and underdevelopment theories. Although development was ostensibly aimed at narrowing the gap between the established and the "developing" countries or between various regions within a country, these efforts resulted in dependency (on input from outside) and exploitation (of human and environmental resources) which threatened the effective functioning and reproductive viability of both the human as well as the natural systems.[17]

The various participants in the development process perceived development aid poured into underdeveloped countries or areas, differently. Critics on the donor side felt that it was taken for granted, delivered erratic results and was a never ending one-way drain of finances and manpower. The recipients on the other hand often felt that their needs were not addressed in order of priority, they were not consulted and on completion of the project were often left abandoned without the means (knowledge, skills, finances) to maintain the new initiative.

Growing criticism of rural development strategies primarily aimed at technical transfers to boost production and generate wealth, resulted in minor adjustments to conventional approaches. The basic shortcoming in the conventional approach was, and unfortunately often still is, that the rural inhabitants are rarely consulted in development planning and often have no active role in development activities.

In answer to this problem the concept of people's participation was developed in the mid-seventies. At the 1979 World Conference on Agrarian Reform and Rural Development the international community recognised this formally and declared the participation by rural people in the institutions that govern their lives a basic human right.[18]

Rural development efforts, however, continued to fail. A 1997 World Bank evaluation found that half of the rural development projects funded by the World Bank in Africa were outright failures.[18] Gradually, development ideologies, endeavouring to reduce dependency and foster ownership began focusing on participative, negotiated premises. Such changes came about because of concerns about the cost of development and the often passive roles of the communities involved in the development process. Good intentions and economic input were often misplaced or poorly coordinated. A needs-driven, bottom-up approach would come in at the correct level with local support and would promote and evolve the potential within the community at a pace the community could maintain.[16]

Even so, securing the long-term participation of the people involved did not as such ensure sustainability of development projects. This fact as well as growing concern about environment issues and poverty all over the world led to the conceptualisation of sustainable development and recommendations for the adoption of sustainable principles worldwide.

Conclusion: The evolvement of development theories is influenced by global experiences and the changing situations in the areas being developed. The experience of occupational therapists, based on their involvement in the development of community based services, has convinced them of the importance of a community driven, participative approach in which role-players from various disciplines are drawn into the process according to the priorities of communities.

For the purpose of this dissertation development is defined as:

collaborative efforts to promote growth.

1.3 Sustainability

The circumstances and concerns that formed the background against which the concept of sustainable development was formed, can be summed up as changes in the world situation and man's ability to sustain or irretrievably damage the global environment. Sustainable development can thus be seen as a reaction to the consequences of earlier attempts to achieve economic growth and development.[19]

The various ideologies that are brought together by the concerns for human rights, economic development and responsible utilization of resources, are based on different theories and propose different ways to achieve solutions. This is the dilemma at the heart of the confusion about definitions, indicators and implementation processes. The theory of sustainable development brings

together two strands of thought – one concentrating on development and the other on limiting the harmful impact of human activity on nature.

1.3.1 Concept of Sustainability

Sustainable development is about the relations between human beings and their natural environment including animals, and between present and future generations.[20]

The concept of sustainable development embraces the following issues[19,21]:

■ Poverty,

■ The growth and distribution of population in relation to resources,

■ Over-exploitation of resources,

■ Excessive consumption,

■ Degradation of land, air and water,

■ Urbanisation and industrialisation,

■ The diversity of species,

■ Basic human rights and needs,

■ Employment and income security, and

■ Unequal distribution of resources and wealth between countries and individuals.

These issues can be grouped into the following categories:

■ Environmental issues: – concerned with the protection of living environments, work environments and the natural resources on a local and global level.

■ Political issues: – about human rights and the prevention of exploitation and inequality.

■ Economic issues: – concerned with the end of poverty and secure income in the present and the future.

■ Social issues: – focused on secure livelihoods.[20]

1.3.2 Definition of Sustainable Development

Webster's New International Dictionary defines the term sustain as follows:

"– to cause, to continue, to keep up, especially without interruption diminution, to prolong."[22]

The many definitions that have been formulated for sustainable development all have to do with:

■ Living within the limits,

■ Understanding the interconnectedness of economy, society and environment, and

■ Equitable distribution of resources and opportunities.[23]

The best-known and most widely used definition is that of the Brundtland Commission (World Commission on Environment and Development, 1987) which defines sustainable development as:

"Development that meets the need of the present without compromising the ability of future generations to meet their own needs."

This definition accentuates human needs and implies that natural systems should be conserved for the maintenance of human needs. A more mutually beneficial attitude is reflected in the definition put forward by the World Wide Fund for Nature in 1991.

"Improving the quality of life within the carrying capacity of supporting ecosystems."

By focusing on quality of life the emphasis shifts from a material to a holistic view of life: sustainable livelihood, which includes cultural, social,

environmental and spiritual dimensions. To improve well-being for individuals or communities some definitions are more service orientated, e.g. the definition formulated by the International Council for Local Environmental Initiatives, responsible for the promotion of Agenda 21 (1996):

"Development that delivers basic environmental, economic and social services to all without threatening the viability of the natural, built and social systems upon which these services depend.[1]

Apart form the differences in definitions because of the evolution of the concept, definitions have been formulated for different situations and purposes, e.g. sustainable community and society, sustainable business and production or sustainable agriculture.

Sustainability requires an integrated view and approach and therefore also multi-dimensional indicators to measure and monitor successes and problem areas.

Indicators are as varied as the systems they monitor, however, effective indicators have certain characteristics in common. Effective indicators are:

■ Relevant – measuring appropriate outcomes for the system,

■ Easy to understand – yielding information for all involved not only the experts,

■ Reliable – giving the same measurement under varying conditions,

■ Based on current, accessible data – allowing for action while there is still time to act.[16]

Indicators of sustainability are different from traditional indicators of progress. Traditional indicators focus attention on traditional solutions which created the unsustainable community in the first place. To ensure that the development will be sustainable it is vital to set indicators that will alert one to problems while there is enough time to find solutions.[24]

■ Environmental indicators of development: – protection of resources with emphasis on biodiversity; urbanisation and the strain this puts on the environment; waste management and the need to control pollution; *working* and living environment.

■ Political development: – political rights, e.g. to live, speak and move about freely; democracy is a strong recurring theme with special attention to *freedom of choice and freedom of discrimination*.

■ Economic development and security: – an end to poverty so that at least the basic needs of all can be met; secure income by *freely-chosen employment* or protection for those who are unable to work.

■ Social development: – food, housing, water, healthcare, energy and transport are the needs to be met for secure livelihoods, good health and *quality of life*; poverty is the major factor in social development, which can only be overcome by sustainable employment and good working conditions.

■ Equality of opportunity and treatment: – ensuring an *active role for all members of the community*, in recognition of the importance of promoting opportunities for *groups with special needs*.

■ Education and training: – basic *education for all*; opportunities to develop skills, *vocational training*.

■ International development: – key issues include distribution of resources and wealth; respect of national sovereignty; fair trade; international co-operation; *international standards*.

(*Emphasis* added to highlight issues of importance in this study)

Sustainable development, sustainable livelihoods, sustainable communities or villages are all concerned with the quality of life in a community. The review of

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sustainable indicators demonstrates the interconnectedness of economic, social and environmental systems in the development of a healthy, productive, meaningful life for all community residents, at present and in the future. The figure below is frequently used to show the connections.[23]
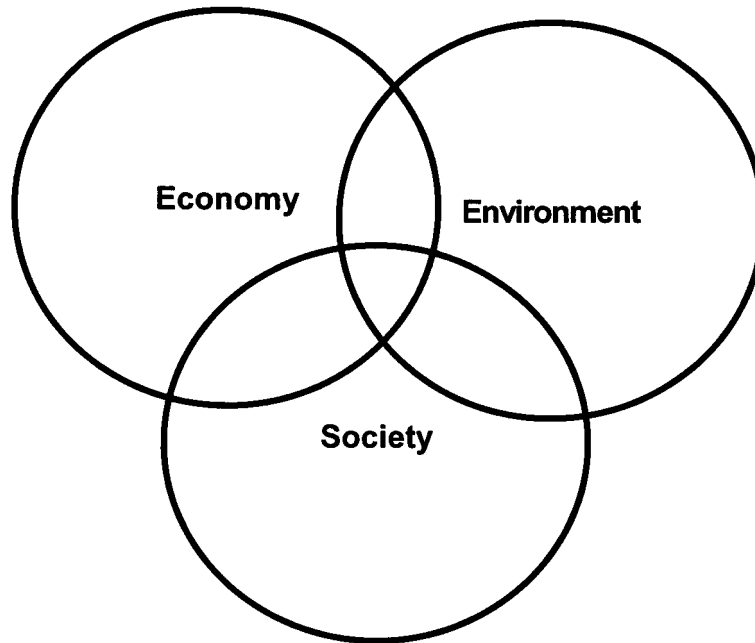
Figure 1.1 Interconnectedness of communal systems

An overriding factor in the progress of sustainable development is the political intent of the government, which influences both the society and the economics of the time.

A more appropriate illustration of a sustainable community by Hart[23] is three concentric circles: the economy exists within the society and both exist within the environment.
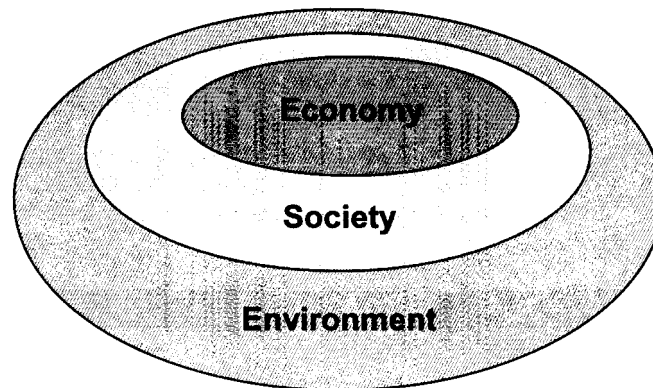
Figure 1.2 Illustration of a sustainable community (Hart Environmental Data)

The economy exists entirely within society because all parts of human economy require interaction among people. Apart from economic activities, society includes many more important elements, e.g. personal relationships, culture, religion and a community's ethics. Society exists entirely within its environment.

In the past the environment largely determined the shape of the society. Today, human activity is re-shaping the environment at an ever-increasing rate. The purpose of sustainable development is therefore to ensure that the reshaping is done responsibly so that the quality of life of future generations is secured.

An operational definition should not only describe the concept according to the latest accepted theory, but should contain all the elements the developers plan to incorporate into the project.

The definition for sustainable development that will be used in this dissertation is the definition compiled by the Hamilton Wentworth Regional Council in Canada. This definition reflects the global recognition of a holistic strategic approach to poverty alleviation, which includes the biophysical, biological, socio-economical and social dimensions of sustainable development.

"Sustainable development is positive change which does not undermine the environmental or social systems on which we depend. It requires a co-ordinated approach to planning and policy making that involves public participation. Its success depends on widespread understanding of the critical relationship between people and their environment and the will to make necessary changes."[25]

The two simultaneous and interactive forces of increased intrusion of the world economy and the social and cultural processes of local communities could lead to increasingly clear solutions to an array of global problems if co-ordinated contributions from governments reach from local to global level.[26]

For such an interchange, local people and their local government need to be actively involved in improving their situation, know what their own development goals are and how they fit into the global picture.

1.4 South African situation

The concept of sustainable development is relatively new to policy discourse in South Africa. It has, however, been accepted and formally adopted in key policy documents.[14]

1.4.1 Perspectives on local rural development

The history of rural development in South Africa has followed the ideological development of the global concept. The implementation of development ideals was carried out by various agents, mostly non-government organisations (NGOs) in an unco-ordinated manner and is marked more by terminations of projects than by successes.

The roots of South African rural development lie in the colonial era, and the various political regimes that followed each affected the implementation of programmes by their policies and budgets. The result of their collective course of action, and particularly the effects of the Apartheid policy, are that the rural

population at present constitutes the country's most under-educated, under-serviced poor.[12,13]

As described in **1.2.1**, most South African rural communities reside in villages or in housing clusters. These clusters and villages constitute ideal starting points for development programmes because of the concentration of people in the area.

Vilakazi[27] expounds this approach in his argument that the African village was and still is the basic cell of African society. He proposes therefore that to move Africa forward, the relationship between the African village and the modern African city must be restructured. He observes that the starting point for development strategies is the city, in the hope that it will trickle down to the countryside. According to Key Indicators of Poverty in South Africa, a Reconstruction and Development Programme (RDP) document published in 1995, 75% of South Africa's poor live in rural areas. Vilakazi therefore declares that "the greatest, most crucial and most poisonous development backlog in the economy and social life of our current society is the extreme poverty and lack of development of African and coloured communities in rural areas.[28]

1.4.2 Policies and strategies

1.4.2.1 The Constitution of South Africa

The country's new Constitution, adopted in 1996, decrees the right to an environment that is not harmful to people's health and well-being and promotes conservation and sustainable development as measures to achieve this right.[14]

The Constitution enshrines the rights of all people in the country to dignity, equality, freedom and security. The Constitution commits government to take reasonable measures to ensure that all South African citizens have access to adequate housing, health care, education, food, water and social security (Act 108 of 1996).

There have been various forms of governance in South African rural areas in recent history. Remnants of systems developed in the independent homelands, traditional authorities, civic councils and regional councils are in the process of transforming into the three-tier national, provincial and local system, where local government will be based on municipalities according to the criteria provided in Act 27 of 1998.[29]

Since local government is expected to implement development policies, it is necessary to briefly investigate the state of local government in South Africa.

In terms of the Constitution of South Africa, local government has certain powers and functions (subject to national or provincial legislation) and can participate in the law making and budgeting processes at national level.[30]

The White Paper on Local Government, published in March 1998, is a broad statement of government policy, which will lay the basis of the framework for the new local government structures. Its purpose is to direct actions toward better quality services and more accountable local government to all South African citizens.

Section B of the White Paper outlines developmental local government, specifically the central responsibility of municipalities to work together with their local communities to find sustainable ways to satisfy their needs and improve the quality of their lives.

Developmental local government is intended to have a major impact on the daily lives of South Africans. It is set to play a central future role in representing South African communities, protecting their human rights and meeting their basic needs. It must focus its efforts and resources on improving the quality of life of all communities, especially marginalized groups, such as women, persons with disabilities (PWD) and the very poor.

1.4.2.2 White Paper on Local Government

Relevant issues from the White Paper[31] are summarised below to facilitate an understanding of the vision of the transformed local government system and it's role in delivery of the above commitment by government:

Characteristics of developmental local government

■ Maximising social development and economic growth

The powers and functions of local government should be exercised in a way that has maximum impact on the social development and economic growth of its inhabitants.

Local government is not directly responsible for creating jobs, but for taking active steps to ensure that overall economic and social conditions locally are conducive to the creation of employment opportunities. Empowerment of marginalized groups is a critical contribution of local government, e.g. facilitating independence for PWD by removing environmental barriers, or establishing support services for small business and community development.

■ Integrating and co-ordinating

Within any local area many different agencies contribute toward development, e.g. national and provincial departments, community groups, trade unions and private-sector institutions. Developmental local government must provide a vision and leadership for the role-players in development in their area as the establishment of sustainable livelihoods depends on the co-ordination of a range of services and regulations, e.g. land-use planning, environmental management, transport, housing, health, education, safety and security.

■ Democratising development, empowerment and redistribution:

> Local government's role goes beyond regulating citizens' actions; it should include leadership, encouragement, practical support and resources for community action. Local government should develop structures for participatory processes and seek the participation of marginalized groups.

> A central principle of the RDP[14] is the empowerment of poor and marginalized groups. This position is endorsed in the Growth, Employment and Redistribution (GEAR) strategy, which calls for "a redistribution of income and opportunities in favour of the poor".

■ Leading and learning:

> Extremely rapid changes at global, regional, national and local levels are forcing local communities to reassess their positions within the greater picture. All communities are searching for ways to sustain their communities or develop sustainable livelihoods. Local government has a key role to play as an institution of local democracy to ensure that its vision and actions reach all the citizens in its area.

Developmental outcomes of local government

Citizens and communities are concerned about their living environment. Local government's responsibilities include the full range of services and opportunities that will meet their basic needs. The key outcomes local government should aspire to are:

■ Provision of household infrastructure and services,

■ Creation of liveable integrated cities, towns and rural areas,

■ Local economic development, and

■ Community empowerment and redistribution.

All outcomes need to be seen within the context of national development and the principles and values of social justice, gender and racial equity, nation building and the protection and regeneration of the environment.

The National Development and Planning Commission, in its findings[32] described the current lack of vision, co-ordination and planning on local government level. Despite the fact that the Constitution and the Development Facilitation Act have set a broad, common direction forward, the provinces have not followed through with implementation.

Once these policies are implemented, it is expected that the recommended approaches will deliver a co-ordinated, goal specific, nation-wide development. To understand the circumstances under which development work is carried out at present it is necessary to investigate the specific area in which it is planned and implemented, because of the varying conditions that currently prevail in rural areas.

1.4.2.3 Green Paper on Development and Planning

The principles of the Green Paper are designed to bring about "radical changes to the low-density, sprawling, fragmented and largely mono-functional forms of development, which resulted under Apartheid in both urban and rural areas"[33]. The principles require a harmonious relationship between settlements and the natural environment and emphasise the importance of environmental sustainability. The policy promotes security of tenure, the use of land development to promote human development, the importance of public participation and conflict resolution.

1.5 Eastern Cape Province

The province in which the researcher was invited to participate in a development project is the Eastern Cape. Therefore, the following section will focus on this province in order to sketch the background to the development project.

The Eastern Cape Province comprises areas of the former Ciskei, Transkei and parts of the Cape Province, thereby unifying underdeveloped, densely populated, rural areas with well serviced urban and commercially farmed areas.
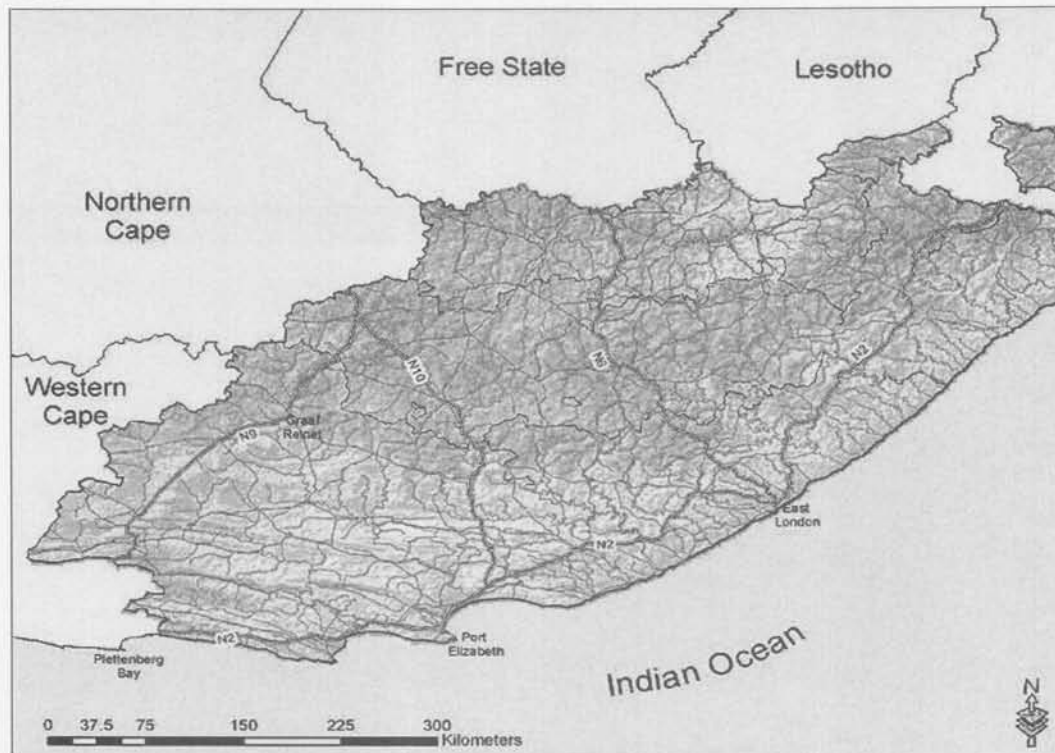
Figure 1.3 Eastern Cape

It is the second largest province of the Republic of South Africa and covers 13,6% of the total land surface of the country. The province experiences a high rate of unemployment. Additional indicators such as dependency ratio, illiteracy levels and size of the potentially economically active population, underline the plight of the general population and explain why it is South Africa's poorest province.

The total population of the Eastern Cape Province is considered to be 6.3 million[34], of which 44% are under the age of 15 and with a marked predominance of women in the age group above 15years.[35]

Eighty-eight percent of the population are black Africans and the principle language of 83.8% of the citizens is Xhosa.

1.5.1 Economic background

Urbanisation and population density vary greatly between the various regions. Only 9,1% of the total population of the former Transkei homeland was functionally urbanised in 1994.[15] The functional urbanisation rate for the rest of the then newly formed Eastern Cape Province was calculated at 85.9%, the highest in the country. These figures clearly indicate the people of the province regard the urban centres as more attractive sources of employment than rural areas, generally characterised by features such as high unemployment, low levels of remuneration and recurring droughts. The spatial distribution of the population is in fact in line with the distribution of economic activity, with clustering prevalent around the main centres. The main income sources are the formal and informal sector, pensions, other social transfers, remittances and unreliable marginal-sector income. In the rural areas people are reliant on the social pensions and marginal-sector incomes, with some income from the formal sector where a family member is employed as a migrant worker outside the area.

However, because the province is to a large extent underdeveloped and neglected, it has a high potential for growth and development.

1.5.2 Cultural heritage

1.5.2.1 Religion

Christianity has influenced the way of thinking over the last few centuries. Other religions like Islam and Buddhism have not reached the general population in rural South African communities. In spite of these more evident religious practices, the connections to African Traditional Religion are still maintained by many. Religion in Africa is not treated as an isolated entity; it permeates all sections of life of both the individual and society. There is no distinction between believers and non-believers since everybody is born into the religion.

Religious beliefs and practices are believed to have originated from the spiritual world and are handed down by word of mouth and through the ancestors who act as go-betweens between the creator and the living.

Amasiko (rituals) are communal religious practices for special purposes like thanksgiving, rites of passage, appeasement, divination or special needs on request by the ancestors. Rituals revive the ancestors and therefore the relationship between the spiritual and the physical worlds. The community then acts out the various forms of worship whereby unity and healing are achieved.[36]

1.5.2.2 Social structures and customs

Urbanised black South Africans preserve their tribal and family ties through participating in societal rituals or maintaining a house in the rural village of their birth. Often the family is split up, some members living in the village and others in town for economic reasons.

In rural areas tribal chiefs, in some villages headmen, still play an important role in social matters. The chief and his wife are approached in matters of social welfare, such as disability in the family, for support and assistance in finding solutions.[37]

A feature of the Eastern Cape rural society is the marked absence of men of the working age group. This places the responsibility for the family's well-being on the women who until recently have not had the legal power to act on their own or their family's behalf. The fact that the women have to spend all their time just to maintain the status quo (household chores, fetching water and wood, weeding and harvesting, care of the domestic animals)[38] contributes to the lack of development in rural areas possibly even the deterioration of the situation.

1.6 Sustainable development project

1.6.1 Perceived need for development

Development of the Eastern Cape, the poorest province in South Africa[39], with all the ingrained problems described above, is thus not only a need of the local inhabitants but of interest to the nation as a whole.

Local communities, and in particular their leaders, are aware of development efforts undertaken in some regions and strive to find support from local or overseas development organisations and funders.[35]

The government policies for development and the local government structures **(1.4.2)** that are to implement these policies have been approved. These policies are in line with the international guidelines and illustrate how international ideology has reached local rural levels. It now remains to be seen if and how this awareness and the application of the ideology locally will affect the global situation.

1.6.2 Perceived need for integrating people with disabilities in development programmes

The Beijing Declaration on the Rights of People with Disabilities in the New Century, March 2000[40], emphasises that the continued exclusion of PWD from the mainstream development process is a violation of fundamental rights. Amongst the priority concerns that need addressing are education, remunerated work and participation in the decision-making process.

The rights and concerns referred to in the Beijing Declaration were first formulated and proposed in 1993 following on the International Year of Disabled Persons in 1981 and the UN Decade of Disabled Persons from 1983 to 1992. The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (2000), an international document, was formulated to focus worldwide attention on the needs of PWD[41]. The purpose of the Standard

Rules is to set international norms and standards to assist countries to develop into better environments to live in, for all their people.[42]

The proclamation of the Year and Decade of the Disabled together with the Standard Rules heralded a major shift in attitudes toward disability. The approach stresses ability, not disability, and encourages society to assist them to assume full responsibility as active members of society.

The *equal rights* emphasised by the Standard Rules are that all governments are responsible to ensure that PWD:

■ live as *dignified and independent* a life-style *as possible* within the community,

■ take an *active part* in the general, *social and economic development* of society, and

■ receive education, medical care and social *services within the ordinary structures* of their society.

The *equal opportunities* that governments should provide are permanent access to basic public services to realise the potential of PWD, because:

Equal opportunities enable PWD to govern their own lives with self-respect and personal dignity. [40]

The global needs, in terms of human rights, addressed in the Standard Rules [41] are echoed by PWD, disabled people's organisations (DPOs)[43] and NGOs in South Africa and have been integrated in the policy documents. However, because of a lack of statistics on the prevalence of specific disabilities and unequal resources in terms of infrastructure and rehabilitation personnel, particularly in rural areas, the providing of opportunities for full integration into society, needs to be addressed now.

For planning purposes the Department of Health undertook a survey to investigate the extent of reported moderate and severe disability and the nature of the experience of disability in South Africa.[44] These crude rates may

be helpful for national planning, but for implementation of rehabilitation strategies at a district level they do not provide enough information. Rural clinics have few or no records of PWD in their area, with the result that at local level PWD are not included in the planning of development projects and their needs not taken into account in structural developments or job-creation projects.

It is thus crucial to identify the PWD, especially in rural areas, examine the available data on prevalence of the specific disabilities and investigate the needed intervention to establish the opportunities needed to ensure that PWD could be active participating members of their communities.

In order to discern the most effective process to generate sustainable development in the South African situation success and failures need to be investigated in order to build on the foundations laid by earlier success or learn from the mistakes. The following section will, therefore, give a short overview of a sustainable development programme In the Eastern Cape. The CSIR (Formerly known as the Council for Scientific and Industrial Research) developed an integrated development model that was implemented in the Lubisi area.

1.6.2.1 The CSIR Integrated Rural Development Model (IRDM)

The purpose of the model is to build a sustainable rural economy by empowering the community through the use of technology. The IRDM engages the community in the development. For sustainable development to take hold, all real constraints need to be addressed concurrently.

The philosophy on which this model was based is that for successful implementation of sustainable development in rural communities there also has to be effective co-operation between sociologists and technologists right from the planning stage.

Their multi-disciplinary team consisted of experts from the following disciplines:

Technology	technology is seen as the main driving force to release the rural communities into productive economic activity. The role of the technologists is to plan and develop an infrastructure that can sustain the socio-economic development and to guide the establishment of modern production technology that will be competitive.
Sociology	the impact of the solutions needs to be taken into account and sociologists liase between the community and the planners and implementers, they guide the community through the process and assist in reaching a compromise between needs and wants and unforeseen problems.
Communication	to connect the rural communities into the mainstream of global electronic communications is essential for their socio-economic development.
Energy	energy is the enabler through which rural communities can stimulate local industry, create jobs and increase disposable income.
Agriculture	modern sustainable farming practices play an important role in these traditionally farming communities to achieve a higher profit margin, while avoiding degradation of the environment.
Marketing	macro-economic reforms are crucial to unlock the potential of the rural communities and establish a regular market system.

The model provides for the facilitation of the process to meet the following basic infrastructural needs:

■ finding sources for funding,

- providing training,

- establishing communications,

- locating and establishing markets,

- setting up a basic transportation structure,

- determining and establishing affordable and sustainable sources of energy, and

- providing preliminary support until community members are capable to maintain a viable micro-economy.[45]

The questions that arise world-wide with respect to the necessity and desirability of intervention in rural communities are relevant for the local communities, e.g.:

- Why is development not initiated from within the community or in response to market forces?

- Why does development require such intensive intervention?

- Is any intervention an artificial action that must inevitably fail as soon as the outside energy is removed?

The CSIR multidisciplinary team analysed these questions in depth and based on their experience believe they have some answers to these questions. They have identified and consider as crucial, certain pre-requisites and constraints that need to be addressed for successful intervention and development to take place.

Pre-requisites:

- The will and motivation to succeed – this pre-requisite is met by selection of a motivated community with strong leadership or leadership potential.

■ Realistic expectations – this pre-requisite is met by a feasibility study, counselling, exposing the leadership to successful projects and guidance.

Constraints:

■ Know-how – appropriate scientific, financial and management knowledge,

■ Access to finance – knowledge of financial management and marketing,

■ Infrastructure – transport, facilities, equipment and knowledge of maintenance,

■ Communication – local and global to access knowledge base and markets.

The IRDM addresses these pre-requisites and constraints in their six-step Funnel and Bridge Process.
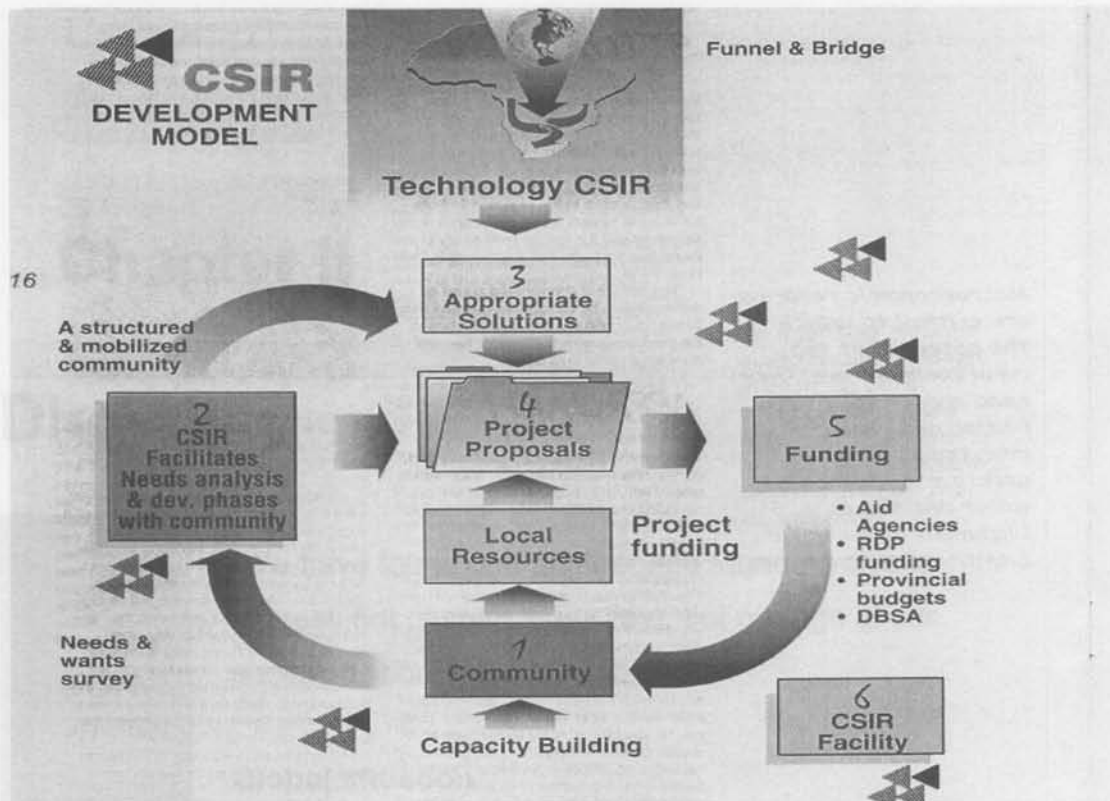
Figure 1.4 Integrated Rural Development Model Development Process

1.6.2.2 CSIR/University of Pretoria Partnership

In 1999 the University of Pretoria and the CSIR adopted a co-operation agreement by which the expertise of the two institutions can be shared to the advantage of both and for the purpose of contributing to national development in a co-ordinated way.

This agreement made it possible for the researcher to accept the invitation of the CSIR to contribute to the development process at Tsilitwa.

1.6.2.3 Tsilitwa

Tsilitwa is a rural village north of Umtata in the Qumbu district and is administratively managed by the Umtata region. The village comprises of 463 households divided into three sections:

- ■ Tsilitwa   204 households,

- ■ Mtondela   29 households,

- ■ Thombeni   220 households.

At an average of eight persons per household, the local development committee estimated the total population as ±3 600 persons.[46]

The village has a motivated leadership that has initiated job creation, health and education projects to develop the potential of their village. The community decided to concentrate on education and then expand to providing opportunities for employment in the village. Most of the job creation projects that were initiated have failed and the leadership is investigating methods to ensure that their efforts are sustainable.

One of the members of the Tsilitwa Development Committee (TDC) expressed concern about the PWD in the community. Sister Madikane, in charge of the local clinic, pointed out that the quality of life of the local PWD was poor. She described the families' poor conditions because of a lack of income and suggested that meaningful employment could counteract depression and improve self-esteem.

The next steps to be undertaken were to investigate the needs and wants of the community, analyse their resources and match them with possible solutions.

1.7 Study

The researcher is one of the two occupational therapists that had been involved on a consultation basis in the planning stage of the Lubisi Dam

Development Project. In the presentations made by the occupational therapists two points were emphasised.

Prevalence:

There is a high prevalence of disability in South African rural communities, because of the extreme poverty, lack of medical services, the country's high crime rate and the violent recent history of the country.

Equity:

Global and national advocacy for equal rights for PWD in terms of opportunities to live as productive a life as possible has resulted in amendments to South African policies and laws to ensure that all South African citizens have equal rights. These rights include the right to participate in local development and access to the facilities and work created by development projects.

The acceptance of this line of reasoning led to the request to investigate the social and economic dynamics of disability in South African rural villages. The request from Tsilitwa to investigate a way to provide work opportunities for PWD in their community was the reason for the selection of Tsilitwa as the community where the investigation would take place.

To investigate such a complex phenomenon a disability survey would have to be undertaken in the specific community in order to identify the PWD within the community and analyse their and their families' problems and needs. Through group discussions with PWD, their families and community members the burden of disability on the community could then be established.

How to integrate PWD into the development process has not been formally researched. It was therefore decided to furthermore investigate the local opportunities for integration of PWD into development projects and in particular into job creation projects.

1.7.1 Research question

The field of investigation in this dissertation is the integration of PWD in sustainable rural development programmes. The Tsilitwa area was used as a case study to examine the issues involved in such integration.

The research question that gave rise to this study was:

> **Can the Tsilitwa PWD be integrated into the workforce of the local development programme?**

The thesis describes the situation during 2000, the year of investigation.

This activity on rural, local level illustrates how global philosophies and trends influence attitudes in remote corners of the world. Working at development, whether as community member, development worker, funder or policy maker unites all involved and draws them into the global network and through local autonomy, communities are globally integrated.

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To investigate the global and local conditions that have led to the realisation that equal rights need to be addressed at a poor, remote, rural level a literature review on relevant disability issues and employment for PWD will be given in the next two chapters.

Chapter II

DisAbility

"We have found one another and found a voice to express not despair at our fate, but outrage at our social position" - *Simi Linton*

Global situation
- ■ **Perceptions of disability**
- ■ **Policies and guidelines**

South African situation
- ■ **Prevalence of disability**
- ■ **Reasons/causes**
- ■ **Burden of disability**
- ■ **Policies and strategies**
- ■ **Health services available**

2.1 Introduction

Nothing about us, without us.

This international motto of DPOs reflects the current driving force behind disability issues, i.e. the PWD themselves. This development of the human rights philosophy will be examined in this chapter.

The spelling of the word disability with a capital A, adopted recently, focuses on ability. This places the emphasis on individual capabilities in contrast to the impersonal group classifications of the past.

These trends representing current global attitudes are intended to empower individuals on the local level to occupy their rightful places in their communities as participating citizens.

Therefore, this chapter will describe and debate the global developments in disability issues that led to these perspectives and the position of PWD in South Africa. Local endeavours to effect the necessary changes to afford PWD the desired status will be examined, as well as the services available to rural PWD in South Africa to become fully integrated members of their communities.

The local traditions (beliefs predating western influence) and culture (customs of the area) are briefly discussed to provide background for the discussion in **Chapter VII** on the influence of western society on the community and its transition into a "modern" society.

International guidelines and the development of the contemporary classification of disability are discussed to rather describe the global attitude shift than as background for the methodology.

2.2 Global situation

To understand the philosophical background of the study and ensure that recommendations would not only answer the community's needs but be in line with international policies and guidelines the global situation and pertinent issues are discussed in this section.

More than 600 million people in the world have disabilities as a result of mental, physical or sensory impairment.[47] United Nations reports reveal that in spite of advances in modern medicine the incidence of disability caused by preventable diseases and natural disasters remains unacceptably high. Disability caused by violence, through war, acts of terrorism, torture and crime is increasing. In addition, economic and technological advances have led to new causes of disablement, e.g. pollution of the environment, stress, heart and circulatory diseases, drug abuse and traffic and industrial accidents.[48]

Dr Pupulin, Co-ordinator of the World Health Organisation's (WHO) Disability and Rehabilitation Team, in the opening session of the workshop on Equal Opportunities for All in Manila, presented a similar view.[49] He said that whilst one could debate the precise numbers, it was clear that a significant portion of the world's population was disabled and in need of help. Moreover, as long as poverty, malnutrition, war and conflict, ignorance and superstition prevailed, the numbers would continue to rise. He stated that according to the WHO's records the majority of PWD presently lived their lives without dignity, in absolute poverty, victimised by beliefs that they were possessed by evil spirits or that their very presence in society was proof of divine punishment.

For too long, have PWD been isolated, their right to develop has been ignored and their potential to contribute to society rejected. Attitudes towards PWD, whereby they are regarded as dependent invalids in need of protection and disability is seen as a stigma, have allowed society to decide on their position and fate. Unfortunately this has usually resulted in isolating the PWD in institutions or hiding them away at home.[50]

The International Year of the Disabled in 1981 and the UN Decade of Disabled Persons from 1983 to 1992 brought about a shift in attitude towards disability.[51] A driving force behind the rise in awareness of disability issues was the World Programme of Action concerning Disabled Persons (UN Resolution 37/52 of 1982) and the Long-term Strategy that is routinely updated to make certain appropriate measures are taken.[52,53]

The new approach stresses the PWD's abilities, instead of their disabilities. It promotes their rights to equal opportunities, their freedom of choice and encourages their participation in society. Therefore it seeks to adapt the environment to the needs of the PWD and encourages society to assist them in taking their rightful place as active, contributing members.

To examine the status quo the following sub-sections will present a literature review of various perceptions of disability.

2.2.1 Perceptions of disability

Persons with disabilities are often categorised in social and political arguments as a minority group. In fact disability is not a minority issue. It is part of the human condition that influences directly or indirectly the lives of hundreds of millions of people globally.

The perception of disability over the ages reflects various societies' philosophical outlook at the time and their religious and cultural principles. For the purpose of this study it is not deemed necessary to provide a complete historical background, but rather to describe the more recent global attitude shift from a medical model to the current social-political models and the magico-religious model of disability that continues to affect the human-rights models in many parts of the world.

2.2.1.1 The medical model of disablement

In the medical model of disablement, disability is defined as an observable deviation from bio-medical norms of structure and function as a result of disease, trauma or a health condition.[54]

This approach, based on variations of human behaviour, appearance, functioning, sensory acuity and cognitive processing, has since the 1980s been increasingly criticised as being biased.[50]

The medical model on which the International Classification of Disease (ICD) was based is depicted as the following sequence:

Aetiology ⟶ Pathology ⟶ Manifestation[55]

However, such a model implies a fixed cut-off point on the continuum between normal functioning and no functioning, at which point the function is described as abnormal and is therefore non-functional. The model does not take into account circumstances that affect the consequences of the pathology.

The International Classification of Impairment, Disability and Handicap (ICIDH), developed in the early 1980s, was an attempt to adapt the medical

model of illness to incorporate a framework that takes the consequences into account.[56] The framework became a basis for communication on the subject of disability and contributed to an awareness of the non-medical factors that influence functioning.

Disease ———➤ Impairment ———➤ Disability ———➤ Handicap

A disability, as defined by the ICIDH,[56] is a lack of ability to perform an activity. Such restrictions, however, depend on the severity of the organ system abnormalities and the individual's physical, psychological and emotional abilities.

The extended sequence of underlying illness-related phenomena portrays a linear causation for functional difficulties of PWD. However, in pointing out the inadequacy of the model, DPOs and various professional disciplines in the field of rehabilitation rejected the medicalisation of disability by reframing disability as a designation having primarily social and political significance.[54]

2.2.1.2 The social model of disablement

The argument for a social model of disability is by no means new. The model arose within social psychology as early as the 1940s with Meyerson's article on Physical disability as a social, psychological problem.[54] A variety of models have been presented over the years based on somato-psychological and attitude theories, United States functionalist sociology and the British Marxist sociology. Emancipists' theories driven by individual PWD and Disabled People International (DPI) have added the insider's point of view and have given substance to the academic and theoretic argument.

The theory underlying these various models will be described briefly so as to bring about an understanding of the background to the current policies and guidelines provided in sub-section **2.3.4**.

Environmental and social circumstances affect the transformation of system abnormalities and restrictions into disadvantages. The process of disablement according to Peters is illustrated below in Figure 2.1[57]:
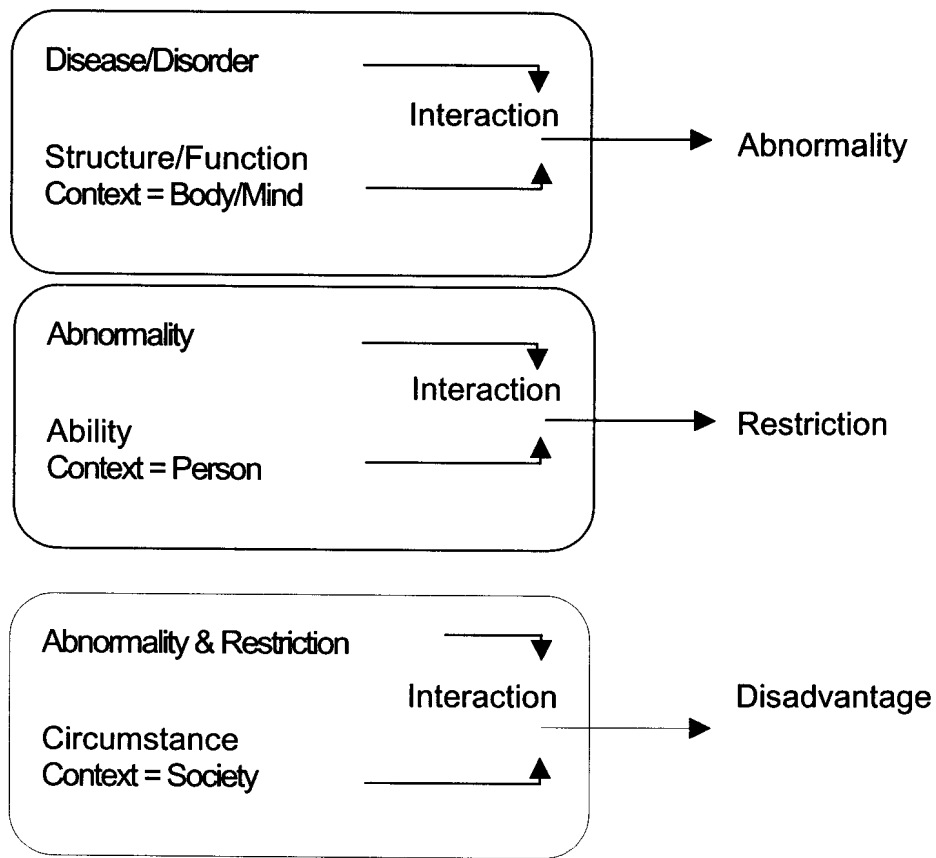
Figure 2.1 Interactional process of disablement

Disadvantage develops within the context of society as a result of the interaction of the individual with the cultural, social and physical environment.

The following comparison of the medical and the social model demonstrates the principal differences between the two models:

Table 2.1 Comparison of the medical and social models of disability

Feature	Social Model	Medical Model
Locus of power	Disabled people make the decisions	Professionals make the decisions
View of disability	Social oppression of a group of people	Personal tragedy
The individual	Focus on abilities	Focus on disabilities
Definition of independence	The ability to choose what one wants to do without assistance	The ability to be independent in activities of daily living
Focus of services	Needs as expressed by the PWD	The professional's view of the need that should be addressed
Criterion for success	Integration into society as an active citizen	Independence in activities of daily living
Role of rehabilitation	A means to an end	Seen as an end in itself

Social theories and political activism are interrelated. Since the source of the disadvantage in the social theories is perceived to be a failure of the social system, the strategies for solutions are political, through changes in attitudes, policies and laws.

The DPI's model of 1976, the UPIAS model, presented by a group of PDW that called themselves the Union of the Physically Impaired against Segregation, was inspired by perceived discrimination and used for such political purposes.

Critics of this model point out that it downplays the importance of the pre-social, i.e. the causes of the disablement. The model appears to be reluctant to highlight the biological and psychological differences that could be used by others to argue the inequality of people. Analysts of this line of argument point out the "dilemma of difference"[58] which is that to end social inequality and discrimination, those who have been disadvantaged have to be identified, and

that can only be done by drawing attention to their difference; yet, if difference is downplayed to support the claim of equality, then the different needs of people may also be ignored.

In practice this dilemma is translated into identification and assessment of individuals with disabilities, evaluation of the environment and determining barriers to integration, so that policies and laws may be brought into action, which in turn depend on society to make exceptions that highlight the differences.

Within the politics of disablement there are the following two perspectives:

■ Disabled people are a social minority group who seek their basic civic rights and fight against discrimination in order to correct the injustices of the past and present.[59]

■ Disablement is a universal human phenomenon that has been systematically ignored with dire and unjust social consequences.[60]

Although the debate between the proponents of the various social models continues, it has influenced the medical fraternity to the degree that the principles of universalism have been incorporated as guiding principles into the revised ICIDH[54] now known as the International Classification of Functioning, Disability and Health (ICF).

2.2.1.3 The magico-religious model of disablement

The term magico-religious model of disablement as used by Zempleni[61] is an umbrella term for the wide range of views on and attitudes to disablement formed by cultural and religious beliefs and traditions.

The literature presented in this sub-section covers the cultural and religious traditions in African society, which have contributed to current views on disability in rural African communities.

In traditional African beliefs the cause of disability can never be limited to the bio-medical level. The bio-medical explanation may be accepted as part of a

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broader rationale. Traditional beliefs are seldom considered relevant in bio-medical thinking, but when working within and in partnership with the community it is necessary to understand and respect the community's value system.

Disability in African culture is classified according to type and reason.

Various sources[62,63] describe three categories of physical disabilities according to which the PWD status of a child in the community is decided. These are termed "ceremonial", "bad" and "faulty". Ceremonial children are not necessarily classified as disabled according to Western medical criteria; their characteristics would be considered medical phenomena, which do not affect their social status. Both bad and faulty children would according to Western criteria be classified as children with a disability, the difference in the African culture being that bad children are associated with the dead and faulty children not.

■ "Ceremonial children" – are believed to have special powers and healing capacities. They are for instance children who "held off the rain", twins, children born with the umbilical chord around the neck or with a hand on the cheek or with hands or feet first. They are welcomed with ceremonies and are given special names, which confer on them a higher status in their community.

■ "Bad children" – are considered supernatural because they were in contact with the anti-world of sorcerers. They include children with hydrocephalus, dwarfism or skin pigmentation abnormalities such as albino. They are seen as inferior and come to this world for a short time before returning to their own. They are given basic care but are marginalized with little interaction with their community.

■ "Faulty children" – are at the same time part of normality and yet not part of it, the term used for their status is liminal[64], meaning between one status and another. They are children with physical deformities from birth complications, poliomyelitis etc. The bodily imperfection is seen as a result of a distorted relationship and more attention is given to finding the cause

and solving the relationship than to the person with the problem itself. They are not necessarily viewed negatively; they deserve a certain respect but should accept their limitations.

The reason for the disability is sought through analysis of the various levels of relationships between human beings and their environment.

Environment

Physical environment – is analysed in terms of weather patterns, e.g. if rain is delayed, but mostly in terms of food prescriptions and sex taboos during pregnancy.

Relationships

■ Relationships with family members – are analysed to establish possible envy, disobedience in terms of following traditional rules or general bad behaviour. The most important relationships are between parents and their close family members. Dissatisfaction with bride price (lobola) is a common reason for bad relationships with families-in-law that could lead to disability. If bad relations are discovered to have existed prior to the occurrence of disability, sorcery is blamed for the disability. The focus in the search for the cause is thus a family matter and not an evaluation of the individual's bio-medical history and symptoms. This is then also often seen as the cause if a disability develops later in life and not at birth.

■ Relationships with the ancestors – are analysed if no signs of bad family relationships are found. When the ancestral rules are not respected, as in a case of adultery or theft, the ancestors may manifest their anger with members of the family through the birth of a child with a disability. Disability is thus considered a punishment to the family.

■ God – is one entity and considered to be the source of everything, good or evil. When the cause of disability is not found in social-familial terms God, as the absolute unknown force, is the only possible cause.

Sorcerers can cause evil with God's consent, in which case it is seen as a test.

Although there are accounts by various researchers of the killing of children with disabilities at birth in various African countries,[50] Ingstad's studies amongst the Tswana people in Botswana show that such practices are not known. The contribution a person can make to the household and community is what is of importance in their culture, not the physical appearance of the person.[50]

The view that disability is a test or punishment, caused by curses as a result of disobedience or bad relationships among family members, does not fit into the global debate on disability issues. Although traditional healers are accepted by the Department of Health as practioners of equal standing health policies and services are planned according to international guidelines. These views are also often no longer the prominent views of specific family members or whole rural communities and can on occasion lead to conflict within a family on the course to be taken in terms of medical intervention. They do, however, affect communication and the efforts of health workers and NGOs in rural communities attempting to develop services and structures according to international and local policies and guidelines. The credibility of researchers and health workers is essential for open communication each individual has to know that their views are fully accepted. Understanding and acceptance of the culture of a community is therefore a pre-requisite for transcultural work. An open relationship with the local participants as well as their credibility is necessary for effective intervention or research.

2.2.2 International policies and guidelines

International policies reflect the viewpoints of the time in which they were drafted. The two widely used guidelines discussed in this sub-section illustrate how the human rights background of the political milieu in which the Standard Rules were formulated changed global attitudes, resulting in the latest integrated approach to the WHO's policies, which take into account the medical, social and environmental factors. The effectiveness of the political

role played by the Standard Rules on the WHO guidelines (in the form of the development of the ICIDH to the ICF) which play a more technical role, is discussed in the following sub-sections.

2.2.2.1 Standard rules on the equalisation of opportunities for persons with disabilities

As a result of the attitude shift that took place during the International Year of the Disabled in 1981 and the UN Decade of Disabled Persons from 1983 to 1992, the member states of the UN agreed in 1993 on the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities.[65]

The Standard Rules are not legally binding but are a powerful tool in achieving equal opportunities for PWD, by becoming customary rules, which encourage governments to accept the strong political and moral commitment to take action. The Standard Rules are intended to:

- ■ Set standards for equal opportunities,

- ■ Outline the action to be taken by governments,

- ■ Give guidance to all those engaged in the disability field, and

- ■ Involve PWD, their families and organisations as active partners in improving the quality of their lives.[51]

The two concepts that form the basis of the approach are *equal rights* and *equal opportunities.*

Equal rights

The Standard Rules underline the responsibility of governments to secure equal rights for all its citizens and therefore to ensure that PWD:

- ■ Live as dignified and independent a lifestyle as possible within society,

- ■ Have an active part in the social and economic development of their communities,

■ Receive education, me̶̶̶̶ices within the ordinary structures of society.

Equal opportunities

Governments should enact laws that prevent discrimination and ensure that PWD become economically contributing members instead of a burden on society. The advantages of equal opportunities are:

■ The untapped potential of PWD is realised,

■ PWD are enabled to govern their own lives, and that

■ Self-respect and personal integrity are achieved for PWD.

For details of the Standard Rules it is necessary to read them in full. A short summary of the four topics of the content follows:[51,66]

■ Preconditions for equal participation – The Standard Rules identify four preconditions (awareness raising, medical care, rehabilitation and support services) as a foundation for the equalisation of opportunities.

■ Target areas for equal participation – Accessibility, education, employment and social security are the main target areas. However, the rules stress the importance of family life, culture and religion, and the value of recreation and sports. The target areas embrace all the essential elements to ensure integration and fulfilment.

■ Implementation measures – The Standard Rules spell out the responsibility of governments to ensure the protection of the rights of the PWD and to implement measures that will allow them equal access to opportunities according to their abilities. According to the Standard Rules the implementation measures should include: information and research, policy-making and planning (including economic policies), legislation, co-ordination of work, involvement of PWD, their families and DPOs, training, national monitoring, and international co-operation.

■ Monitoring mechanism – To ensure effective, long-term implementation the Standard Rules contain a built-in follow-up system. The Monitoring System is co-ordinated by the UN Special Rapporteur and is open to advice from PWD through the DPOs.

In South Africa these rules are advocated by the local DPOs as a useful tool to achieve an equal share in the improvement in living conditions resulting from social and economic development. The DPOs strong human rights stand is gradually becoming known and is generally seen as the ideal to achieve in the society at large. Attitudes toward disability issues are perceived to be mixed in rural areas. The value to research such attitudes is debateable because they are continually changing according to local conditions and experiences. It is however necessary to establish views and attitudes within a community if changes are introduced into a community.

2.2.2.2 International Classification of Disability

The value and application of the original and the revised version of the ICIDH have been widely described and discussed in the literature. Some relevant points will be presented here for the purpose of clarifying the terminology and scope used in this study.

Since the compilation of this literature review the ICIDH-2, after international trials, has been accepted and named the International Classification of Functioning, Disability and Health (ICF) in January 2001 (Agenda item 3.5 54th World Health Assembly)[67] The principles of the ICIDH have remained, which means that the information gathered in the review is relevant. Where sources describing and discussing the trial ICIDH-2 are used, the classifications will be named as such. For the rest of the document the new name, ICF, will be used.

The ICIDH was developed as a result of resolution WHO29.35 of the 29th World Health Assembly in May 1976[56]. It was deemed that the ability-capability gap, and the discrepancy between what health care systems were

doing as opposed to what they might do, were the greatest challenges for those concerned with health care and welfare. In the hope that improvements in the availability of relevant information would contribute to the development of more appropriate policies, it was decided to develop a classification to gather uniform global information.

The requirements agreed upon for information relevant to health experiences were:

■ Routinely available data,

■ Data for evaluation, and

■ Data on the consequences of disease.

The ICIDH based on the medical model was widely used and provided a unifying framework for policy makers and planners, health professionals, and PWD and their families. The terminology and definitions of *impairment*, *disability* and *handicap* that were used to classify disability became the basis of international and interdisciplinary communication.

Global developments in the perception of disability subsequently necessitated the development of a new format for data collection. The result is a classification that provides an appropriate instrument for the implementation of the stated international human rights mandates as well as national legislation. Because of its value for interdisciplinary application it is referred to and incorporated in the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities.[52,65]

The purpose of the classification has remained the same but the properties of the instrument have been designed to meet current needs.

Properties of the ICIDH-2

The properties of the ICIDH–2 are its:

■ Universality – Encompassing all aspects of human functioning and disability; the functional states associated with health conditions brought about by socio-economic factors independent of health conditions.

■ Scope – A framework to organise information regarding all human functioning and disability, in a meaningful, interrelated and accessible way. The instrument organises the information according to three *dimensions*, (*body level,* comprising structures and functions; *individual level*, covering the complete range of activities performed by an individual; and *society level*, classifying the participation in all areas of life) and domains in each of the dimensions (e.g., body structure – the nervous system; the eye, ear and related structures) The instrument includes a comprehensive scheme of environmental factors that interact on all three dimensions. See the sub-heading **Terminology** for definitions and **Table 2.1** for an overview of the components of the ICIDH–2.

■ Unit of classification – The instrument classifies functioning and disability from the individual's perspective. It therefore classifies the domain of functioning and not people. Each dimension or component can be expressed in terms of positive or negative aspects.

The new classification thus needed to include new terminology.

Terminology and definitions of the ICIDH-2

Body level:

■ **Body functions** are the physiological functions of the body systems.

■ **Body structures** are anatomic parts of the body such as an organ, limbs and their components.

■ **Impairments** are problems in body function or structure such as a significant deviation or loss.

Individual level:

■ **Activity** is the performance of a task or action by an individual.

■ **Activity limitations** are difficulties an individual may have in the performance of activities.

Societal level:

■ **Participation** is an individual's involvement in life situations in relation to health conditions, body functions and structure, activities and contextual factors.

■ **Participation restrictions** are problems an individual may have in the manner or extent of involvement in life situations.

Contexts:

■ **Contextual factors** represent the complete background of an individual's life and living.

■ **Environmental factors** make up the physical, social and attitudinal environment in which people live and conduct their lives. The factors are external and can have a positive or negative influence on the individual's participation as a member of society, on performance of activities of the individual or on the individual's body function or structure.

■ **Personal factors** are the background of the individual's life and living, composed of features of the person that are not part of a health condition or functional state. These may include age, race, gender, educational background, experiences, personality and character style, aptitudes, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, profession.

The table below gives an overview of the levels and dimensions and provides users with a guide for assessing the complex collection of factors involved in establishing a PWD's functional abilities.

Table 2.2 ICIDH-2 Model of functioning and disability

	Body functions and structures (B)	Activities (A)	Participation (P)	Contextual factors
Level of Functioning	Body (*body parts*)	Individual (*person as a whole*)	Society (*life situations*)	Environmental and personal factors
Characteristics	Body function Body structure	Performance of individual's activities	Involvement in life situations	Features of the physical, social and attitudinal world and attributes of the person
Positive aspect (Functioning)	Functional and structural integrity	Activity	Participation	Facilitators
Negative aspect (Disability)	Impairment	Activity limitation	Participation restriction	Barriers
Qualifiers: First	Uniform qualifier: Extent or Magnitude			
Second	Localisation	Assistance	Subjective satisfaction	

The ICIDH–2 provides a multi-perspective approach to the different dimensions and domains that describe the evolutionary process of functioning and disability. It is an integration of the medical and social models in an attempt to achieve a synthesis of biological, individual and social dimensions.

The medical model, which views disability as a personal problem caused by medical condition and management, is thus aimed at cure. The social model sees disability as a complex collection of conditions, many of which are created by the social environment. Disability therefore is seen as a political issue. By integrating the models the ICIDH–2 used a bio-psychosocial approach (**Figure 2.2**).

Health condition

(disorder or disease)

Body functions & structure

Activity

Participation

Environmental factors

Personal factors
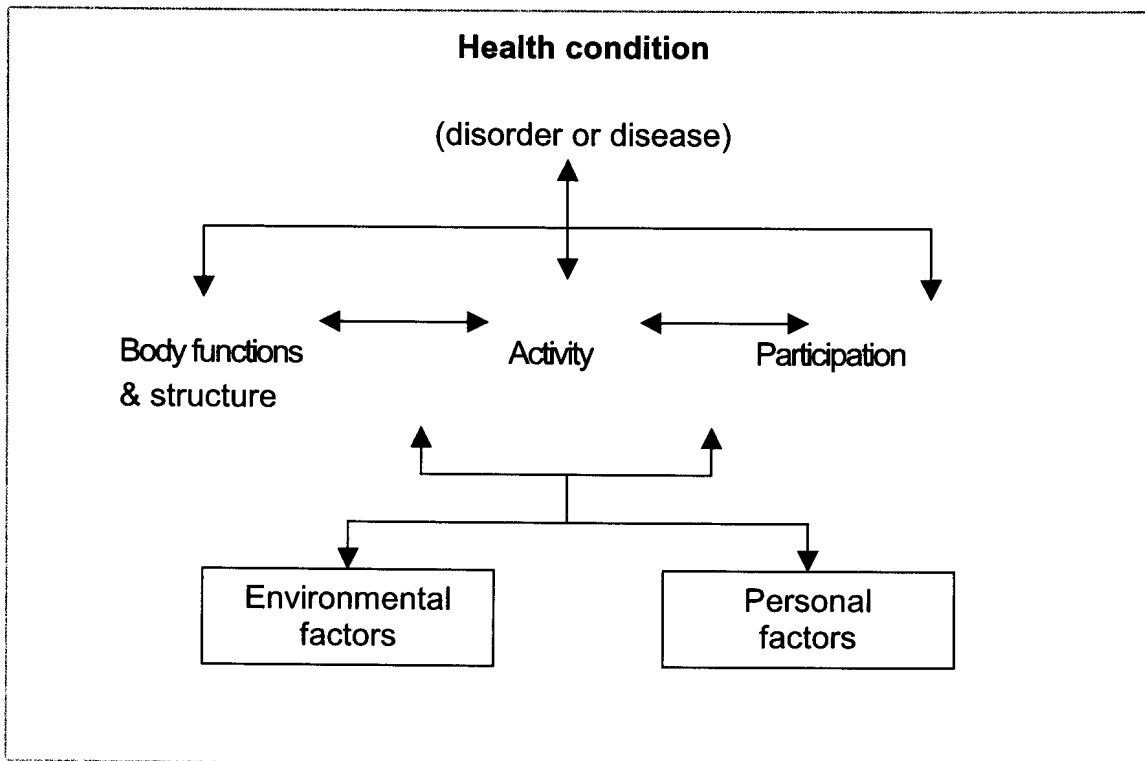
Figure 2.2 Model of functioning and disability

Functioning and disability are seen as a dynamic interaction or complex relationship between health conditions and the individual's contexts. The model demonstrates the role that contextual factors play, how they interact with the individual's health condition and determine the extent of the individual's functioning.

The original ICIDH was used by many disciplines and occupational therapists found it useful for the purpose of recording data. With the ICIDH-2 version the occupational therapist now has a tool with which to record all the domains and contexts of his/her clients to obtain functional profiles, analyse the difficulties and plan interventions in a holistic approach.

The rehabilitation guidelines that have been developed in accordance will be discussed in **Chapter III**.

The ICIDH as a research tool

The ICIDH, since its first version (1980) has been useful as a:

■ Statistical tool – for collecting and recording data,

■ Research tool – to measure outcomes, quality of life and environmental factors,

■ Clinical tool – for needs assessments, treatment planning, vocational assessments, rehabilitation and outcome evaluation,

■ Social tool – for policy development and planning,

■ Communication tool – for collaborative research, publications and conferences, and

■ Educational tool – in curriculum design and to raise awareness.

Rigorous scientific studies were undertaken on the trial ICIDH-2 to ensure that the ICF would be applicable across cultures, age groups and genders to collect reliable and comparable data on health outcomes of individuals and populations. The WHO is currently using the ICF in worldwide health surveys.

The ICF is a global tool in changing the understanding of disability. It provides a different perspective on measures that can be taken to optimise a person's ability to remain in the workforce and live a full life in the community. While traditional medical health indicators are based on mortality rates, and disability based on the concept of abnormality, the ICF shifts the focus on "life" and functioning, i.e. how people live with their health conditions and how these can be improved to achieve productive, fulfilling life. One hundred and ninety-one countries have accepted the ICF as the international standard to describe and measure health and disability.[68]

2.2.3 Definition of disability

Definitions of disability reflect the development in perceptions of disability and the various theoretical backgrounds described in **2.2.1**.

Based on the view that disability arises from the way that society is organised, rather than from individual impairment, McLaren et al used the following definitions for their district disability situational analysis in KwaZulu-Natal:

- Disability is a complex system of social restrictions imposed on people with impairments.

- Disabled people are people with sensory, intellectual and physical impairments and people with mental health difficulties.

The Employment Equity Act of 1998[69] defines PWD as people who have long-term or recurring physical or mental impairment, which substantially limits their prospects of entry into or advancement in employment.

The National Disability Survey 1999 defined disability as someone experiencing limitations in activities.[44]

For the purpose of this dissertation the definition of a PWD is based on the terminology of the ICF and is defined as follows:

A person who experiences long-term activity limitations, which prevent him/her from performing activities successfully and safely.

2.2.4 Burden of disability

International studies on the burden of disease and disability do not present comprehensive statistics of the burden of disability. Descriptions of the calculations of years lived with disability (YLDs) do not apply the definitions used in the ICF. The statistics do not indicate whether post-morbid the person had activity limitations understood to be disability or suffered participation restrictions. The figures are therefore not helpful in calculating economical burden accurately.

The purpose of these studies is to investigate current rates and patterns of ill health, risk factors and economic burden. They draw comparisons of these factors for established market economies and developing regions. Projections of future mortality and disability are then presented as an aid for planning health research, capital investment and training.[70]

The projections show that in developing countries, in spite of dramatic improvements in child health in Group I disorders, perinatal disorders will continue to contribute to the burden of disability. In these regions it has also become apparent that neuro-psychiatric conditions from the Group II disorders are a considerable contributor to the burden of permanent disability. In Group III intentional injuries seem to be a particular problem in developing regions and special mention is made of sub-Saharan Africa. In such areas the burden is compounded by neglect and inadequate health services.[71] The comparisons between prevalence, in the form of disability-adjusted life years (DALYs), and health spending give an indication of the effect of inadequate resources on the population of the developing regions.[i]

Projections up to the year 2020 were done according to three scenarios. Although they predict that global health trends will be determined mainly by the aging world population the life expectancy for sub-Saharan populations is the lowest worldwide. The baseline prediction for both men and women falls under 65 years of age.[70]

Although these studies illustrate the extent of the problem globally and regionally, they appear to have simply followed a medical model for the investigation of disability, which does not indicate the level of disability and the effect thereof on function. These studies are therefore limited for the

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[i] Group I, consisting of communicable diseases, maternal causes, conditions arising in the perinatal period and nutritional deficiencies, Group II encompassing the non-communicable diseases; and Group III, comprising intentional and unintentional injuries.

Chapter II DisAbility   **56**

investigation of economic a ~~UNIVERSITEIT VAN PRETORIA~~ disability for specific countries and communities.

The burden of disability as a social phenomenon is described in the literature mostly by members of the Disabled Movement and is often very personalised. Few figures are available on the economic burden of disability and even less empirical evidence of the burden on the community, the family and the individual.

The burden is experienced in the form of discrimination, lack of opportunity and poverty. Examples from Africa[72] are:

Facts and figures:

- 50 million PWD in Africa – most live in rural areas,

- 2% of PWD have access to rehabilitation services,

- 2% of children with disabilities receive any education,

- 70% of PWD are unemployed and live in poverty,

- Transport systems are not accessible for PWD.

Attitudes:

Tribal and religious beliefs affect communities' attitudes toward PWD, e.g. disability is often seen as punishment, even for sins of ancestors, or PWD are sometimes considered as bad omens. They are perceived as unproductive and are frequently mocked or abused. These attitudes lead to various forms of exclusion, e.g.:

- Teachers refuse to teach children with disabilities,

- Village women refuse to help villagers with disabilities,

- Employers refuse to employ PWD,

- PWD are denied shelter or food or assigned certain quarters at the fringe of the village,

- PWD are abandoned and left in institutions.

Services:

- Rehabilitation services are not widely available,

- Technical aids are expensive,

- Opportunities for education are scarce and expensive,

- The few residential institutions separate PWD from their families.

Discriminatory legislature:

- Few African countries have laws that uphold the rights of PWD, and where they are included in the constitution these laws are not always enforced.

- PWD in some African countries do not have the right to vote.

These social features of the burden of disability are best illustrated by descriptions of personal experience of the burden.

"I used to work as a translator in an office. I had a very good work record and was respected by the director. When he left a new director arrived at the office, I was suspended from my job. The new director simply did not want to work with a disabled person. Because of his attitude, I was chased away." *Lokana Ngandru, Zaire.*

"I am deaf, I have six children whose father left long ago and is no longer alive. My father and mother are also dead and I have no other means of financial support. What I need is financial aid to start working ...." *Pale Solange, Mali."*

"Using a wheelchair has double problems. They are not easily available and they are expensive. And they are not suitable for rural areas where there are no roads." *Reuben Makasi, Kenya.*

Against the above background on the global views on disability, the South African situation needs to be examined to comprehend the effect of disability on local rural communities and find the appropriate basis for co-operative undertakings to address the problems PWD have in rural communities in South Africa.

2.3 South African situation

South Africa's unique blend of first and third world conditions, caused by past political strategies and the variety of cultures, presents with contrasting health conditions in the various population groups. Because of the focus on rural conditions, this section will concentrate on conditions in South African rural communities and the national policies and guidelines developed to address disability issues in these areas.

To plan, execute and interpret the study it was important to investigate how many PWD live in South African rural areas, what the effect of their disability was on their lives and what support structures were at their disposal.

2.3.1 Prevalence of disability

The UN Development Programme does not provide any figures for PWD in Sub-Saharan Africa.[16] This is an indication of the lack of studies of disability prevalence in African countries. The same was true for South Africa,[73] where until recently international estimates were used to determine national prevalence figures. These varied according to different sources, e.g. a 10% prevalence was published by the WHO in 1976. Such variances are attributed more to the methodology used in the surveys than changes in the actual numbers of PWD in the countries surveyed.[74]

The Co-ordinating Committee for the 1986 Year of the Disabled Person presented a figure of 12.75%.[75] More recently, global estimates were used to arrive at a national projection of 5.21%, which for the estimated population of 40 million, computed to 2 084 000 persons with moderate and severe disabilities.[76,77]

Even less was known about prevalence in rural areas; once again projections for developing countries were used for planning and as assumptions in local studies. Individual 2-stage studies were undertaken to establish prevalence figures however such studies were not co-ordinated to arrive at generilsable disability prevalence rates for rural South African conditions. McLaren (1987) gave an overall crude rate of 6.5% for confirmed motor disability in the Manguzi area of KwaZulu-Natal.[78] Concha and Lorenzo's study, undertaken in the late 1980s, on prevalence of moving disabilities in a rural population, provided a disability rate of 4.59%. They pointed out, however, that many disabilities reported had little influence on the independence status of the individual.[79]

The following table illustrates the results of rural disability prevalence studies. The difference between reported disability and confirmed impairment illustrates the problem of over-reporting.

Table 2.3 Disability prevalence rates in rural populations of South Africa

Study	Motor disability rate as % of total population	Total disability rate as % of total population
KwaZulu-Natal 1987 (McLaren)	8.6% Reported disability 6.5% Confirmed impairment	Not studied
Gelukspan 1987 (Cornielje)	13% Reported disability 2.5% Confirmed disability/impairment 13% of disabled aged 18 – 65 unemployed	No overall rate calculated
Gazankulu 1987 (Concha)	5.3%	4.5%
Tiyani 1991 (Anderson)	2.6%	8.1%

In 1999 the South African Department of Health presented the first official figures on reported moderate and severe disabilities in South Africa.[44] A one-stage national survey to establish baseline data found a crude overall reported disability rate of 5.9%. If extrapolated to the general population, it means that there are between 2.3 and 2.5 million people with reported disability in South Africa.

Relevant issues from the report are summarised below, with emphasis on the Eastern Cape.

The survey investigated the prevalence of permanent, moderate and severe disability. All types of disabilities were included in the survey. The results show that the Eastern Cape had the highest average disability prevalence in the country.

Table 2.4 Prevalence rate reported disability, by province

Province	Prevalence (%)
Western Cape	3.8
Eastern Cape	8.9
Northern Cape	4.5
Free State	5.8
KwaZulu-Natal	6.7
North-West	3.1
Gauteng	5.2
Mpumalanga	4.5
Limpopo	6.3
National average	**5.9**

Both the White and the African population groups of the Eastern Cape had the highest reported disability prevalence nationwide in their category. See **Table 2.5** below.

Table 2.5 Reported disability prevalence rates, by province and race

Province	African (%)	Coloured (%)	Indian (%)	White (%)
Western Cape	3.9	3.9	2.3	3.3
Eastern Cape	9.0	6.1	-	11.8
Northern Cape	4.0	4.3	-	7.4
Free State	6.1	0.0	-	5.6
KwaZulu-Natal	6.9	9.4	5.3	6.2
North-West	2.9	-	-	5.8
Gauteng	5.5	5.5	1.8	4.5
Mpumalanga	4.7	-	-	2.6
Limpopo	5.8	-	-	10.4
National average	**6.1**	**4.5**	**4.8**	**5.3**

On average, Africans at 6.1% have a significantly higher reported disability prevalence rate than the other race groups.

More multiple disabilities were reported in rural areas, which suggests that people in rural areas do not have access to services that could prevent complications that would develop into further disability.[44] However, the breakdown of the figures according to type of disability (**Table 2.6**) leads this examiner of the report to question the use of the term disablement in the survey. Although the investigators describe their definition of disability as an activity limitation, they included *Daily life activities* as a type of disability. All the other types of disability they used in their classification would have some form of limitation on daily life activity, if the definition were applied.

The figures will, however, be presented here to illustrate that the highest reported disability found was a lack of movement ability.

Table 2.6 Reported disability prevalence rates, by type of disability

Type of disability	Prevalence rate (%)
Movement activity	2.0
Daily life activities	1.8
Seeing	1.7
Moving around	1.7
Learning	1.2
Emotional	1.1
Intellectual	1.1
Hearing	1.0
Communication	0.8

This table illustrates that the prevalence of the group classification of *physical disabilities,* which includes the categories *Movement activity, Moving around* and possibly some of the PWD classified under *Daily life activities*, is the highest.

The survey found that the distribution of the various types of disabilities did not differ significantly across the provinces. The finding that the highest portion of PWD live in the Eastern Cape and Kwa Zulu-Natal appears to

concur with global assumptio [UNIVERSITEIT VAN PRETORIA / UNIVERSITY OF PRETORIA / YUNIBESITHI YA PRETORIA] prevalent in rural areas of developing countries.[49,71]

Table 2.7 Distribution of total sample with reported disability across provinces

Province	Distribution across provinces (%)
Eastern Cape	23.7
KwaZulu-Natal	23.5
Gauteng	15.9
Limpopo	12.9
Free State	6.5
Western Cape	6.2
Mpumalanga	5.3
North-West	4.4
Northern Cape	1.6

Although the methodology used and the accuracy of the reported prevalences may be questioned, it is the first time that we have a national picture of the extent of moderate to serious disablement in South Africa. These figures, being the only figures available, will thus be used, in the hope that individual studies will be co-ordinated in future to expand the national database until more accurate figures are be established.

No figures are available for the Qumbu District or Tsilitwa and its surrounding villages.

2.3.2 Causes

In the literature reviewed, causes presented for high incidence of disablement in developing countries were: poverty, lack of health services, violence, ignorance and superstition.[49] Reports published by the National Department of Health state that the most cited causes for disability, in their surveys, are violence, accidents, poverty, lack of information, unhealthy lifestyles and environmental factors *(sic)*.[80]

The table below illustrates the findings of the Department of Health Survey.

Table 2.8 Causes of reported disability

Cause of reported disability	%
Illness	26
Don't know	21
Before and during birth	19
Accident	15
Other	9
Violence	5
Witchcraft	3
Ageing process	2
Total	**100**

The effect of these complicating factors will be discussed briefly for the South African situation with emphasis on the rural community in the Eastern Cape.

2.3.2.1 Poverty

The unemployment rate in the Eastern Cape has been among the highest in the country for a long time. The main sources of income are the informal sector, pensions and remittances. The migrant labour system still influences dependency due to money sent home, but the closing down of many mines and the return of the retrenched mineworkers has added to unemployment figures in recent years.[15] In 1991, nearly one in every two adults in the Eastern Cape reported having no monetary income. The province occupies the bottom position with regard to socio-economic development in the country.

2.3.2.2 Health services

The Apartheid politics of the past and the poverty of the Eastern Cape have led to an inequitable distribution of already inadequate resources for health care in the province.[15]

Because of long distances to basic health care facilities, poor condition of roads and a lack of transport, the services provided are not easily accessible.

Specialised medical care and comprehensive health care are only available at major centres and even in those centres are limited by a lack of funds and personnel [81]

2.3.2.3 Violence

No specific literature on violence in the country was studied as it falls outside the field of this study. However, the influence of the violence of the country's recent past and the high crime rate on the prevalence rate have been repeatedly reported by the Department of Health.[80,82]

Violence has played a role in retrenchments from the mines, and faction fighting and crime are reported problems of the area.

2.3.2.4 Knowledge of contributing factors

The lack of information on health matters that can lead to disability can be linked directly to the lack of health services in the province. A low literacy rate[15] and poor access to information from media sources contribute to isolation in terms of medical matters. This results in an inability for secondary prevention of further disability.

The presence of traditional and cultural customs and beliefs exacerbates disability caused by neglect.

The 1999 National Disability Survey of the Department of Health mirrors these factors in its investigation into causes of disability in the country.[44]

2.3.3 Burden of disability

Personal

The life stories and focus-group results from the National Survey on Disability[44] found that PWD in South Africa are subjected to lack of tolerance

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and prejudice which impact profoundly on their lives. The lack of accessible transport and facilities in rural areas prevents many PWD from participating in social activities of their communities. Barriers to education and employment as well as social integration result in isolation.

Most PWD do not want to be dependent on others and experience this dependency as the most depressing facet of their disablement.[72]

Family

Research in contemporary African circumstances has revealed that care of PWD is mostly regarded as a family matter, not a community responsibility. Because families are large and there often is support from the extended family, the burden of the disability is shared. Labour migration and poverty alter the family structure and its ability to carry the additional burden. Findings from studies in Zimbabwe and Botswana[83] are relevant for the South African situation because of the similarities in the social structures, the geographic remoteness and the culture. These studies have shown that when labour migration takes the healthy and able household members away, the old, very young and infirm are left to survive on subsistence farming and some irregular remittances. The studies have described that the relationships are marked by loyalty and affection but because coping with the care of the PWD depends on the disposition of the families' resources there is an increasing demand for programmes for PWD.

The National Disability Survey[44] found that only 12% of PWD are employed; yet 68% do not receive a disability grant. African respondents were even less likely to be employed or to receive grants or private pensions than other population groups. As many of the PWD need specialised equipment or care the financial burden on the family is multiplied.

2.3.4 National policies

The development of current national policies on disablement was strongly influenced by global guidelines from the WHO and the UN as well as national and local disability rights movements.

The **Disability Rights Charter** of South Africa published in 1992 put forward 18 demands of the PWD in South Africa.[84]

A brief summary of relevant articles follows:

- Article 1 Non-discrimination – equal opportunities,

- Article 2 Self-representation – representation on all matters affecting PWD; resources to fulfil this role,

- Article 3 Health and rehabilitation – effective, accessible, affordable services to all PWD in South Africa,

- Article 5 Employment – employment in the open labour market, appropriate training programmes; quota systems, incentives for employers; state assistance for workshops, self-help projects,

- Article 13 Independent living – encouragement, support to live independently in own communities; development of skills to participate in society at large.

The **Integrated National Disability Strategy** (INDS) published in 1997 contains the government's vision, policies and strategies on disablement.[82] The basis for the vision and the policies can be found in the government's policy framework, the Reconstruction and Development Programme,[85] which provided directives for the National Health Plan for South Africa.[86]

The National Health System, based on the Primary Health Care (PHC) approach, was designed to promote health and to provide health care services. The PHC approach is centred on the individual, the family and the community. In the promotion of health, prevention of illness and treatment of disease there should be close cooperation with other health-related sectors. e.g. education, social welfare, agriculture.

Special care for high-risk groups (children, pregnant women, the elderly and PWD) was identified as a priority by the work groups for the National Health Plan of the previous government.[87] In the National Health Plan of 1994

services in rural areas and care of the disabled population were two of the five priorities of the new health plan. Guidelines for rehabilitation services, in line with WHO recommendations, were developed over the following years, culminating in the INDS.[88,89,77] An important aspect of these guidelines is the emphasis on community based rehabilitation (CBR) as component of the PHC system.

Policy guidelines were developed on:

- Prevention

- Awareness raising

- Health care

- Rehabilitation

- Barrier-free access to physical environment, communications, education, employment

- Social welfare and community development

- Housing

- Sport and recreation.

Relevant features of the guidelines for employment and community development follow with emphasis on the study-related aspects.

Employment

The policy objectives identified were:

- The unemployment gap between non-disabled and disabled job seekers must be narrowed.

- Conditions must be created to *broaden the range of employment options* for PWD so as to provide an occupational choice.

■ The *vocational integration of PWD must be facilitated*, whatever the nature or degree of the disability(ies).

Strategies to meet the objectives are focused on occupational choice, inter-sectoral collaboration and personnel training.

The employment opportunities are to be provided within the open labour market, in small, medium and micro-enterprises (SMMEs) and in sheltered/protected employment environments.

Documents and Acts that support these strategies are:

■ The Constitution of South Africa (1996)[90]

■ The Labour Relations Act (No 66 of 1995)[91]

■ Basic Conditions of Employment Act (No 75 of 1997)[92]

■ The Employment Equity Act (No 55 of 1998)[69]

■ Promotion of Equality and Prevention of Unfair Discrimination Bill (B 57B - 99) [93]

■ The Code of Good Practice on Key Aspects of Disability in the Workplace – Draft (No R 19 April 2001)[94]

Community development

The policy objectives identified were:

■ Develop social welfare services that aim to integrate PWD within all activities in their communities.

■ Develop social welfare services that recognise the needs of PWD.

■ Facilitate the reorientation and training of personnel to provide disability-sensitive and integrated community development processes.

The integration process for development was placed under the auspices of the Department of Social Welfare (now known as Department of Social Development).

The strategies to meet the objectives include public awareness raising, personnel training and inter-sectoral collaboration, which include NGO involvement.

Recommendation 4 of the White Paper on an Integrated National Disability Strategy[82] is the development of a national rehabilitation policy that sets guidelines for co-ordinated rehabilitation services and an investigation into the feasibility of developing a Disability Services Act for South Africa. In November 2000 the National Rehabilitation Policy was published.[95] The policy was developed in co-operation with state departments, professional associations, NGOs/DPOs and the private sector.

The goal of the policy is to improve the accessibility to all rehabilitation services and to afford all citizens their right to access health services. The policy is a vehicle to bring about equalisation of opportunities for PWD, thereby addressing poverty and the disparity in socio-economic circumstances.

The underlying principles of the policy are that:

■ All human beings have equal worth and equal rights,

■ All parties are willing to share opportunities and the means needed for self-realisation,

■ The PWD is a full participant in the life of the community.

The policy emphasises that PWDs are not a uniform group, but individuals with differing needs, beliefs and values. Rehabilitation services should therefore accommodate these differences and recognise the individuals' needs, strengths, weaknesses and abilities.

Services should be equitable, affordable and accessible to all. This will be achieved by a balance between institution-based and community-based services in order to improve access to services for disadvantaged and vulnerable groups, particularly in rural areas.

Relevant aspects of the policy's guidelines for the establishment of a rehabilitation programme are:

■ Social re-integration and participation of PWD into their communities and society at large,

■ A comprehensive service including medical rehabilitation, vocational rehabilitation, social rehabilitation and the provision of assistive devices,

■ Participation of PWD in planning, implementing and monitoring rehabilitation services,

■ Provision of the necessary resources to achieve physical, social and economic independence for PWD and re-integration into their society,

■ Services should be co-ordinated between service provision levels and

■ Delivered in inter-sectoral collaboration.

The role players in the intersectoral collaboration are the Departments of Health, Labour, Social Development and Education; NGOs and DPOs, such as South African National Council for the Blind, National Council for Persons with Disabilities of South Africa (NCPPDSA), Deaf Federation of South Africa, (DEAFSA) African National Epilepsy League (SANEL) now Epilepsy SA, South African Federation for Mental Health (SAFMH) and the disability rights movement under the leadership of DPSA.

The **Health Sector Strategic Framework** 1999 – 2004 has identified assistive devices for PWD and employment integration as their two focus points in terms of disability issues for the five-year plan.[96] The Department of Health intends to monitor reduction of the backlog in issuing assistive devices and improvement of employment figures for PWD in the country.[97]

The national policies, guidelines and strategies to assist PWD to have access to opportunities, according to their needs, for full integration are thus in place. The next steps would be to develop the Act and to ensure that these guidelines are implemented in terms of planning and monitoring by local government.[98]

To complete the outline of the South African situation it is necessary to investigate what services are available to PWD in terms of health and rehabilitation. For the purpose of this study the focus will be on the Eastern Cape, and in particular the area serviced by the Sulenkama (Nessie Knight) Hospital.

2.3.5 Health services available in the Eastern Cape

Health services in the Eastern Cape are divided into five health regions.[99]

Table 2.9 Health regions of the Eastern Cape

Region	District	% Population
A	Port Elizabeth, Graaff-Reinet, Uitenhage, Humansdorp	17
B	Queenstown, Aliwal North, Elliot, Cradock	14
C	East London, Albany, Fort Beaufort, King William's Town	31
D	Umtata, Qumbu, Libode, Tsolo, Mqanduli	20
E	Mt. Ayliff, Kokstad, Mt. Fletcher, Kwabhaca, Siphangeni, Umzinkulu	18

Figures on public sector rehabilitation personnel employed in the Eastern Cape in 2000 showed that it had the second lowest number of people working in this field in the country.[95]

Table 2.10 Rehabilitation posts in South Africa according to province 2000

	WC		EC		NC		FS		KZN		GP		MP		Lpopo		NW	
	V	F	V	F	V	F	V	F	V	F	V	F	V	F	V	F	V	F
OT	80	21	14	29	4	5	33	38	48	21	168	60	16	30	27	44	15	72
OTA	3	2		7			1	3		1	15	4			2	1		
PT	75	44	34	50	2	9	42	59	100	53	181	123	10	25	22	65	17	21
PTA	2	4	1				1	2	4	2	12	4			1	1		
ST	13	14	3	3		8	4	14	21	5	53	16	1	2	28	29		
STA	1	1								1					1			

V – active vacant posts, F – active filled posts
OT – Occupational Therapist/OTA – Occupational Therapist Assistant
PT – Physiotherapist/PTA – Physiotherapist assistant
ST – Speech & Hearing Therapist/STA – Speech & Hearing Therapist assistant

Umtata is the regional health centre for Qumbu district (which now falls under the OR Tambo District EC 156 Mhlontlo Municipality) in which the study was executed. Sulenkama is the district hospital, servicing the health districts Qumbu, Libode and Tsolo, despite its location at the north-eastern end of the region and the poor condition of the access road. Details of the services reported to be delivered by the hospital in 2000, follow. [100]

Table 2.11 Hospital services – Sulenkama Hospital (2000)

Hospital	District/Number of clinics	Facilities	Services
Sulenkama	Qumbu: 13 (Tsilitwa) Tsolo: 11 Libode: 2	180 beds 1 theatre 23 maternity beds	General medical General surgical Infectious cases Orthopaedics X-ray Physiotherapy Occupational therapy Medical laboratory

The clinic at Tsilitwa delivers a PHC service to the surrounding villages, including immunisation and routine maternity facilities. The nurse in charge, assisted by one qualified nurse, runs the clinic. A solar energy system provides power for night confinements and the refrigerator that is used for medication. The clinic is dependent on rain for its water supply.[101] The clinic is

built on a hill on the outskirts of the village with six steps leading to the entrance. Outside toilets and the access paths are not accessible to wheelchairs.

A referral system to Sulenkama and from there to Umtata General Hospital is in place for serious cases depending on the ambulance service from Sulenkama Hospital. There is no public transport available from Tsilitwa to the main road to Sulenkama and the road condition is so poor that the hospital refuses to deliver medicine to the clinic.

In spite of the reported posts for rehabilitation at Sulenkama Hospital no such services were available in 2000 and according to the matron it was not certain whether the posts existed.[102] No PWD were referred to Umtata for rehabilitation purposes. The reasons given by the matron were that the ambulance service could not accommodate the extra patient load and that PWD from the area found it difficult to come to Sulenkama Hospital because of financial and transport problems.

The international ideals, described in this chapter, clearly cannot be put into action in the study area because of the current lack of health services. It is also not appropriate to impose these ideals without consideration of the needs and customs of local communities. According to human rights principles each PWD has equal right to access to the best health services. The government policies and strategies, supported by the local DPOs, are designed to work towards the international ideals. Communities are thus confronted with these views and incorporate them into their way of life. The DPSA supports the social model of disablement as well as the Standard Rules; according to which PWD have the freedom to fully participate in their own community's culture with dignity. These guidelines thus allow transcultural interpretation. In developing countries it is important that to allow a natural progression, driven by communities needs towards professional services for all.

The complexity of disability issues is further compounded by the complexity of individual disability. The review showed that although the ICF's properties might be intricate for research and service delivery by community members,

the scope ensures that a holistic approach to both can be planned to address individual and collective needs.

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The literature review presented in this chapter illustrates the present situation on the desired position of PWD in society. Full integration can be achieved through a comprehensive, including CBR, rehabilitation programme, functioning within the support structures developed by the government of a country. For this study it is therefore necessary to examine the literature for guidelines on rehabilitation with the focus on integration into the workplace.

Chapter III

The theory of rehabilitation and the workplace

"Engagement in occupation provides opportunities for individuals to influence their well-being by gaining fulfilment in living." – *Charles Christiansen*

Theory of rehabilitation
- ■ **Comprehensive rehabilitation**
- ■ **Occupational therapy**
- ■ **Vocational rehabilitation**

The workplace
- ■ **Accessibility**
- ■ **Training**
- ■ **Placement**

Examples of programmes
- ■ **Global**
- ■ **National**

3.1 Introduction

Rehabilitation for all

"The equalisation of opportunities for persons with disabilities cannot be achieved without action-oriented programmes that are designed and implemented with the involvement of such people."

The introductory catchphrase, *Rehabilitation for all*, together with the above quote from the preamble of the National Rehabilitation Policy[95] confirms the significance of the role of rehabilitation in the process of full integration for

PWD into society. This is a case in point of putting into operation the UN World Programme of Action concerning Disabled Persons (WPA), which has rehabilitation together with equalisation of opportunities and prevention as its three major strategy themes towards a society for all.[103]

This chapter will briefly describe the rehabilitation process and provide more detail on relevant components of the process required for integration into the workplace. This information provides the background against which the methodology was developed, the terminology used and the theoretic basis for the recommendations. Lastly, some examples of integration of PWD into development projects will be examined.

3.2 Rehabilitation

The WHO defines rehabilitation as *a process that assists PWD to develop or strengthen their physical, mental and social skills.*[104]

The extended definition, adopted by the Gauteng Department of Health, describes the process in more detail. *Rehabilitation is a goal-oriented process aimed at the optimal development of the physical, mental and social functioning of a patient or client within the context of the family and the community. This process can be initiated or terminated at tertiary, secondary or primary levels. It includes prevention and treatment and is terminated once integration into the community has been attained. Rehabilitation can be considered successful once a positive impact on the health status, life style and environment of the PWD has been achieved.*[105]

Various international service models have been developed according to respective local situations. Some of the models reflect the approach of the specific discipline by which it was developed.

The delivery models most commonly described in the literature are:

■ **medical rehabilitation**, which concentrates on community health, primary prevention of disability and early medical intervention;

■ **educational rehabilitation**, which concentrates on the education of disabled children and adults through formal and non-formal education;

■ **economic rehabilitation (also known as vocational rehabilitation)**, which concentrates on the provision of vocational training to PWD in order to promote economic activity;

■ **community development**, which emphasises community awareness and creative innovation in all aspects of development, including the rehabilitation of the disabled population;

■ **comprehensive rehabilitation**, which encompasses all aspects of development pertaining to the prevention of disability, early intervention, rehabilitation of PWD, as well as community development. This model covers all categories of PWD and follows a holistic approach.[106]

3.2.1 The comprehensive rehabilitation programme

A comprehensive rehabilitation programme thus includes medical, psychological, educational, vocational and social rehabilitation.[82] Such a programme is delivered by a rehabilitation team that includes occupational therapists, physiotherapists, speech and language therapists, audiologists, psychologists, social workers and appropriate other disciplines according to the needs of the client and the situation.[107]

The roles of the various professionals recommended by the WHO[104] and envisaged by the South African Department of Health[82,95] to deliver rehabilitation programmes are summarised in the following table to illustrate how a comprehensive programme is compiled.

Table 3.1 Professional and their roles in a comprehensive rehabilitation programme

Discipline	Role
Occupational therapist	Analysis; adaptation and/or use of activities and environments to enable a client to retain or regain her/his place in society. Physical and psychological components in the personal, work/school/play, leisure and social spheres.
Physiotherapist	Physical rehabilitation and prevention of secondary disablement.
Speech and language therapist	Treatment of speech, language, and swallowing problems.
Audiologist	Treatment of hearing deficits.
Social worker	Assists the client to develop her/his full potential on an emotional, financial and social level.

The various components of the comprehensive rehabilitation programme and the inter-sectoral collaboration for their implementation are summarised as follows:[82,95]

Table 3.2 The Comprehensive Rehabilitation Programme

Type	Goal	Department
Medical rehabilitation	- limit or arrest the effects of impairment and disability, enable physical and functional abilities, continue their development and enjoy quality of life in they're natural setting.	Health
Psychological rehabilitation	- improve the client's mental health, reconstruction of thought processes, improvement of concentration and memory and the development of interpersonal skills.	Health, Education, Social Development
Educational rehabilitation	- provide rehabilitation to learners with special educational needs in order to enhance their learning abilities, enable them to develop functional abilities to enjoy a good quality of life.	Education, Social Development, Labour
Vocational rehabilitation	- develop vocational skills and aptitudes, provide guidance regarding job options, assist in the securing and training for suitable employment.	Labour, Health, Welfare, Education
Social rehabilitation	- develop interpersonal and social skills for integration into society.	Health, Welfare

The South African Health System does not have a mid-level worker or community rehabilitation worker category. The therapy assistants of the various disciplines fill the role in institution-based services.[105] The involvement of trans-disciplinary community-based rehabilitation workers in the South African service delivery system, recommended by the WHO[104,108] and strongly supported locally, is still under discussion.

As mentioned in the introduction to rehabilitation, the process can start and be terminated on any of the three service delivery levels. Ideally a rehabilitation programme should offer institution-based and community-based rehabilitation (CBR) services that are interlinked with an effective referral system, so that the services can complement each other.[77]

3.2.1.1 Types of rehabilitation services

The various types of rehabilitation services employed in the public sector are defined as follows:

- **Institution-based rehabilitation services** – are provided in a residential setting or hospital, where PWD receive short-term intensive therapy or treatment provided by specialists in a particular field. The focus is on minimising the disability.[104]

- **Outreach rehabilitation services** - are provided by health care professionals based at institutions who visit PWD in their homes. The focus is on the person's family.[104]

- **Community-based rehabilitation** – is a strategy within community development for equalisation of opportunities and social integration of PWD. Community-based rehabilitation is implemented through the combined efforts of PWDs themselves, their families and communities, and the appropriate health, education, vocational and social services. The focus is on the community.[109,110]

This study, as part of a multi-disciplinary, inter-sectoral project and because of its nature as a community development project was planned and carried out according to CBR principles. To follow the recommended guidelines it was necessary to examine this subject in the literature. The following sub-section describes the theory of CBR.

3.2.1.2 Community-based rehabilitation

Policies

The UN Expert Group Meeting on a long-term strategy to further the implementation of the World Programme of Action concerning Disabled Persons to the Year 2000 and Beyond[111] identified rehabilitation as one of the priority themes and made the following recommendations:

■ "In order to achieve the rehabilitation goal it is important, for social, psychological and economic reasons, that as far as possible, rehabilitation occurs in the social surroundings in which the person feels he/she belongs; and that it is aimed at developing coping skills to live in that community.

■ "Rehabilitation within the community is given preference to any approach involving institutionalisation and/or long periods out of the community.

■ "Community-based rehabilitation and prevention should be integrated into the normal service structures in the community. Persons needing rehabilitation should also be given equal access to all community programmes and services such as health care, education and employment programmes targeted towards their peers."

South African policy statements and discussions on the topic resulted in acknowledgement of the lack of rehabilitation services and the need for the implementation of a national policy and strategy as a priority, as well as the realisation that "CBR should form the basis of such a national rehabilitation policy"[112]. This was then formalised in the Government Gazette, Vol. 369[113].

Approach

The Integrated National Disability Strategy stresses that a *human rights and development approach* should be followed that focuses on the removal of barriers to equal participation and the elimination of discrimination based on disability.[82] These underlying rehabilitation service principles emphasise the importance of CBR as a component of the South African health services.

Community-based rehabilitation is a *systemised approach* to helping PWD within their own community, making the best use of local resources and helping the community become aware of their responsibility in this regard. Responsibility is given to the PWD as a part of that community.[114,115]

Community-based rehabilitation is recognised as a *comprehensive approach*. It encompasses disability prevention and rehabilitation in primary health care (PHC) activities, the mainstreaming of children with disabilities into ordinary schools and the provision of opportunities for gainful economic activities for adults with disabilities.[116]

Service delivery in the health district

Primary health care essentially takes place in the community and is the responsibility of local authorities; the **district** is the key level for integrated, preventive and rehabilitative components of such health care services. CBR is seen as an extension of the role of the local authority with regard to extending rehabilitation into the community.

An ideal district health care system is seen as a more or less self-contained segment of the national health system, responsible for a well-defined population, living in a clearly delineated administrative and geographical area. It consists of a large variety of related elements.[88] Multi-disciplinary professional services based at the district hospital, health posts, clinics and health centres are complemented by community-based services. These are

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provided by PHC workers who may work from these facilities and also by community-based health workers who may be volunteers.[117]

The WHO, in their description of PHC[118], stresses the principle of community involvement in the development of health services. This leads to self-reliance and reduces dependence on services delivered outside the district, as well as international assistance. Although the WHO admits that such development could lead to conflict, it is convinced of the importance of the active participation of communities in defining health problems and needs, the development of solutions and the implementation of programmes. In terms of rehabilitation, the process to establish this participation and provide these services is through CBR.

Definition and characteristics

The WHO, UN and International Labour Organisation (ILO) define CBR as follows:

> *"Community-based rehabilitation is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities.*
>
> *"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."[116]*

Miles[119] describes the key ingredients of CBR as awareness raising, public education, counselling, multi-sectoral collaboration, community development and integrated education. Naidoo,[120] in his summary of the main features of CBR, highlights three features. Murthy and Gopalan[114] agree with these features in a more expanded description of CBR and also stress the role and inter-relationship of the PWD with her/his community.

The following table compares the main features described by these authors:

Table 3.3 Features of Community based rehabilitation

Miles[122]	Naidoo[123]	Murthy and Gopalan[117]
■ Community-based	■ Community-based delivery service	■ Services are delivered to PWD in their own communities.
■ Awareness raising ■ Public education ■ Community development ■ Multi-sectoral collaboration	■ Community involvement ■ Appropriate technology	■ Community involvement - community recognises the needs of the PWD. ■ Local resources are used - specialised agencies play a supplementary role.
■ Integrated education		■ Equal opportunities are developed according to aptitude and training. ■ PWDs are regarded as recipients of and contributors to community welfare. ■ Mainstreaming of all activities regardless of disability. ■ PWD are encouraged to play a leadership role concerning disability matters.

Community-based rehabilitation is an element of community development and therefore part of planned change. Momm and Konig[106] emphasise this in their report From Community Based Rehabilitation to Community Integration Programmes. They state that a core element of any CBR programme is to change the attitude of the community towards the PWD and healing methods.

Community-based rehabilitation may be the best answer for the majority of PWD, but it is vital that each person and his/her situation is carefully assessed and an individual rehabilitation plan is put into action that will allow him/her equal opportunities for development.[121]

The WHO[117] describes the CBR team that carries out this assessment and intervention, as consisting of community workers and volunteers supported by professional specialists on secondary or tertiary levels who specialise in CBR. Co-operation between team members necessitates effective referral and support network systems and these aspects will therefore be investigated briefly.

3.2.1.3 Support networks and referral systems

Networks and referral systems are essential for the effective functioning of a CBR system.

Support networks

The purpose of a support network is to enable the community to make the best use of the resources available to them. **Figure 3.1**, a network from India, illustrates in detail the integration of private and community organisations and the government bodies that may be involved as a support network for a community.[114]
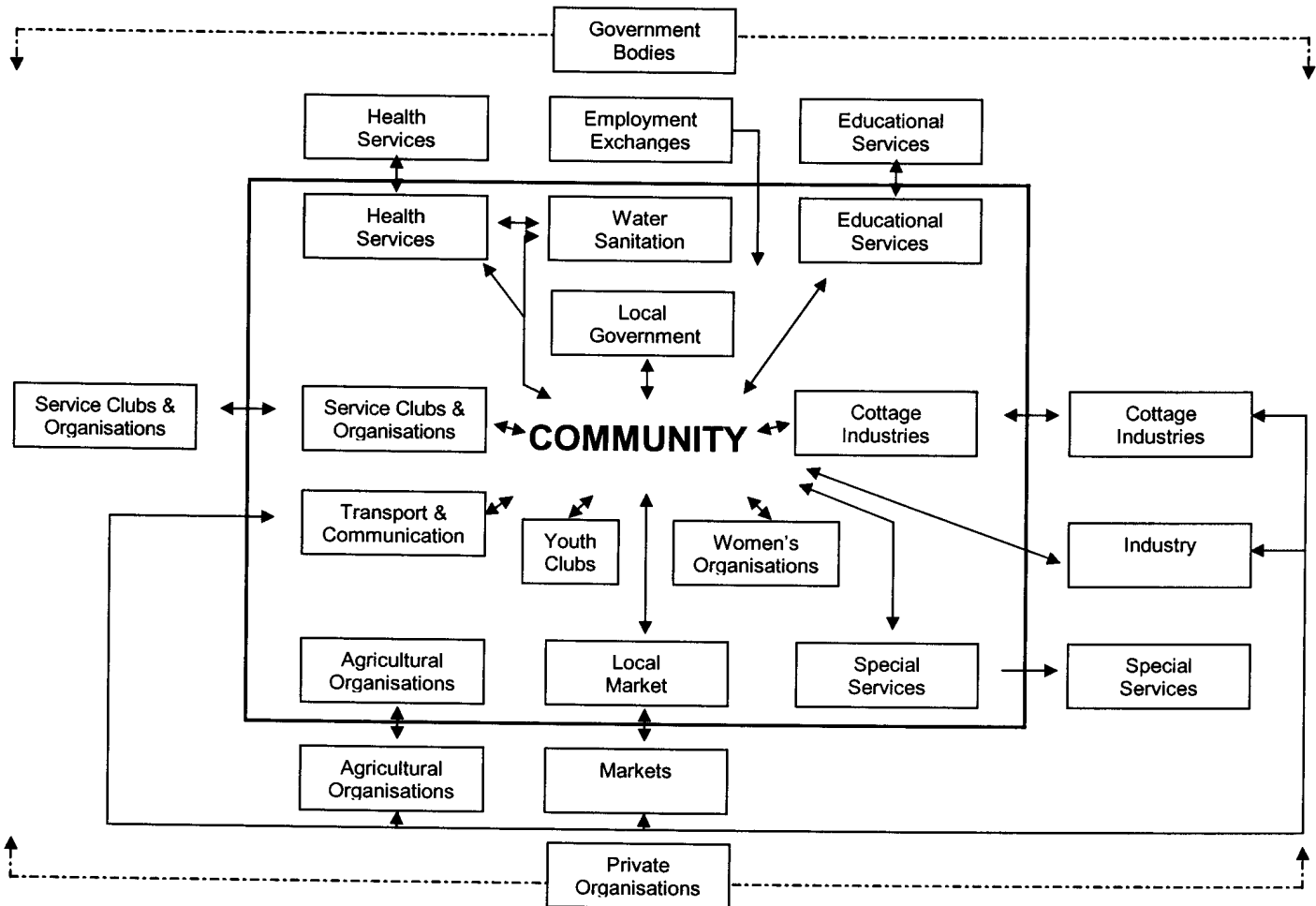
Figure 3.1 Support network (India) for the community

Referral networks

Networking is an informal yet systematic process through which people communicate to share ideas and resources in order to solve common problems and reach common goals.[122]

Formal referral networks can be established with the various governmental sectors involved as well as within the various sectors themselves to ensures effective use of resources.

The following diagram, by the WHO Committee on Rehabilitation[123] illustrates the referral pathways from within the community to the sectors involved.

REFERRAL SYSTEM

REFERRAL SYSTEM

COMMUNITY

EDUCATIONAL

| FAMILY PWD | FAMILY PWD |

SOCIAL

| FAMILY PWD | FAMILY PWD |

VOCATIONAL

MEDICAL

COMMUNITY
COMMITTEE
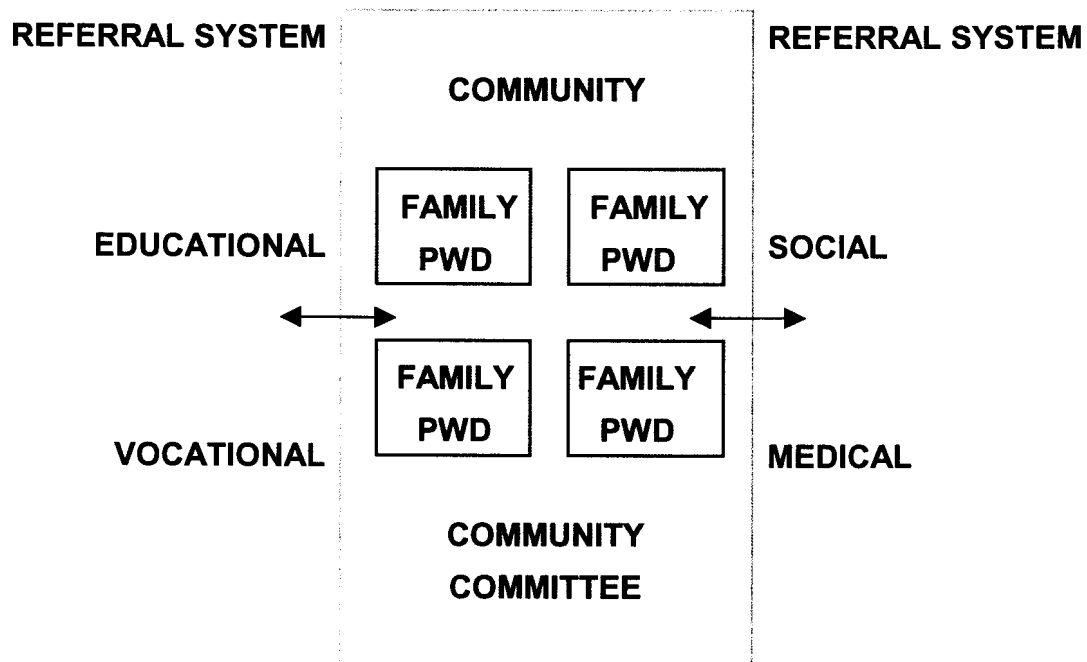
Figure 3.2 World Health Organisation Referral network

The WHO stresses the importance of support and supervision for workers at the community level.[104,109] Although the professionals are not in charge of the direction and contents of the service, Bradley and Knoll[124] emphasise the importance of specialised – and ultimately special – services in the individual education and rehabilitation plan.

The referral system allows clients and workers to utilise the various resources and services available to them on the three service-provision levels.

Figure 3.3 summarises the services available at the different levels of the three-tier health system.[108]
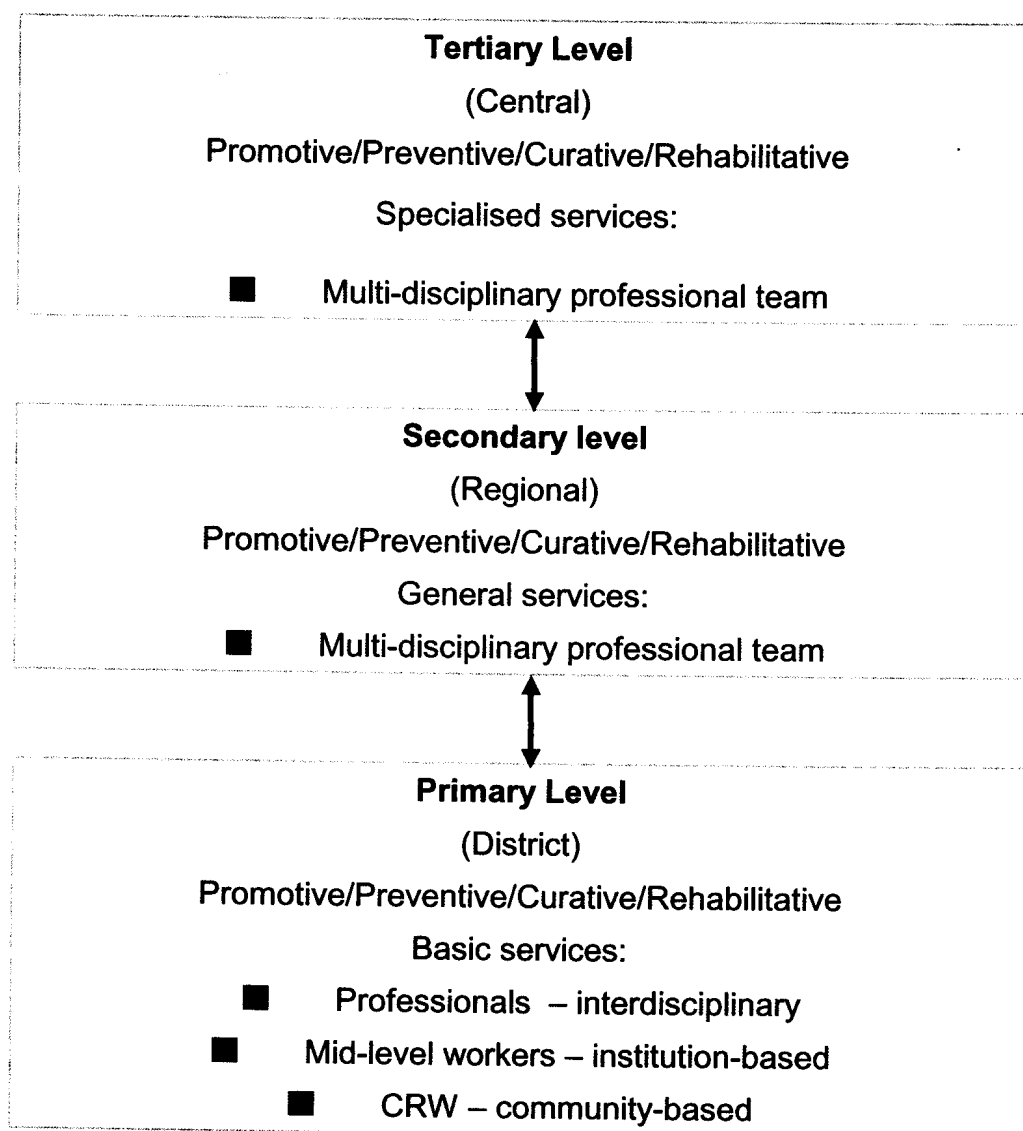
Figure 3.3 Referral network

Jackson and Mupedzwiswa[125] provide an example of how the theory was applied in Zimbabwe to provide a "chain" from community to national rehabilitation centres. From their *village worker in the community*, to the *rehabilitation assistant at the district hospital*, to the *rehabilitation team at their central hospital*, to the *rehabilitation specialists at national rehabilitation*

centres, the referral chain can be entered at any level and used up or down the chain.

The importance of access to resources and support cannot be over-emphasised for the sustainability of a CBR programme, especially in remote rural areas. Across-the-board support and referral networks are the means by which this can be achieved.

3.2.2 Occupational therapy

The occupational therapy component of the comprehensive rehabilitation programme is involved in the physical, psychological and cognitive functioning of a client on a personal and social level. The goal is to achieve optimal independence in home, workplace and community activities, for full integration into society. The focus of this study is integration into the development projects for PWD with physical disabilities and therefore the rehabilitation needed to realise this needs further investigation. A synopsis of the theoretic framework of occupational therapy will be presented with specific attention to the occupational therapist's role in vocational rehabilitation.

3.2.2.1 Definition of occupational therapy

Definitions of occupational therapy have varied over the years as the profession developed and the global views on disability evolved, for example this definition from 1947:

"Any activity, mental or physical, medically prescribed and professionally guided to aid a patient in recovery from disease or injury."[126]

The more recent definition (1998) reflects the important role taken by the recipient in current rehabilitation approaches:

"Occupational therapy is the art and science of helping people do the daily activities that are important to them despite impairment or disability."[127]

Central to all the definitions is the *use of activities* as a medium of treatment and as a *desired outcome* with the goal of integration into the community.

3.2.2.2 Theoretical basis

Occupational therapy is described as a *health* discipline rather than a *medical* discipline, because of its focus on the effects of the disease or injury and not the condition itself.[126] Instead of the more commonly used reductionist point of view in medicine, a holistic viewpoint is used to bring the abstract and concrete elements into a gestalt.[128]

Models and frameworks

To illustrate the differences between the two metamodels, some of the important concepts are summarised in the following table:[128,129]

Table 3.4 Comparison between holistic and reductionist metamodels

Holistic	Reductionist
The person is greater that the sum of its parts.	The individual is divisible into components which may be studied separately.
Systems are interactive and adaptable.	Systems are closed and fixed.
Locus of control is internal, allowing for conscious, rational decision-making.	Locus of control is external or involuntary.
Present/future oriented.	Past/present oriented.
Thoughts, feelings and perceptions are important and affect behaviour.	Behaviour is important, thoughts and emotions are by-products of physiology and/or behaviour.
Behaviour exceeds the utilitarian.	Behaviour is utilitarian.
Spirituality is acknowledged.	Spirituality is not usually acknowledged.
Subjective methods of research are valid.	Objective methods of research are valid.

Rogers[130] explores the distinction between occupational therapy and medicine by examining their views on the concepts of order, disorder and control.

Table 3.5 Comparison between medicine and occupational therapy

	Occupational therapy	Medicine
Order	Competence in occupational performance in work, play, self-care, social activities	Absence of disease – "health"
Disorder	Performance dysfunction	Disease
Control	Internal	External

The philosophical roots of occupational therapy can be traced back to the moral treatment movement in psychiatric hospitals, early in the nineteenth century, but Meyer, in his address to the 5th annual meeting of the National Society for the Promotion of Occupational Therapy in 1922, is widely credited for conceptualising the role of performance and completion. He emphasised the importance of achieving self-fulfilment and suggested that "mental illness" is a problem of living rather than a structural disorder and that occupational therapy provides the opportunity "to work, to do and to plan and create."[126]

Christiansen and Baum[126] summarise the important beliefs and values of occupational therapy as follows:

■ Engagement in occupation is of value because if affords individuals the opportunity to influence their well-being by gaining fulfilment in living.

■ Through the experience of occupation or doing, the individual can achieve mastery and competence in skills and strategies for coping with problems and adapting to limitations.

■ With competence the individual gains autonomy and independence.

■ Autonomy implies choice and control over the environment, thus opportunities for exerting self-determination are a characteristic of intervention strategies.

■ Occupational therapy is a collaborative process between the therapist and the recipient of care, whose values are respected and whose needs and choices influence decisions for intervention.

■ The focus is on life performance. It is neither somatic nor psychological, but concerned with the unity of body and mind in doing.

Occupation is defined as:

Behaviour which is motivated by an intrinsic, conscious urge to be effective in the environment in order to enact a variety of individually interpreted roles that are shaped by culture and tradition, and learned through the process of socialisation.[131]

The understanding of occupation includes all the things people do, the relationship of what they do with who they are as humans, and that through occupation they are in a constant state of becoming different.[132] A dynamic balance between doing and being is central to healthy living. Occupational therapy enables occupation for personal well-being, community development, prevention of illness, and advances social justice.

Occupation is the domain of concern as well as the medium of therapy for activating participation that is presented through coaching, facilitating and other enabling approaches.[133]

Occupation is not simply any activity, not even any purposeful activity; it is an activity that is both meaningful and purposeful.

Meaning refers to the personal significance of the activity for the client and provides a source of motivation.

Purpose pertains to the client's personal aim, reason for doing or intended goal and helps to organise the client's performance.[134]

An important conceptual framework in current practice is the *person-environment-performance framework*. This framework takes into consideration the multiple factors that influence occupational performance, including

characteristics of individuals, their unique environments and the nature and meaning of their activities, tasks and roles. The open system approach of the framework allows studying human behaviour within the social sciences, incorporating information from other professions and disciplines. It embraces concepts, addressed by respected authors like Mosey (1974, 1985) and Engel (1977) and included in familiar occupational therapy models, such as Kielhofner and Burke (1980) and Howe and Briggs (1982). The key arguments are as follows:

- Performance is the result of relationships between the individual as an open system and the specific environments in which the tasks and roles occur.

- Stages of development influence motivation, skills and roles, and therefore affect occupational performance.

- Occupational performance is a bio-psycho-social phenomenon determined by biological, psychological and social factors.

- Occupational therapy is viewed as a means for facilitating an individual's adaptation when performance deficits are identified.[126]

The unique contribution of occupational therapy is to maximise the fit between what it is the individual wants and needs to do, and his or her capabilities to do it.[126]

Motivation to perform the tasks and activities of one's life roles is an important factor in occupational performance. As an intrinsic enabler, motivation has many theories and approaches used according to various academics' and practitioners' background, but it remains a central factor in occupational therapy. It is the focal point of occupational therapy practice and receives constant attention as intrinsic enabler as well as a treatment objective. The roots of theories reach as far as Maslow's hierarchy, but for the purpose of this study the researcher selected the Vona du Toit model of Volition and Action. The following sub-section provides a summary of the theory of this approach.

Vona du Toit – Volition and Action

The aim of Du Toit, in the development of the model, was to develop a guide for assessment and treatment of volition. A person's volition is assessed through observation of her/his behaviour. The response of an individual towards opportunities offered is termed creative response. Instead of subjective evaluation, she developed a scale of measurement to recognise symptomatology of the stages in the sequential development or recovery of creative ability.[135]

Du Toit describes motivation and action as the two components of volition. *Motivation* represents the energy source of occupational behaviour and governs the *action*, which is the expression of the motivation that exists within the individual.[136]

The advantages of the approach based on this model are:

■ The characteristics of motivation and action at each level of growth or recovery may be analysed.

■ The direction and content of treatment aimed at restoring motivation by means of action is defined.

■ Demands made on an individual interpersonally and socially are systematised.

■ Criteria for selecting, presenting and grading activities on each level of motivational recovery can be extracted. The level attained by the individual can be stabilised and the next level stimulated.

■ The work readiness of an individual can be determined.[137]

The levels of motivation and action as described by Du Toit are illustrated in **Table 3.6**.

Table 3.6 Levels of motivation and action

Level of volitional growth	Level of activity participation
Positive tone	Pre-destructive action Destructive action
Self differentiation	Incidental creative action
Self presentation	Explorative action
Participation: ■ Passive ■ Imitative ■ Active ■ Competitive	■ Participative action ■ Passive ■ Imitative ■ Original ■ Product centred
Contribution	Contributive action (situation centred)
Competitive contribution	Competitive-contributive action (society centred)

The quality of the product resulting from the action and the employment potential of the individual are summarised in **Table 3.7**

Table 3.7 Levels of volition and work potential

Level	Quality of product	Employment potential
Positive tone	No product, fleeting focus or haphazard movement	No employment potential
Self differentiation	No tool handling, no construction – coincidental product	1-step guided activity in institution or home
Self presentation	Explorative handling of tools and materials – semi-planned product	Sheltered workshop – production < 50%
Passive participation	Product centred with guidance	Sheltered workshop – Production > 50%
Imitative participation	Product centred with supervision – product completion according to basic norms	Repetitive, imitative work in sheltered workshop or in selected open labour market
Active participation	Product centred, independent – quality control	Open labour market after training
Competitive participation	Complexity of the product and standard depend on interest and abilities – takes personal responsibility	Open labour market
Contribution	According to situation	Managerial and high responsibility position
Competitive contribution	According to interest	Do. – research

The scale of volition and action can be used effectively in the community where the individual is observed in activities of daily living and in social settings. The value of the scale lies in the explanation of the individual's level of functioning and its capacity to predict functioning in work situations for PWD.

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Treatment in a holistic approach includes not only the physical and psychological aspects but its success depends on whether the therapist assesses the level of motivation correctly, so that the intervention can be presented on and for the right level. The personal circumstances and opportunities of the client provide the basis of the plan for intervention. The needs and aspirations of the client, the potential abilities (depending on rehabilitation prognosis) and the opportunities are all considered in setting the treatment goal. This is done in co-operation with the client and in consultation with the family where possible.

The following sub-section outlines the occupational therapy process.

3.2.2.3 The occupational therapy process

Although the occupational therapist carefully crafts an individual treatment programme for each client, the process remains the same. **Figure 3.4** illustrates this process adapted from Christiansen and Baum.[126]

Case identification or referral

Screening

Assessment:

■ **Condition and background**
Occupational performance
contexts

■ **Needs and aspirations**

■ **Occupational performance**
areas

■ **Performance components**

Continuous adjustment and
refinement take place
during these processes

Intervention plan

Intervention with conscious
evaluation

Formative assessment

Summative assessment

Termination of treatment

Figure 3.4 Occupational therapy process

Assessment

In many institutions, particularly where a more medical model is applied in treating acute patients, therapists use a bottom-up assessment and treatment approach, which focuses on the deficits of components of function.

The rationale underlying this approach is that generic task abilities support tasks in all occupational performance areas and that by re-establishing these abilities the occupational performance will be restored.[127]

In post-acute programmes and particularly in community-based programmes therapists use a top-down approach, which starts with an inquiry into role competency and meaningfulness that clarifies the purpose of occupational therapy. Discrepancies between present, past and desired future roles are identified as well as further assessments to establish which tasks are affected are carried out through a functional assessment. Finally, the performance components that cause the functional deficits are investigated so that activities that would improve the component can be selected for treatment.[138]

The fundamental rationale underlying the top-down approach is that although impairments cannot always be cured, performance of valued roles can be improved by adaptive task performance.[127]

Structured or semi-structured clinical interviews are used to establish the:

- Organisation of daily living routines,

- Life roles,

- Interests, values and goals,

- Perceptions of abilities,

- Environmental influences on the occupational performance.[139,]

In clinical settings a variety of assessment tests and formats are used to evaluate the occupational performance in the various performance areas (e.g. Functional Independence Measurement (FIM)[140] for activities of daily living,

the Valpar assessment system for work skills etc.). In community-based programmes a preferred method is a functional assessment carried out in the PWD's home so that whilst the activities of daily living are assessed, the social context can be taken into account. Family roles, dependency on family members, performance expectations or available adaptive equipment and the effect of the disability on the PWD and the family can be observed.[141,142]

Clinical assessments of component deficits (e.g. muscle strength, range of motion) and standardised tests to complement the clinical expertise (e.g. memory, visual perception) are used to measure the deficit for treatment or compensation.[143]

An appropriate mix of assessments is carried out during treatment programmes and at the termination of treatment to establish whether the outcome has been reached.

Treatment

In promoting independent, safe and adequate task performance an occupational therapist may use either a remedial, rehabilitative (compensatory) or educational strategy.[126,144]

The three strategies can briefly be explained as follows:

■ A *remedial strategy* aims at correcting physiological or psychological, performance components to achieve normal occupational performance.

■ A *rehabilitative strategy* is followed to compensate for impairments in performance components by compensating with another component or adapting the task or the equipment used to execute the task. This occurs when the medical prognosis indicates that no, or no further, improvement can be expected. In situations where opportunities for intensive treatment programmes are limited, a therapist might opt for this approach to maximise a client's occupational performance.

■ An *educational strategy* is used when imparting information can assist the individual to enhance his/her occupational performance.

In **Table 3.8** these strategies are explained by using examples from the physical field, which is the focus of this study.

Table 3.8 Treatment strategies in occupational therapy

Major intervention strategies in occupational therapy

Use of occupation as a therapeutic medium

Strategies for sensory and neuro-motor remediation	Adaptation of physical environment	Assistive devices	Education and training strategies
Include:			
strategies directed toward remediation of sensory and motor deficits; based on biomechanical and neuro-physiological principles	strategies to modify aspects of the physical environment	the use of mechanical or electronic devices which enable the client to fulfil his roles despite limitations	strategies which enable the client to acquire abilities and skills necessary for occupational performance or roles with remaining abilities
Example:			
Neuro-motor techniques used to relearn motor control after strokes	Ramps to allow access for individuals in wheelchairs	Typing aids to assist quadriplegic persons to use the computer	Joint-conservation techniques for persons suffering from rheumatoid arthritis

Each client is unique and his/her circumstances differ from anyone else's. Therefore intervention is planned individually for maximum effect. However, there are general principles that apply to everyone.

General principles relevant to occupational therapy are:

■ The patient is an agent of change – Occupational therapy has a collaborative, co-operative orientation to intervention. The client is not a passive recipient of care, but is actively involved in establishing goals and developing skills. The final outcome of the treatment is ultimately dependent on the will and determination of the client.

■ The occupational therapist serves as a teacher-facilitator – The therapeutic relationship fosters an understanding of the client's terms of past and present with the purpose of planning and working for the future. It is characterised by belief in the dignity and the worth of the client's potential for growth and caring. The therapist guides the process.

■ The treatment setting is an environment for developing life performance skills – Each treatment session represents an opportunity for progress. The setting is organised to promote maximum performance by integrating relevant challenges with an appropriate context.

■ Occupation is the preferred medium of treatment – Occupational performance, when analysed with expertise and selected with knowledge of the client's level of ability, motivation, skill, interest and goals, is the most effective intervention strategy. Purposeful activity is meaningful to the client and therefore an effective vehicle for the change she/he desires.[126]

The process can thus be summarised as a dynamic process of determining the occupational performance needs of the client, designing and implementing intervention that is uniquely suited to his/her life circumstances and is sensitive to the individual's interests, values, roles and aspirations. The process enables improvement in abilities and skills needed for satisfying life performance.

The various fields of specialisation in occupational therapy are:

■ Paediatrics

■ Psychiatry

■ Physical:

■ Spinal

■ General medicine (burns, cardiology etc.)

■ Orthopaedics (hands, amputations etc.)

■ Adult neurology (stroke, head-injury etc.)

■ Vocational therapy.

The following section presents a brief overview of the theory of vocational therapy and international policies that support the integration of PWD into the workplace.

3.2.3 Vocational therapy

Engagement in productive or work activities is fundamental to human endeavour. Integration into the workplace is the gaol of most adult rehabilitation programmes.

Vocational therapy, work-related programming or work practice are some of the terms used for occupational therapy programmes that focus on pre-vocational skills (e.g. social skills like eye-contact, co-operative behaviour; task focus; motivation, reliability) and vocational skills (capabilities to perform specific tasks needed for a position of employment) for participation in productive activities.[145,146]

Productive activities or work, according to Kielhofner, are those activities that provide a service or commodity needed by another or that add new knowledge, artistic objects or performances to the cultural tradition. Productive activity thus maintains and advances society.[147]

The fundamental motive for work is economic. Cultural norms of a society dictate the methods and motives for productive activities.

Work is perceived differently in different circumstances. In western societies work is typically restrained by schedules and discipline. Workers have little autonomy and the product is made for the benefit of somebody else.

Subsistence workers, in developing countries, work to satisfy their own needs. They produce their own commodities and exchange excess for other goods they require.[148]

Work is highly valued in modern society and the worker role provides individuals with:

■ A means for practical survival,

■ Improved feelings of self-worth,

■ A sense of belonging by contributing to society,

■ Structure to their life,

■ Social connections.

The following diagram, based on the terminology of the ICIDH-2,[149] illustrates the combination of personal abilities and contexts in work activities and how the participation in work activities can positively affect the individual.

ABILITY   CONTEXT

Personal factors   Environmental factors
(Body functions and structures)   (Participation in life situations)

TASK
(Work
activities)

Satisfaction   Contribution
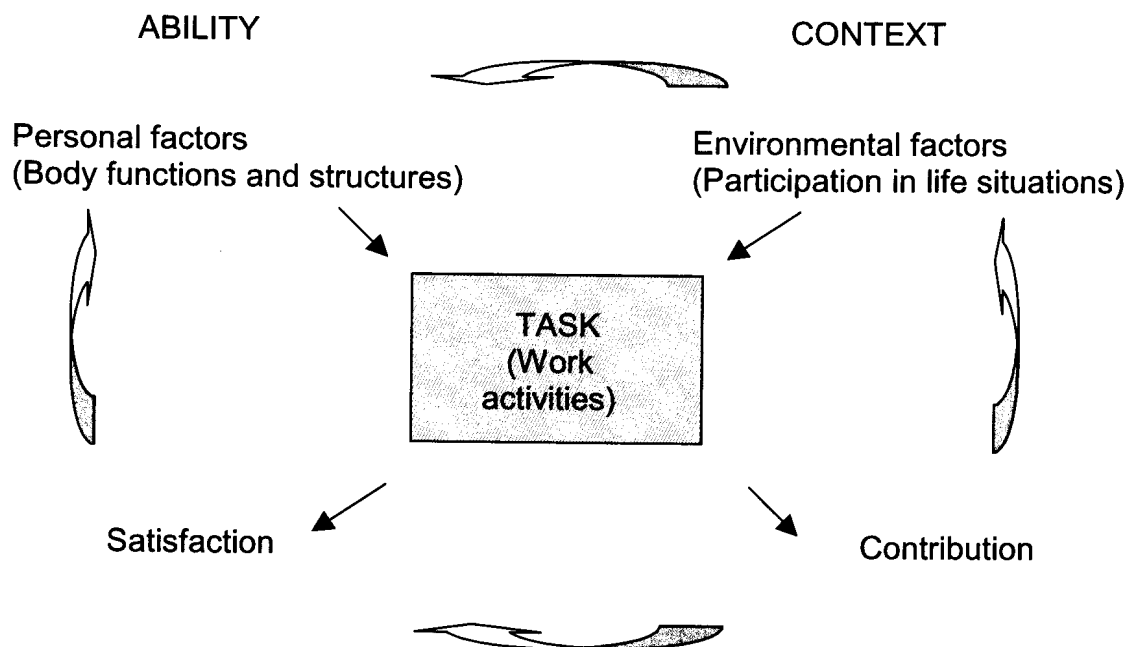
Figure 3.5 Value of work activity performance

According to the person-environment fit framework, a fit between the person and the culture of the workplace is the prime determinant for successful employment. Affording clients control over facets of their employment situation is an important aspect of increasing job satisfaction and reducing stress.[148]

3.2.3.1 Occupational therapy vocational rehabilitation process

Vocational therapy as defined by the ILO is *the continuous and co-ordinated process of rehabilitation which involves the provision of vocational services e.g. vocational guidance, vocational training and selective placement, designed to enable a PWD to secure and retain suitable employment.*[150]

The process of work reintegration begins with assessing the client's rehabilitation potential to return to work. It is followed by clinical reasoning and analyses of both the client and the potential work, which leads to a job match and ends in placement.[151,152]

Assessment

The occupational therapy assessment procedures performed are:

- Review of medical, educational and vocational records,

- Interviews with the client, family, employer (if employed before the incident), teachers (if school leaver) and rehabilitation professionals,

- Observation during simulated activities or work samples that relate to the client's interest field,

- Standardised tests.[150]

The purpose of the assessment is to predict the current and future employment potential of the client. Mental, emotional and physical abilities and limitations are evaluated along with the client's interest and special needs for adaptations. The focus is on the individual's strengths and weaknesses in relation to employability factors and specific vocational skills.[146]

Functional capacity assessments are increasingly used to determine role performance, task breakdowns and activity analyses. These assessments evaluate clients' over-all physical capacities for work-related tasks. They mainly involve the use of hands in bilateral activities, bending and lifting.[148]

Treatment

Remedial and rehabilitative treatment objectives may be set for the enhancement of pre-vocational or specific vocational abilities to reach the client's optimal level of functioning for work. Once this level has been reached the necessary adaptations can be determined.

Programmes include education and instruction in injury prevention, postural awareness, pain management and joint protection.

Work hardening programmes are designed to improve the client's productivity. A comprehensive interdisciplinary approach is used in which graded work-simulation addresses bio-medical, psychological and social problems.[148] Emphasis is placed on prevention of repetitive strain injuries and accumulative trauma disorders.[153] The purpose of these programmes is to:

- ■ Restore lost confidence,

- ■ Build morale and self-confidence,

- ■ Instil good work habits,

- ■ Increase work tolerance.[154]

Education programmes for return-to-work issues include job interview skills and skills to retain employment.[151] Team building methods are often employed to create opportunities for socialisation and development of self-esteem.[155]

Training

Recommendations are made for training of PWD who have not worked before or are considering a new career. The following basic principles apply:

■ If a PWD can be placed in suitable employment without training, vocational training is unnecessary.

■ Training should wherever possible be carried out under the same conditions as for non-disabled persons.[156]

■ Training should continue until the PWD has the necessary skills to work on an equal basis with non-disabled workers, if she/he is capable of doing so.

■ Training is wasted unless it leads to placement in the learned trade.[154]

Placement

The placement provided should, wherever possible and appropriate, be in the occupation in which the PWD was previously employed or with the previous employer in a related position.[150] The South African Labour Relations Act and Code of Good Practice on Key Aspects of Disability in the Workplace prevent unfair dismissal because of disablement and implement the international guidelines for job-retention after an injury.[156,94,157]

Successful placement depends on recognition of the PWD as an individual with personal interests, abilities, qualifications and experience. The skill in matching the person with the requirements of the job depends on knowledge and expertise in vocational assessments and job analysis.[154]

The placement process involves the following steps:

■ Workplace assessment – including job analysis to establish motor, sensory, cognitive, perceptual, emotional and social requirements[158] needed for the job, as well as possible modifications that will make a match possible. The job analysis includes a description of observable activities or end products and the identification of required work behaviours.[159]

■ Job match – including practical adaptations.

■ Employer counselling – in terms of adaptations, handling and supervision.

■ On the job training – including evaluation of adaptations and productivity.

■ Follow-up and support – including check of adaptations.[151]

Employment options

Full integration into the open labour market is the desired outcome of vocational rehabilitation. However, personal and environmental conditions might necessitate the consideration of other options. The following options exist:

■ Open labour market – assisted by removal of architectural barriers, legislation and incentives for employers.

■ Self-employment – provided the PWD has the necessary business acumen, knowledge and skills for the specific business, and sufficient capital.

■ Co-operative for PWD – if possible in collaboration with co-operatives of non-disabled.

■ Sheltered employment – provided for PWD who, because of the nature and the severity of their disability, cannot function independently in any of the above options.[154]

3.2.3.2 Inter-sectoral collaboration

For effective integration of PWD in employment the following sectors of government need to collaborate:

■ Department of Health – the continuous process of rehabilitation that has as its outcome successful placement, starts with medical rehabilitation and ends with vocational rehabilitation. It is initiated by health authorities and in many countries remains their responsibility.

■ Department of Education – mainstream education that addresses the specialised needs of PWD resides with the Department of Education, which needs to ensure that PWD have access to all types of training.

■ Department of Labour – legislation to afford PWD equal opportunities to employment is generated by this department, which is then also responsible for creating employment opportunities and initiating the removal of barriers.

■ Employers' and workers' associations – play a role in determining the extent of employment opportunities by including the issues of equal opportunities in their agendas.[154]

Collaboration between these government departments as well as social welfare departments will provide co-ordinated policies. Planning and delivery of programmes should, however, be undertaken in close partnership with DPOs to ensure that services are appropriate and adaptable to the needs of the PWD themselves.

3.2.3.3 Community-based approach to vocational rehabilitation

Vocational rehabilitation is mostly delivered from an institution that has the necessary testing equipment as well as strong links for placement with the Department of Labour, the open labour market and various DPOs and NGOs that offer sheltered employment opportunities,.

The literature did not provide published work on community-based programmes except an ILO paper, titled Guide for community-based vocational rehabilitation of disabled people – The case of the Philippines.[160] This paper, although it provides advice for starting a vocational rehabilitation programme, actually describes the establishment of a workshop for PWD in a rural community. The issues of assessment, analyses and job-matches executed by those volunteers were not addressed.

However, valuable points to note from the paper are that:

■ No community-based services can be imposed on a community; they should be understood and wanted by them.

■ Community resources include informal help from within the families and are driven by goodwill and interest.

■ As many people as possible, including local government, should be involved to strengthen the support network. Public awareness should be created and maintained by regularly informing the community of objectives and progress.

■ The start should be small.

■ A relationship of trust and understanding is vital for the sustainability of the programme; this includes relationships with the PWD, their families and the community at large.

■ Education in the form of information about disablement issues and training are cornerstones of the programme.

3.2.3.4 Integration of persons with disabilities into employment

Integration can only occur if accessibility to the workplace is enhanced and stereotypes are removed. PWD are excluded from employment because of inadequate or inappropriate education, combined with physical and social barriers to employment. Equal rights not only mean treating people the same in spite of their differences but also treating people as equals by accommodating their differences, providing so-called "same life opportunities". A transition in social orientation combined with curriculum development, assessment and training facilities is needed to bring about access to employment opportunities.[161]

3.2.3.5 Categorisation of work

Functional assessment of work capabilities is complex, is not practical in all situations and cannot be carried out by persons without knowledge and expertise in the field. The following classification of work according to its physical demands can be used for evaluation and recommendations about the general categories of work that would be suitable:[162]

Table 3.9 United States Department of Labour - Physical demand characteristics work chart

Physical demand level	Occasional: 0-33% of the day	Frequent: 33-66% of the day	Constant: 67-100% of the day	Typical energy required
Sedentary	5kg	Negligible	Negligible	1.5-2.1 MET
Light	10kg	5kg and/or walk/stand/push /pull of arm/leg controls	Negligible and/or push/pull of arm/leg controls while seated	2.2 - 3.5 MET
Medium	10 - 25kg	5 - 12.5kg	5kg	3.6 - 6.3 MET
Heavy	25 - 50kg	12.5 - 25kg	5-10kg	6.4 - 7.5 MET
Very heavy	Over 50kg	Over 25kg	Over 10kg	Over 7.5 MET

MET – Metabolic equivalents

This chart can be used to make recommendations regarding the PWD's fitness for work. Specific job placements will then be undertaken according to the physical demand level of the position.[146] This type of categorisation is useful in well-resourced rehabilitation systems of developed countries where work demands have been analysed and work is performed in a controlled environment. For community based services recommendations for placements need to be based on individual work and workplace analyses.

3.3 The workplace

Physical accessibility and the effects of the work environment on performance, productivity and the health of employees are well documented. A brief overview of the most important factors involved in allowing full access to a workplace follows.

3.3.1 Physical accessibility

Physical accessibility includes suitable transport; ramps and wide doors to allow wheelchair access; ergonomic considerations in terms of work surface or equipment positioning; assistive devices like hands-free telephones etc.[145,163]

Ramps and door widths should be included in general architectural and ergonomic design. Some of the other adaptations need individual attention to ensure maximum productivity.

Design considerations include task specialisation, attention to lighting or adjustments to controls or displays, to reduce stress and physical effort.[164]

The philosophy behind placement of PWD, however, is to find placement solutions that require minimal adaptation.

PWD who need assistance because of mobility limitations or difficulty with minor tasks can be placed together with an assistant, to ensure the support needed to enable the individual to execute the work she/he was employed for.[161]

3.3.2 Access to opportunities

Ensuring that PWD have equal opportunities and therefore access to work they can do, depends on government policies (see **Chapter II**) and attitudes of employers.

Special legislation, which promotes quota schemes and for which registration of disabilities is required, is perceived as discriminatory by DPOs. The resulting categorisation confines disability and conditions to specific definitions that do not recognise the abilities of individuals.[161]

3.4 Examples of programmes

Although full integration is promoted internationally and policies and guidelines clearly support equal opportunities, the policies do not seem to be put into practice. The literature search provided examples of specialised workshops and projects for PWD or examples of self-employment initiatives,[165,166,167] but little on efforts to integrate PWD into mainstream work opportunities and even less on involving them in community development projects. Finding effective processes to implement the policies in the varied circumstances of our global community is thus of utmost importance.

3.4.1 Global

Developed countries in Europe provide access for PWD to the workplace, although the successes are limited.[161,168] In the United States of America legislation provides for PWD in rural areas and facilities for rehabilitation and workshops for the disabled are provided.[169]

Siriwardane from Sri-Lanka addressed employment for PWD in developing countries, in line with the global philosophy. He analysed the situation and found that most of the PWD with motor and upper limb disabilities in the Asia Pacific region live in rural areas. Their needs and constraints are education, employment and transport. District health and social services provide basic services and sometimes also vocational rehabilitation.

Traditionally it is considered the family's responsibility to look after the PWD. In rural areas poverty, lack of knowledge, social attitudes and beliefs affect the extent to which the individual PWD may be able to develop.

He found that there are income-earning opportunities within rural communities, but a lack of understanding often prevents PWD from participating in such endeavours.

He concluded that the following is needed to fully integrate rural PWD into their communities:

- ■ Awareness programmes to change negative social attitudes,

- ■ Facilities for education,

- ■ Financial aid to engage in income generating projects,

- ■ Correct assistive devices,

- ■ Better health and recreational facilities,

- ■ Better rehabilitation facilities.[170]

Hanko in her studies of rural PWD in Cambodia, Lao PDR, Thailand and Vietnam investigated the re-adaptation and reintegration of PWD into their communities.

She stated that to create centres uniquely for PWD meant to limit the range of opportunities and, consequently, of interest. Integrating PWD into existing co-operatives is the fastest and most feasible way for the individual to participate in community life.

She recommended that the UN Food and Agricultural Organisation should consider the following in the development projects they set up in rural areas:

- ■ Suitable land in terms of accessibility for the project;

- ■ Facilities that are suitably adapted to allow access for PWD;

- ■ Transport facilities, good roads and paths that are wheelchair passable and public transport that accepts persons with wheelchairs;

- ■ Accessible workspace with ramps and accessible toilets;

■ Appropriate tools and machinery, which may require adaptations or modifications;

■ Recreational facilities for socialisation;

■ Medical care with special attention for PWD, rehabilitation services that include vocational rehabilitation and promote employment opportunities;

■ Educational opportunities for all;

■ Welfare and supervision to monitor human rights;

■ A running budget until the activity becomes profitable and self-sustainable.

She recommends that detailed studies be undertaken to establish the type of disabilities and evaluate the industries and sectors in which PWD may be integrated most successfully.

Her plan of action provides for:

■ Networking with various organisations and sectors (health, welfare, education, employment). Networking would also provide advocacy for disability issues;

■ Funding from relevant government institutions, NGOs and development agencies;

■ Identification of the organisation that would provide training and skills development for PWD;

■ Development of projects that are market and development policy related;

■ Adaptation of physical environment.

In closing, she emphasises that integration into existing structures allows immediate access to participation in income generating activity and allows a greater freedom of choice for the PWD. Although the main objective is income

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generation the objectives of physical rehabilitation, emotional stability, self-satisfaction and happiness lead to a normal, healthy lifestyle.[171]

Liton reports that in Bangladesh PWD have established groups that meet weekly. These meetings have increased their mobility in the community, built confidence and reduced dependency. Oxfam-GB organised workshops on "integrating disability issues into on-going development activities without additional financial support". Since then a few partner organisations have established education centres for adults that include PWD. These initiatives appear to have created awareness and increased acceptance of PWD in the communities. At the time of the report 699 PWD were involved in existing income generating activities on the strength of their abilities, knowledge and experience. Capacity building for PWD was undertaken by involving them in various training programmes.

This application of the policies is encouraging, because it shows the positive effect of such integration. However, Liton reports that they encountered problems that need to be addressed to strengthen the process, e.g. a lack of mobility aids, accessibility problems, a lack of awareness of family and community, absence of rehabilitation facilities and shortage of experts in the field.[172]

3.4.2 National

Personal communication with the Department of Health's directorate of Rehabilitation, DPSA and the Disability Action Research Team (DART) established that no integrative employment programmes were in existence or even planned.

The invitation to work with the interdisciplinary development team from CSIR afforded the researcher the opportunity to investigate the feasibility of integrating PWD in South African rural areas into development projects and develop a methodology to allow such integration to become part of rural development programmes nationally.

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Personal experience of research in rural communities and the freedom accorded the CSIR team to design a research approach and methodology according to need lead to the development of the methodology described in the following chapter.

Chapter IV

Methodology

"There is one thing even more vital to science than intelligent methods; and that is, the sincere desire to find out the truth, whatever it may be."
- *Charles Sanders Pierce*

Introduction

Aims of the study

Research design

Population

Research Materials

Procedures
  ■ **Data collection**

4.1 Introduction

Needs should be identified where they emerge, not out of textbooks. C.C. Chen

In spite of the growing awareness of integration of PWD globally and locally during the last decades of the previous century, the literature and agency work reviewed show little evidence that these guiding principles are being applied in development work. This study in itself is thus development of research into the field of holistic development, i.e. development without discrimination ensuring equitable access for the most neglected of the marginalized groups, the PWD in rural communities. Effective implementation of policies and guidelines depends on investigations that establish whether these documents meet the needs of the people they are to assist.

This chapter therefore describes not only the final methodological process applied during the implementation of the study, but will also outlines the reasoning that led to the actions carried out in the study.

4.2 Aim and objectives of the study

The Tsilitwa Development Committee (TDC), by voicing their concerns about the PWD in their community to the CSIR team, provided the impetus for this study. The aim and objectives were finalised and approved in consultation with Sister Madikane and concerned members of the TDC.

The participatory research approach ensures that the intended beneficiaries are involved in the setting of priorities.[173] The priority identified by the community for this sub-project within the sustainable development project in Tsilitwa was to investigate opportunities for work for the PWD within the community.

4.2.1 Research question

An important point on the agenda for the first meeting between the researcher and those members of the TDC assigned to the new sub-project for PWD in Tsilitwa was to refine the primary research question. In the discussion the following factors were considered:

■ Work opportunities are scarce in rural villages in the Eastern Cape.

■ The projects initiated in the past by various groups in the community did not involve PWD.

■ The skills and abilities of the PWD in Tsilitwa have not been assessed.

■ The barriers that prevent full integration have not been ascertained.

■ PWD have the right to be included in their community projects according to capabilities and not to be separated from the rest of the community.

■ The Employment Equity Act ensures the right to employment opportunities for all inhabitants.

■ Facilities have to be accessible if the Act is to be implemented.

■ New development planning should take the above-mentioned factors into account.

■ Not all PWD in Tsilitwa receive a government disability pension.

■ Some recipients of disability pensions use the money to maintain undesirable habits out of boredom and frustration (e.g. substance abuse).

■ Notwithstanding policies that advocate full integration, development projects worldwide have not yet included PWD as citizens with full rights to participate in the planning of development and be included in the resulting income generating projects.

These considerations led to the formulation of the research question that is feasible, novel, ethical, of interest to the research team (the researcher, the CSIR team, the TDC members involved and the research assistants) and above all relevant in the present local, national and global climate.[174]

Can the Tsilitwa PWD be integrated in the local development programme?

4.2.2 Aim of the study

From the boundaries that were set by the discussions on priorities and the questions identified as pertinent to address the needs and aspirations of PWD in terms of integration into the local workplace the following aim and objectives were formulated:

The aim of the study is to investigate the opportunities for the integration of PWD into the TDC's development programme.

4.2.3 Objectives of the study

The objectives to be met to achieve this aim were to:

1. Draw up a community profile in terms of the adult PWD

Because of the current lack of information on demographics of PWD in rural South African communities it was necessary to investigate the number of persons involved, their specific disabilities, needs and aspirations, residual and potential work skills, as well as the community's attitude toward their inclusion in the development programme. The following points were agreed upon for investigation:

■ Number of adults with physical disability,

■ Needs and aspirations of the PWD and the community/care-givers for integration into the workplace,

■ Level of skills of the PWD in the area,

■ Attitudes of the PWD, caregivers and community to equal employment opportunities for PWD.

2. Investigate the planned job creation projects in the IRDM for suitable integration of the PWD

To establish opportunities to involve the PWD in the projects planned by the TDC, a list of these projects was obtained. The projects were to be analysed in terms of the physical requirements needed to perform the various tasks they consist of. The facilities in which the projects were to be housed needed investigation in terms of accessibility according to the needs of the various types of disabilities found in the area. It was also decided to investigate local resources for vocational rehabilitation and adaptations needed to place the

PWD successfully in the planned projects. To achieve this objective it was therefore necessary to analyse and investigate the following:

- Job analyses of planned projects,

- Facilities,

- Resources in terms of the training and adaptations needed by PWD.

3. **Assess the placement possibilities for integration of the PWD into the workplace developments.**

In order to establish whether the PWD of the community could be successfully integrated in the income generating projects their abilities needed to be matched with the job requirements established in the job analyses. This included whether adaptations would be required to perform the tasks. The objective thus required the following two tasks:

- Job match and

- Establishing the adaptation requirements for the match.

4.3 Research design

4.3.1 Assumptions

According to Bailey[175] assumptions are underlying principles that the researcher accepts but are difficult to prove and affect the approach taken to a specific situation.

In the nature of the community-driven development approach taken in this project, where the community is the initiator, the partner and the beneficiary of the process, certain assumptions are pertinent. It is therefore assumed that the community and the participating assistants and subjects will contribute in an honest and reliable manner.

Payton quoted by Jenkins et al[176] admits that the society within which the scientist works influences the research performed and the interpretation of the data. In a participatory approach this is not only acceptable, it is desirable. It is argued that the research will be appropriate to the situation and more likely to meet the needs of the community if there is an exchange of ideas and a collective decision making process.

4.3.2 Approach and design

4.3.2.1 Research approach

The setting in which the research took place, local and global policies and the boundaries set by the assumptions described above directed the choice of research approach toward a participatory model.

The concept of community participation in research is by no means new. In 1973 in its document on Organization Study on Methods of Promoting the Development of Basic Health Services, the WHO in its quest for Health for All by the year 2000 concluded that community participation was essential for health improvements for the majority of the world's people.

They state: "This (community participation) has no disadvantage in terms of national policies and has enormous advantages as it can result in tapping of local resources for health service purposes…"[177]

Rifkin[178] describes case studies from the 1970s that were instrumental in developing the theoretic framework for modern theories, driven by the 1978 Alma Ata Conference on Primary Health Care when community participation had already become a major element in the WHO's presentations. She compares six critical health planning issues of traditional approaches to emphasise her point of the relevance of a participatory approach in the following matrix (**Table 4.1**).

Table 4.1 Matrix of approaches and issues

Issues Approach	Health Services	Partici-pation	Role of pro-fessional	Role of CHW	Evalu-ation	Finance
Medical (External approach)	Major programme component	Provide better services	Key	Service extender	Health status statistics	Whatever source available
Health planning (Multiple approach)	Necessary, not sufficient for health improvement	Maximising resources	Component	Service extender / change agent	Efficiency	Outside working to self-reliance
Community development (Internal approach)	Means for community mobilisation	For creating improved social structures	Resource	Change agent	Educative process	Self - reliance as primary goal

CHW-Community health worker

Stewart and Bhagwanjee[179] have shown that a participatory research approach is a valuable tool to reduce dependency on service providers and to increase awareness of the factors related to the empowerment of people with physical disabilities. They considered a reflexive process of theory-action-reflection to be critical to achieve genuine collaboration between health professionals and community members.

Because of the lack of services available to PWD in the area an *operational research approach,* in which the emphasis is on maximising output by progressive modifications in services and improved management of resources,[180] could not be considered as the main research approach. However, it was decided to investigate the services available in the region and to include them in a support network that would improve the sustainability of the implementation.

The researcher had developed a model for participatory research on development work in community-based rehabilitation during a study completed for her master's degree.[108] The model was based on the principles

described by Elden and Levin, in their model of participatory research, focusing on cogenerative learning.[181]

According to Elden and Levin cogenerative learning produces local theory as a basis for collective action. They believe their model to be relevant in situations where people with different forms of expertise and frames of references collaborate in creating a common conceptual domain for collective action. The aim is to overcome the expert's monopoly in defining the possible and deciding on the action to be taken.
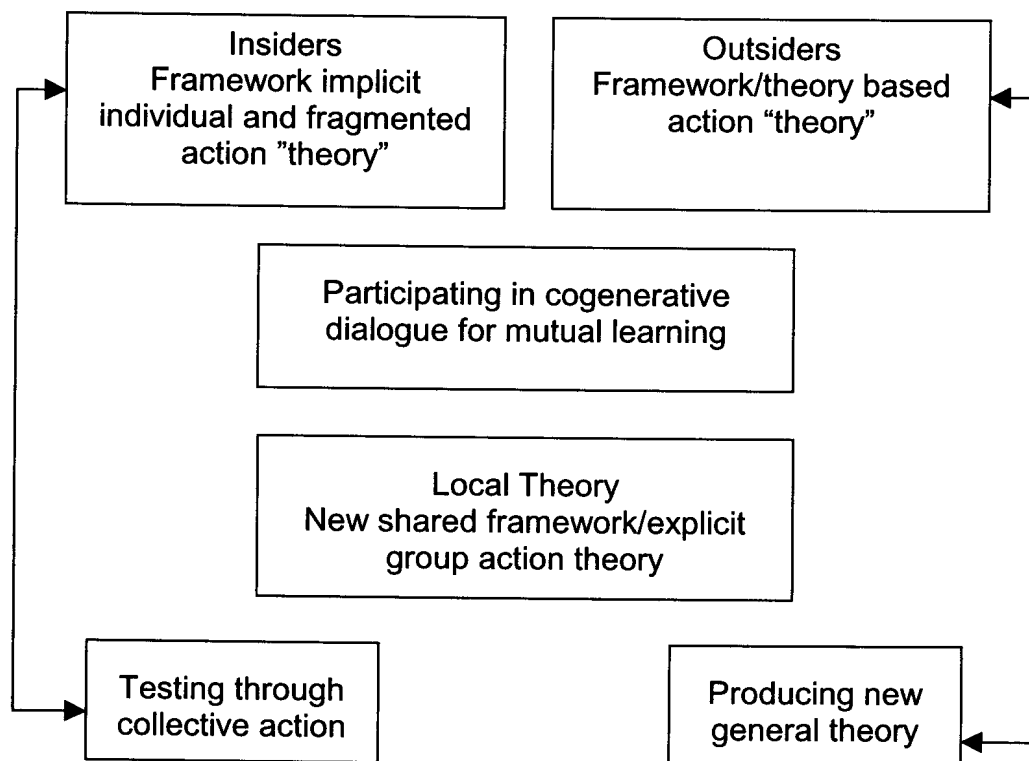
Figure 4.1 Model of participatory action research Scandinavian style: the cogenerative way

The model developed by the researcher in her master's study was considered appropriate to be used and could at the same time be tested. This research study provided an opportunity to refine the model and determine its usefulness for research in development work in general.

The model, named the Mutual Benefit Research Model (MBR) because of the collaboration for an outcome that benefit the various participating parties, was thus adapted for universal application as illustrated in the following figure.
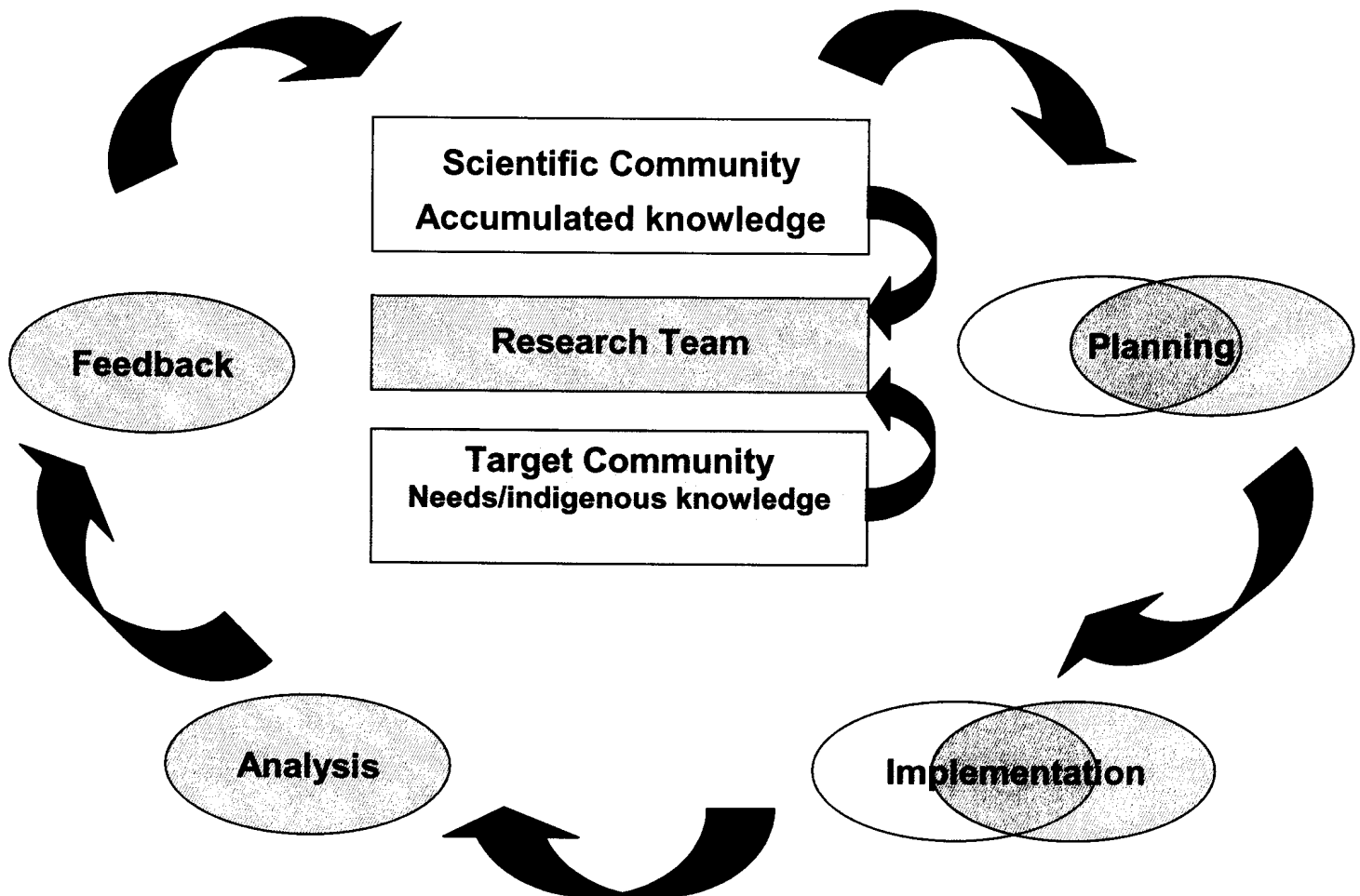
Figure 4.2 Mutual benefit research model (MBR Model)

The four phases of the refined MBR model illustrated in **Figure 4.2** are:

■ Planning - In this phase the accumulated, global, academic knowledge is brought together with the specific knowledge and experience of the members of a multi-disciplinary team and the indigenous knowledge of the community in which the research study will be carried out. Sub-projects, aims and objectives are discussed, decisions are reached by consensus and the activities of the various role-players are resolved.

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■ Implementation - During this phase all the role-players perform their activities in the sub-project according to the plan. The involvement of community members in the implementation improves the validity and reliability of communications with the local inhabitants and its interpretation. They can also monitor the progress and ensure that the process remains on track to meet the community's needs.

■ Analysis – This phase is carried out by statisticians in consultation with the researcher to ensure results of an international standard, which can be used to expand the accumulated knowledge base.

■ Feedback – The results are communicated to the community and the multi-disciplinary team, and published to reach development workers globally. The community can use the information in the implementation of their development and the research team will use the information and experience gained to improve their skills in guiding development projects. Globally, the information can provide statistics on development activities and add to the guidelines for encouraging and stimulating development.

The process, if effectively completed, should result in meeting the needs of the community and allow them to proceed searching for solutions to new needs. The enlarged accumulated knowledge should lead to improved skills and knowledge of development work. The cycle should then repeatedly trigger the start of the process in a spiralling fashion.

The MBR model was applied in the following way:

Phase I – Planning

Before describing the steps taken in the planning it is important to establish the perspective of the research team, the researcher and the Tsilitwa community.

1. The IRDM team's aspirations to a holistic approach in their development projects lead to the inclusion of the researcher, an occupational therapist, in the team. Their goal was to be able to include

all inhabitants in their future development projects, and therefore they needed to investigate the number of PWD in the Tsilitwa community, the needs in terms of training and work, the barriers that exist in local communities and the socio-dynamics of disability in local rural communities.

2. The researcher's interest in the Tsilitwa project was the opportunity to investigate the possibility to routinely include PWD in general development projects. Her viewpoint on current employment issues around disability in South Africa were:

■ There are no funds or plans to provide special workshops for PWD in rural areas in South Africa.

■ It is not desirable to establish separate facilities for PWD with the exception of those with severe disabilities who need specialised care and facilities.

■ Integration into the workplace for PWD should be standard procedure for any PWD who has the potential to be trained and work.

■ Policies and laws are in place in South Africa for equitable access to employment.

■ Awareness of the abilities of PWD must be raised.

3. The community had decided to focus on training and work projects in their development programme. They were also concerned about the PWD and their families in their community.

The following principles of a needs assessment of PWD within the family and community described by Cassam in Bumphrey were used in this phase.[182]

1.   Deciding on the scope of the negotiations/study

■ During discussions with the persons identified by the TDC for the sub-project of their development programme, it was decided to focus on work access for persons with physical disabilities. The perceived needs of an

income for their families, the improvement in self-esteem and the identification of the physical barriers preventing their integration into the village social life could be met with this study.

■ It was decided that a household would be carried out to identify all the PWD in the community, as no accurate statistics or addresses were available and the study would provide an opportunity to collect such information for the local clinic.

2. Choosing the setting

The commitment by the CSIR to assist Tsilitwa in their development programme provided the setting for the study. It was further decided to use the Tsilitwa Clinic as an operational base for meetings and from where the study would be executed.

3. Clarifying expectations

The researcher and the members of the TDC as a group were in agreement that this study was fundamental for effective implementation of the needed equity in their development programme and that it did not entail any direct advantages for PWD and their families as yet. They were nonetheless concerned that the study could raise expectations of a guaranteed workplace or income among the PWD and their families in the village. Another concern was that PWD with mental or psychiatric disabilities might believe that their problems were not being addressed and consider themselves unfairly neglected. The following preventative measures were therefore decided upon:

■ The person visiting the individual households needed to be well informed on the scope of the study and in the introduction to the survey inform each head of the household on what could be expected from the survey.

■ The researcher and the clinic sister would address appropriate village meetings to reinforce the message carried out in the interviews with heads of households.

4. Prompting participation

■ Various members of the TDC, not involved in the sub-project, were invited to attend discussions and planning sessions.

■ It was also decided that local inhabitants would carry out a screening survey for the identification of people with physical disabilities. This would introduce a different category of village inhabitants into the participative process and add another dimension to inputs from the community.

5. Establishing trust

■ The TDC is respected in the community as a body committed to the improvement of the village and all its inhabitants. As such it enjoys the trust and support of the community.

■ The researcher was welcomed into the village on the recommendation of the TDC, explained her role in the sub-project and took care to meet the committee's reasonable expectations of her in the context of that role.

■ The local research assistants were to be trained by the researcher and supervised by the clinic sister to ensure well-executed interviews in which the questions asked by inhabitants could be confidently and correctly answered or referred to the clinic sister. This would in turn establish confidence and trust among the inhabitants of the village.

6. Setting priorities

The priorities had already been indicated by the concerns of the TDC and were refined during the discussions into the aim and objectives as described in sub-section **4.2.2** and **4.2.3**.

Phase II - Implementation

The application of the model in the implementation phase will be described under the heading Data collection (sub-section **4.5.1**).

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Phase III - Analysis

The account of the analytical process will be given under the heading Data analysis (sub-section **4.5.2**).

Phase IV - Feedback

■ This dissertation is part of the feedback process in that it will become part of the accumulated knowledge of the scientific community.

■ The gained knowledge will also be communicated through publication in appropriate international journals.

■ A report on the outcome of the study was delivered to CSIR for development of the IRDM.

■ The final report to the CSIR was· discussed with the community members and the TDC members involved in the study, for input and approval and then submitted to the TDC for consideration in their development programme.

4.3.2.2 Research design

A descriptive study was undertaken, containing elements of explorative, naturalistic field studies.

The following table illustrates the design characteristics of the processes of the various steps of the study.

Table 4.2 Design details of the study

Objective	Information required	Research process	Instrument (Method)	Type of data collected
1. Profile of PWD in Tsilitwa	Identification of adult physical disability with emphasis on the movement component	Explorative field study conducted in the natural setting, examining population to: ■ discover new information on unstudied phenomena[183] ■ examine characteristics of specific variables[184]	Questionnaires and interview – PWD and family Questionnaire Phase I selfreporting Questionnaire Phase II – assessment by researcher Video recordings of functional assessment to test validity and inter-rater reliability	Quantitative
	Needs and aspirations of the PWD for integration into the workplace	Explorative field study, conducted in the natural setting (do)	Questionnaire and interview – PWD and family	Qualitative as well as Quantitative
	Attitude of the community/caregivers to equal employment opportunities for PWD	Explorative field study, conducted in the natural setting (do)	By focus group method – community and family[185] Frequencies will be recorded for quantification[186]	Qualitative as well as Quantitative
	Level of work skills of the PWD in the area	Explorative field study, conducted in the natural setting (do)	By occupational therapy functional analyses	Quantitative

2. Work and workplace analyses	Enterprises/job requirements of planned projects	Explorative field study, conducted in the natural setting (do)	By video recordings and occupational therapy task analysis	Quantitative
	Accessibility of facilities under construction for projects	Explorative field study, conducted in the natural setting (do)	By occupational therapy workplace analysis	Quantitative
	Resources available in the region for vocational rehabilitation and adaptations	Explorative field study, conducted in the natural setting (do)	By interview – health team	Quantitative
3. Assessment of placement possibilities	Fit – potentials to requirements	Analytical process (Estimating probability)[187]	Analytical occupational therapy process	Quantitative

4.3.3 Population

The population in this study were adult PWD, in the Tsilitwa area in the Qumbu district of the Eastern Cape, now known as Mhlontlo Municipality of the OR Tambo District.

4.3.4 Sample

The sample, agreed upon during the first meeting with the research team, was all PWD with physical disabilities in the age group 16 to 40 in the three villages of the Tsilitwa area.

The selection criteria were thus physical disability and age.

The age limitation was decided on in a meeting with representatives of the TDC. The study addressed issues around work. The lower age limit of 16 years was set because it is the age for legal employment. The upper age limit was discussed at length. The reasoning behind the final decision was that the PWD would need to be trained if they did not posses the necessary skills for specific jobs and the costs and time invested in the training would warrant at least a couple of years of employment to justify the investment. The cut-off age at 40 years would also exclude disabilities caused by the normal process of aging.

Variables inherent in this group that could affect the outcome of the study but could not be controlled further within the selection criteria of the sample, were:

- Degree of disability and residual ability,
- Age,
- Gender,
- Physical barriers within their personal environment,
- Attitudes toward disability issues.

4.4 Research materials

The research materials to establish the group of PWD in the set age group in Tsilitwa and the attitude of the community to the issues investigated consisted of two questionnaires and an assessment kit for a functional assessment. The analyses of income generating projects were done according to occupational therapy task analysis.

In the assessment of disability, the focus was on the consequences of disease and trauma. This required not only a precise knowledge of the pathological processes and the resulting impairments, but also an even more precise knowledge of the consequences for the person in terms of activity limitations and role restriction affecting their rightful place in society. According to Van Bennekom[188] the challenge for clinicians and researchers lies in constructing assessment methods that organise and condense the information needed for effective intervention.

A further challenge in this study was to design an assessment format that could be implemented by non-professional community workers during this study and would lead to the development of assessment methods that could be routinely utilised by community health and rehabilitation workers at a primary health care level.

The six steps described by Jaeschke and Guyatt[189] were applied in the development of the questionnaires:

- Select the item pool,

- Reduce the number of items,

- Choose response options,

- Determine reproducibility,

- Determine validity,

- Determine responsiveness.

The development of the materials will be described in the order of implementation.

4.4.1 Questionnaire - Phase I: Screening for impairments

The questionnaire to screen the inhabitants of Tsilitwa for physical disabilities (**Appendix I**) was adapted from the WHO disability survey questionnaire. The format was selected because of successful utilisation of an adapted format by Concha and Lorenzo (1993) and Katzenellenbogen (1995), in South African situations.[79,190] This format was based on the previous ICIDH[191] and therefore the ICIDH-2[192] in its format at time of the development of the questionnaire was taken into consideration to ensure that the data collected was relevant and could be interpreted in accordance with the latest development in disability issues.

The development of the questionnaire according to Jaeschke and Guyatt's six steps:

Step 1 – Selecting the item pool

The item pool comprised all the functions listed in the ICIDH-2 under the dimension Body Functions and Structures. The term used for problems in body function or structure, representing a significant deviation from the generally accepted population standard, is impairment. The purpose of the screening questionnaire was to identify adults with impairments relating to physical disability in Tsilitwa (see **Step 2**).

Step 2 - Reduce the number of items

In collaboration with the representatives from the TDC it was decided to focus the survey on PWD with physical problems and in particular movement related dysfunction. The effect of visual impairments on movement functioning was discussed and it was decided to include this domain. The aim of the study being employment and because speech and hearing as well as intellectual an psychological dysfunction are both compounding factors for persons with

physical dysfunction, these two domains were added as additional information.

This decision resulted in the following abridged list of ICIDH-2 functional domains:

- ■ Mental,

- ■ Intellectual,

- ■ Temperament and personality,

- ■ Sensory,

- ■ Seeing,

- ■ Hearing,

- ■ Voice and speech,

- ■ Speaking,

- ■ Cardio-respiratory,

- ■ Sensations associated with cardio-respiratory functions,

- ■ Neuromusculoskeletal and movement,

- ■ Movement functions.

Step 3 - Choose response options

A self-reporting methodology, recorded by local research assistants, would be adhered to by means of a structured interview. Therefore the items were selected to identify impairments according to lay understanding of body functioning. The Phase II assessment would then be undertaken by a professional with the necessary background to interpret the functional impairment and the effect on activity performance.

The format in terms of layout and phrasing was simplified to make it user-friendly for the local research assistants and understandable for the respondents. Another reason for the use of simple language was to investigate the effectiveness of the screening method for future use by community-based health and rehabilitation workers.

All questions were phrased in the positive. The purpose of this was to use the opportunity of contact with every family in the village to focus on the abilities of PWD and not their disabilities. This would create awareness of possible integration and, therefore, the interviews could be seen as an advocacy drive for disability issues.

A further adaptation of the questionnaire used by Concha and Lorenzo[79] was that the response options for each question needed to be changed because of the positive nature of the questions asked, e.g.:

Concha and Lorenzo:
"Do you have difficulty moving your arms?" – Response option: yes/no
Tsilitwa screening questionnaire:
"Can (name) move his right arm?" – Response options: well/with difficulty/no

Not only did the questions provide specific information about whether only one side of the body was affected, the response options made it possible to distinguish between some function or no function at all.

Step 4 - Determine reproducibility

This questionnaire was a further attempt in the quest to develop an effective screening tool to identify adults with physical disability in developing areas. The results of the survey as well as feedback from the research assistants would be taken into account for recommendations. Past experience of other published researchers[44,78,79] as well as personal experience with professional and grass root level personnel was incorporated to produce a questionnaire that could be universally used in disability surveys by rehabilitation professionals and community workers.

Step 5 - Determine validity

It was decided that trained, local research assistants would carry out the screening survey. The content and the phrasing of the questions were discussed with them and the designated members of the TDC to ensure that the meaning was clearly understood and the answers would yield the desired information. The fact that the local assistants would carry out the interviews in the local language (Xhosa) further increased the validity of the process. These steps were taken to improve the face validity of the instrument[174] in the realisation that the results would need to be investigated as part of the development of an effective screening tool for disability surveys.

The reliability of the process was addressed by training the assistants to reduce bias and improve the inter and intra–rater agreement of the interviewers[193]. The training would include practice sessions with all three assistants and the researcher present in the three zones. This would help identify possible questions regarding rating still remaining after the training. After completion of the screening the researcher would carry out random checks in the three zones.

Step 6 – Determine responsiveness

To achieve maximum responsiveness the following safeguards were incorporated:

■ The household survey would ensure a response from every household in the village.

■ The format and phrasing as well as the training would make the enquiry comprehensible.

■ The use of local research assistants would prevent cultural bias and incorrect interpretation of the responses.

■ A cover letter in Xhosa and the background given by the research assistants as introduction to the interview would assist in obtaining consent and eliciting co-operation before continuing with an interview.

The six steps described above were performed in co-operation with the statistician and the personnel from the University of Pretoria's (UP) data capturing department to ensure that the required data would be collected in a format, which could be interpreted statistically.

4.4.2 Questionnaire – Phase II: Assessing activity limitation

The Phase II questionnaire (**Appendix III**) was designed to record findings from a functional assessment and an interview on employment history and personal aspirations and needs. The requirements for this measuring tool were:

- Assessment of neuromusculoskeletal functioning,

- Assessment of activity limitation,

- Verification of findings of the screening questionnaire,

- Focus on abilities needed for work,

- Suitable for use by rehabilitation professionals and community based health workers,

- Providing an adequate record of both the assessment and the interview.

Jaeschke and Guyatt's six steps were used again in the development of the questionnaire.

Step 1 – Selecting the item pool

In order to evaluate the activity limitations of the persons with physical impairments identified in the Phase I survey, the items selected for the Phase II questionnaire were the same as in Phase I, described in the form of an action.

A record of the structured interview, carried out during the same home visit, was included in the form. The interview was planned to establish cognitive

functioning, the motivational level of the person and to assess aspirations and needs of the PWD.

The item pool of the questionnaire thus comprised a wider range of functions than for Phase I, under Body functions as well as an item pool for a needs assessment.

Step 2 – Reduce the number of items

The items were checked and finalised in consultation with rehabilitation professionals experienced in community-based rehabilitation.

The reduced list of ICIDH-2 items for the assessment of activity limitations was worded as actions and focused on the basic actions required for work activities.

The ICIDH-2 functional domains included were:

- Global mental functions

  Energy and drive

- Specific mental functions

  Memory

  Higher level cognitive

- Sensory functions

  Seeing

  Hearing

  Vestibular

  Proprioceptive

  Touch

  Voice and speech

- Neuromusculoskeletal and movement related functions

Mobility of joints

Stability of joints

Muscle power

Muscle tone

Muscle endurance

Control of voluntary movement including gait

Step 3 – Choose response options

Various functional assessment scales were investigated in the hope that an existing already proven scale could be used for the assessment of the functional level[174,194,188,195,196] etc. The fact that there are so many assessments and scales indicates the complexity of the issue and emphasises the point that different purposes and contexts each need their own approach. Hence the debates and critiques in the literature.

For this very reason it was decided to develop a scale that would be appropriate for this study. The purpose was to develop a scale that might be suitable for community-based health workers to use in future and to test the specific context, i.e. rural communities, in the early stages of development services.

The primary division of the scale, to reflect levels of independence and dependence, is an element borrowed from the Functional Independence Measure (FIM).[195]

The five levels were then formulated for use in both the functional assessment and the job analyses in an attempt to find a unifying classification that would make job matching easier for non-professional workers in the field.

Three levels describe independent functioning and three levels dependence on assistance (see **Table 4.3** below). Level 3 is the turning point, although dependent on intervention, the result is independent action.

The levels reflect the extent of underlying impairment from least at Level 1(identified function) to most at Level 5 (no function). Importantly, they do not

reflect the resulting activity limitation in the same way, because one person might be fully independent with an adaptation or assistive device and function equally well as another person on Level 2.

Table 4.3 Assessment scale

Level	Definition of functioning	Description of level for functional assessment	Description of level for job analysis
Level 1	No function (total assistance)	No performance is carried out without assistance.	Task can be successfully completed without this aspect of functioning
Level 2	Dependent function (with assistant)	Performance is dependent on another person for safety reasons or physical assistance for positioning and/or execution of some of the tasks.	Performance is only required to take up position and/or during occasional complexities that may occur but are not routinely part of task execution.
Level 3	Independent function (with assistive device or activity adaptation)	Performance is/can safely be carried out independently with adaptation to the activity or environment or with an assistive device.	Performance is only required in alternate method or position.
Level 4	Independent function (abnormal)	Performance is/can safely be carried out independently with abnormal pattern, and reduced speed and accuracy.	Normal movement pattern in terms of speed and accuracy is not required for successful and safe completion of task.
Level 5	Independent function (normal)	Normal performance, without modification, carried out safely within a reasonable amount of time.	Normal performance in terms of speed and accuracy is required for safe completion of task.

Step 4 – Determine reproducibility

The principles used to develop the questionnaire as well as the elements and items that make up the measurement tool are recognised and have been

tested in the health professions. They were taken into consideration to ensure reproducibility as far as can be done in the development of a new measurement tool. A pilot study was undertaken in the Bedford Hospital and several occupational therapists were consulted to improve the reproducibility.

One item was added after the consultations. The researcher, for her own purposes of determining the permanency of the activity limitation, also felt the need to add a question on the cause of the underlying impairment.

The final test of reproducibility would be the use of the measurement tool in the field.

Step 5 – Determine validity

The functional assessment as a field observation performed by a professional or trained community health worker has excellent internal validity according to the current literature. This aspect will be discussed in further detail under **4.4.3**.

The researcher would be assisted by the research assistants who would ensure that instructions are clearly understood and provide precise translations of the answers in the interview.

The researcher would execute all the assessments herself to ensure reliable data, and videotape a random sample of assessments for confirmation of her findings by an expert occupational therapist in the field of community-based rehabilitation.

Step 6 – Determine responsiveness

All persons, identified in the screening survey as persons with physical disabilities, were to be visited in their homes for the assessment, thereby ensuring maximum response.

The Phase II questionnaire Functional assessment - is attached as **Appendix III**.

4.4.3 Assessment kit for functional assessment

From the literature studied in **Chapter III** and based on personal professional experience it was decided to use a functional assessment format for the Phase II assessment to confirm activity limitations. The assessment would serve a dual purpose, namely the confirmation of activity limitations, thereby establishing whether the person could be classified as PWD or not, as well as establishing the functional capacity for the planned job matching.

The reasons for the choice were:

■ A clinical observation of a person in a functional activity reveals true activity limitation better than deductions from tests of the various performance components.

■ It is more difficult to be consistent in faking a disability during functional activity and inconsistent patterns can be observed. The method is therefore effective for discerning true problems in activity participation.

■ The use of appropriate, known activities is important for the rural community context.

■ Heavy and expensive or computer-based testing equipment is neither practical for transport nor available in the area.

■ The test kit would have to be reproducible for community-based health workers in the poorest and most outlying rural communities in the future.

■ An appropriate functional assessment can be carried out in any home situation or if necessary under a tree or in the clinic.

To devise an appropriate functional assessment for the situation the theory discussed in **Chapter III** was used as basis.

The assessment had to:

■ Result in a full body functioning assessment,.

■ Be appropriate for both genders,

■ Be appropriate for the social and the cultural contexts,

■ Be executed within a limited time,

■ Contain nothing that could not be transported on foot over considerable distances.

Another important factor to consider was that the format would be tested for possible future use by community-based health workers and, therefore, had to contain the most important elements at an appropriate level of complexity.

The performance components selected to establish functional abilities for work were:

Sensorimotor -

■ Upper limb functioning with focus on hand function,

■ Dynamic postures,

■ Lower limb functioning.

Cognitive -

■ Perception.

The information from the functional assessment would be used to find possible job matches within the income generating programmes planned for Tsilitwa. Therefore the information had to yield a profile of the functional capacities of the PWD.

The key functional capacities included in the assessment were:

■ Hand and foot use,

■ Full body mobility,

■ Walking

- Bending,

- Lifting,

- Carrying,

- Climbing.

The activities chosen to evaluate the above performance components and functional capacities and what could be deduced from them, are given in the following table.

Table 4.4 Functional assessment

Activity	Assessment observation purpose
1. Putting on of long-sleeved shirt and fastening buttons	Range of motion of both upper limbs, muscle tone, balance reactions in sitting, bilateral hand function (individual finger movements, grasps and co-ordination) unilateral hand function, spatial perceptual aspects, praxis
2. Bending (while sitting or standing – highest position that can be maintained) and lifting a brick	Trunk mobility, balance reactions, upper limb muscle strength
3. Standing up from seated position	Whole body mobility, balance reactions, lower limb muscle strength
4. Squatting (clients able to walk)	Balance reactions, lower limb muscle strength.
5. Walking over uneven (outside) surface or negotiating steps	Gait, balance reactions
6. Carrying brick	As 2 and 5
7. Peeling and eating a naartjie	Bilateral hand function, grasps, touch, perception, co-ordination, object handling, cognitive functioning

■ Long-sleeved shirt

■ Brick,

■ Naartje,

■ Carry bag.

The findings of the functional assessment would be recorded on the Phase II questionnaire.

4.4.4 Video recordings

Video recordings have the advantage that detailed analyses can be made of actions and procedures at a later stage or by a person not present at the time and place of recording.

Video recordings were therefore useful in this study for:

■ Recording a random sample of the Phase II functional assessments for the purpose of consulting an expert to establish the validity of the assessment and the reliability of the assessor,

■ Recording authentic income generating programmes in local communities for the purpose of a detailed job analysis, as part of data gathering process.[175]

4.4.5 Form to record community attitudes toward disability issues

The process to establish the Tsilitwa community's attitudes toward disability issues will be discussed in detail under the heading Procedures in sub-section **4.5.1.2, Visit 7-8**. In accordance with the participatory approach a joint decision was made to call for a representative meeting and that the attitudes would be elicited by small group discussions facilitated by trained community members.

Because of time constraints a semi structured group interview method would be used rather than a focus group method. The once-off large group of participants that were expected and the limited experience of the newly trained facilitators would make it difficult to uncover why participants felt the way they did and to investigate the process of how opinions were formed. All groups would take place at the same time in and around the school hall. For practical and financial reasons tape recordings of the various groups would not be possible. It was decided to keep a written record of opinions from the groups.

The questions that would be put to the groups were discussed and formulated with input from all team members to ensure that everybody in the meeting would understand them.

The researcher then constructed a form, for use by the facilitators, to record the attitudes expressed in the small group discussions (See **Appendix V**).

4.5 Procedures

The procedures carried out in this study will be described according to the four phases of the participatory action research model discussed in sub-section **4.3.2.1**. Phases 1 and 2 are discussed under the heading Data collection (sub-section **4.5.1**) and Phase 3 under Data analysis (sub-section **4.5.2**). Phase 4 will be described under its own heading in sub-section **4.5.3**, as this is an aspect not customarily described in scientific or academic reports.

A diagrammatic presentation of the procedures is presented in **Figure 4.3**.
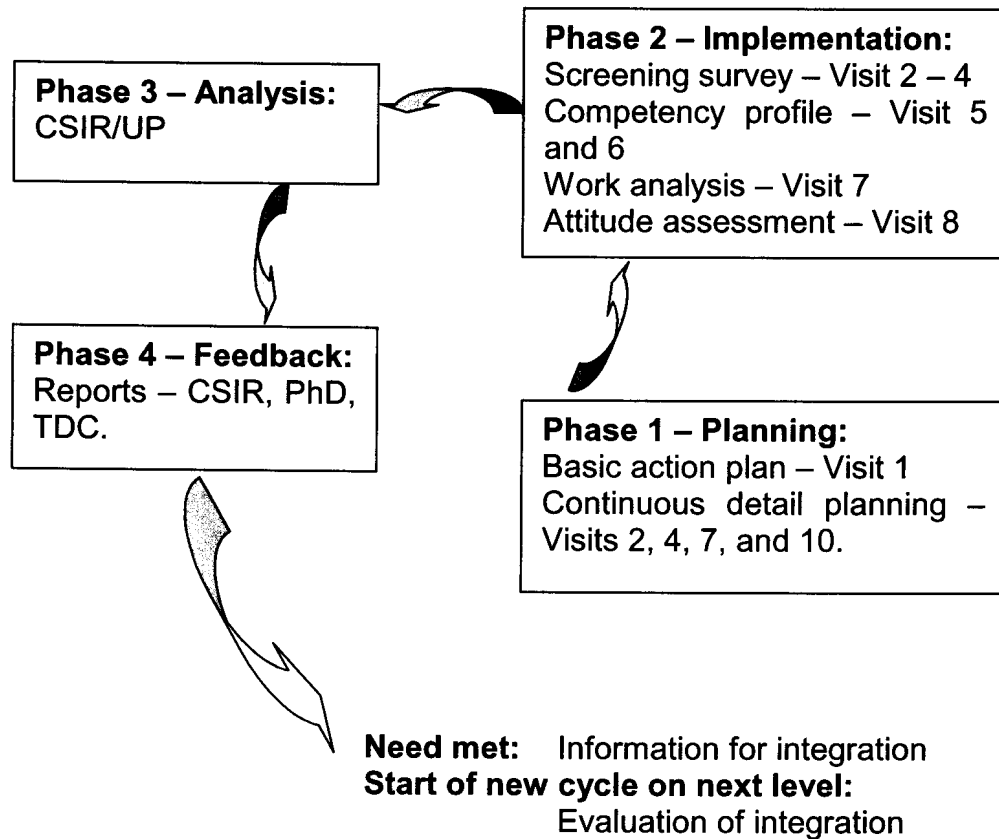
Figure 4.3 Diagram of implementation

4.5.1 Data collection

4.5.1.1 Phase 1: Planning

The request for this investigation was made to other members of the CSIR development team and not to the researcher herself. The first visit to the community was thus used to establish contact, meet the TDC and gather first-hand information on their attitude and commitment to this sub-project of their development programme.

Visit 1

The first day was spent collecting basic information about the village and establishing the precise need of the community that prompted the request for the study.

On day two the researcher met with the representatives of the TDC who would be involved in the sub-project on disability for the purpose of planning the course of action. The following agenda points were addressed:

- ■ Communication channels – direct and regular contact with Mr Jikijela, chairperson of the TDC and Sister Madikane, the clinic sister who would be involved in the implementation of the study.

- ■ Involvement of TDC and community members – committee members were welcome to give inputs at all time to guide the sub-project and ensure that the community's needs were met; three research assistants would be identified by the community to be trained by the researcher and would also act as interpreters; every household in the community would be visited in the survey and would thus be involved in the study.

- ■ Basic plan of action and timeframe – the plan of action and timeframe agreed upon are summarised **Table 4.5**.

- ■ Responsibilities of various participants – the researcher would be responsible for the execution of the plans; Mrs Madikane would represent the sub-project at the TDC and would be available to the researcher for practical implementation issues; Mr Jikijela would act as consultant and be actively involved in the decision making process throughout.

- ■ Desired outcome – a report to the TDC with guidelines on the integration of the PWD in the Tsilitwa development process.

The planning phase in reality does not end after the initial agreement on the scope and the general course of action that has been decided on. Because of the dynamic nature of the process new developments within the community need to be incorporated throughout.

The continuation of the planning process is described as part of the implementation.

Table 4.5 Action plan

Visit/Date	Action	Persons involved
Visit 1 **February 2000**	■ Establish contact, set up participatory team ■ Gather background information ■ Planning	■ TDC ■ Researcher
Visit 2 **March 2000**	■ Train research assistants ■ Plan screening survey	■ Mrs Madikane ■ Research assistants ■ Researcher
Tsilitwa **April 2000**	■ Undertake screening survey	■ Mrs Madikane ■ Research assistants
Visit 3 **May 2000**	■ Establish reliability of screening survey	■ Research assistants ■ Researcher
Visit 4 **June 2000**	■ Hand in screening questionnaires ■ Plan assessment of activity limitation	■ Mrs Madikane ■ Research assistants ■ Researcher
Visit 5 and 6 **July 2000**	■ Undertake assessment of activity limitation	■ Research assistants ■ Researcher
Visit 7 **August 2000**	■ Plan attitude assessment	■ Mr Jikijela ■ Mrs Madikane ■ Researcher
Visit 8 **September 2000**	■ Visits of Umtata rehabilitation team members	■ TDC ■ Community ■ Researcher
CSIR/UP **October 2000**	■ Data analyses	■ Statistician ■ Researcher
Visit 9 **October 2000**	■ Attitude assessment	■ TDC ■ Researcher
Visit 10 **November 2000**	■ Final report to TDC ■ Way forward	■ TDC ■ Researcher

4.5.1.2 Phase 2: Implementation

The implementation followed the action plan, with an additional visit planned during April because of concern whether the assistants were implementing the survey methodology correctly. The visit could not be carried out because of poor road conditions and was compensated for by faxing some of the completed questionnaires and telephonic communication.

The implementation will be described per visit, starting with Visit 2 after the planning phase through to Visit 8 (see **Figure 4.3**). Each visit is divided into two sections, the preparation work done for the visit and the visit itself.

Visit 2

Preparation

■ Development of questionnaire: The development of the questionnaire was described under Research materials (sub-section **4.4.1**). The final product was discussed with the data processor to check the format.

■ Development of a training programme and handout for research assistant training workshop: - The training programme for the research assistants included the purpose of the sub-project; the objective of the survey, an explanation of the survey methodology and basic interview skills, including how to introduce themselves and explain the purpose of the survey to heads of households In addition, definitions of the concepts of disability and normal functioning, an explanation and examples for each of the questions on the questionnaire and how to score possible responses to them was covered. The handout prepared for the workshop was based on personal experience in grassroots training and basic principles for such training described in the literature.[197,198] It was kept uncluttered, in understandable language, with illustrations and had room for the trainees to write down examples to enhance retention and to refer to, in case of uncertainty, when the trainer was not present (See **Appendix II**).

Visit

■ Training: Two of the three research assistants were trained (See **Appendix II** for programme). The third trainee was unfortunately not available on the day. The two trainees met the criteria decided on during the planning visit, namely: basic English, education to senior certificate level and in dire need of an income. The training programme was completed and comprehension was checked throughout with questions and answer sessions. Mrs Madikane attended the training so that she could later train the third research assistant.

■ Questionnaire: The content of the questionnaire and the cover letter, explaining the purpose of the survey, was discussed with Mrs Madikane and she agreed to translate the cover letter in Xhosa for the final version of the questionnaire.

■ Planning: The discussion on details of the implementation led to the following decisions and actions: Mrs Madikane would train the third research assistant; each assistant would do three interviews for practice and as a pilot run for the questionnaire; Mrs Madikane would supervise the process and fax the pilot questionnaires through; she would also send through comments from the assistants and herself on the content and the format of the questionnaire; payment for the work was agreed upon; each assistant was given a code number; the village was divided into three zones, namely Tsilitwa, Mtondela and Tembeni and given code numbers (see **Table 4.6**); each assistant would visit one third of the village households, they would divide Tsilitwa, the biggest area, accordingly among themselves.

Table 4.6 Research assistant codes

Research assistant code		Zone code	
Bukeka Libala	5	Tembeni	05
Esther Rorwana Jikijela	6	Tsilitwa	06
Victoria Nkwindama	7	Mtondela	07

The researcher was concerned about not having met and trained the third research assistant and decided on the said additional visit to ensure the reliability of the data collection.

Visit 3

Preparation

The pilot run of the questionnaire was done in Tsilitwa and also in the Lubisi area. With input from Mrs Madikane and the various research assistants necessary adjustments were made. The Xhosa translation of the cover letter was checked by a lecturer in African languages at the University of Pretoria, attached to the questionnaires and sent through to Tsilitwa for implementation.

Visit

■ Screening survey: A workshop follow-up session was used to check on the progress made in the survey and to discuss uncertainties and difficulties in scoring. The survey was progressing well. The third assistant's English was poor and the indirect communication, through translations, was less satisfactory and slowed the session down. The assistants reported full compliance from the households visited and a keen interest in what the outcome of the survey would mean to them. The assistants' answers on these questions were checked and found to be according to the agreement with the TDC and their training. However, it was clear that the community needed to be informed of the purpose of the survey to prevent misconceptions.

■ Awareness: A graduation ceremony at the Stophile Makhenkesi Technical High School in the village afforded the researcher an opportunity to explain the purpose of the survey to the gathering when she was asked to give a motivational speech to the graduates.

■ Planning: The attitude assessment of the community was discussed and Mrs Madikane was asked to put it on the agenda of the TDC meeting for their input.

■ Network: A visit was paid to local rehabilitation services in Umtata (Occupational Therapy, Physiotherapy, Speech Therapy) to establish contact and learn about the services offered and the referral procedures. The purpose of these visits was to establish a support network for Tsilitwa in terms of rehabilitation services, an important factor for the sustainability implementation of the recommendations to the community.[114]

Visit 4

Preparation

In consultation with the statistician a random selection of 15 completed questionnaires was made that would be checked by the researcher to establish the reliability of the data collection. At an average of 20 minutes needed per questionnaire, as reported by the assistants, it was estimated to be a practical quantity for one day's work.

Visit

■ Reliability check: Of the 15 selected households 10 were checked by the researcher. At three households nobody was home and the process took longer than anticipated so that the last two could not be checked before the researcher had to leave. A 90% consistency was found, eliminating satisfactorily the possibility of including false negatives in the sample group. At a community function the research assistants were thanked for their work and received their payment.

■ Awareness: The opportunity was once again used to explain the purpose of the survey to the gathering.

■ Planning: Details for the activity limitation assessment were discussed with Mrs Madikane and Mr Jikijela. It was decided that all persons with physical impairments would be visited in their homes for a detailed

assessment of activity limitations to identify the number of PWD in Tsilitwa, the prevalence of various types of disability and a competency profile of the PWD. The assessment would include a needs survey. The home visits would afford the researcher an opportunity to establish the social and environmental barriers that each of the PWD face. The research assistant who visited the household during the screening survey would accompany the researcher and either Bukeka Libala or Esther Jikijela would act as translator in the households covered by Victoria Nkwindama. An in-depth discussion on the aim and outcome of the study followed with Mr Jikijela.

Visit 5

Preparation

■ Data analysis: The data processing department of the University of Pretoria determined the households in which persons with physical impairments were recorded.

■ Development of questionnaire: The development of the assessment questionnaire is described under Research materials (sub-section **4.4.2**). Professionals in the field of community-based rehabilitation were consulted to ensure that the data collected would be appropriate. The final product was then discussed with the data processor to check the format.

■ Kit: The functional assessment kit described in sub-section **4.4.3** was acquired in Umtata.

■ Pilot run of questionnaire: The questionnaire was tested on a group of patients in the Bedford Hospital in Umtata and an adjustment was made.

Visit

■ Assessment of activity limitations: The assessment kit (see **4.4.3**) was used to establish activity limitations and assess the ability to use performance components needed to execute activities. The findings of the functional assessment were recorded on the Phase II questionnaire (see **4.4.2**) and the additional information for the questionnaire was gathered in

an interview with the PWD and caregiver where applicable. An average of six households was visited each day. A recurring problem was households with nobody at home or the person with the reported problem being absent. The researcher was left with the conviction that the functional assessment was effective in eliminating false positives from the self-reporting screening questionnaire.

■ Planning: A suitable time for the completion of the assessment was arranged and the committee's opinions on suitable income generating projects were discussed. The final list was: bread baking, gardening, sewing, poultry, with a special request for leatherwork and shoe repairs from Mrs Madikane, because of the interests of one of the identified PWD.

■ Network: The researcher met with the head matron of Sulenkama Hospital under which Tsilitwa clinic is zoned and which is the district hospital through which referrals to the Umtata hospitals have to take place. The purpose of the visit was to inform the matron of the endeavors in integrating PWD into work projects and to draw together the strings of the support network.

■ Job analysis: Two income generating projects were visited in the Umtata area with the purpose of investigating appropriate projects to develop in Tsilitwa and acquiring permission for video recording of the projects for the job analyses. The types of work provided in the projects were: sewing, beadwork, bread baking, poultry and communal gardening.

Visit 6

Preparation

Files were compiled for the three research assistants containing official letters about the training they had received, work they had done and photos of them at work.

Visit

■ Assessment of activity limitations: After the still recurring problems of absence hampered progress on the first day, it was decided to ask persons with reported impairments who had been visited at their homes three times without success to report to the clinic for assessment there. The argument was that persons roaming around don't have serious mobility problems and their home environment probably does not present them with any barriers. By the end of the visit all persons, with reported physical impairments in Tsilitwa at the time, had been assessed and it was decided to end the assessment.

■ Planning: The results of the screening survey were reported back to the representatives of the TDC. Because analysis showed a high number of hearing impairments, it was decided to approach the speech and hearing therapists at Umtata General Hospital for a day's screening in the village. Similarly Mrs Madikane and the researcher believed that some of the identified PWD would benefit from home visits by the occupational therapists at Bedford Hospital. It was decided that the visits should take place during the researcher's next visit so that she could provide the necessary transport and make the introductions. Mr Jikijela and Mrs Madikane felt strongly that the whole community should be invited to a meeting to establish their attitudes toward disability issues because the TDC wanted to be transparent and allow all inhabitants to participate in the process of their development. It was decided that details would be planned at a meeting during the next visit.

■ Network: The researcher suggested the above-mentioned visits and made the arrangements in order to introduce the various professionals within the network to each other and to create awareness of the available services among the clinic staff and in the community.

Visit 7

Planning

The data was analysed by the data processor. In consultation with the statistician a random selection of three identified PWD and three persons with no activity limitations from their impairment was made. It was decided that six home visits would be feasible, because of the average number of visits achieved in the assessment. Video recordings were to be made of these six persons for the purpose of consulting an expert in community-based rehabilitation to check the reliability of the researcher's findings.

Visit

- Assessment of activity limitations: The three PWD were video taped but only one of the three non-disabled persons was home. According to memory, the closest-living person previously assessed was then used as a substitute for the randomly selected person.

- Network: The visit of the occupational therapist and the occupational therapy assistant from Bedford Hospital in Umtata established a renewed commitment to community work because of the successful home visits. The contact with the clinic staff was effective in creating an awareness among them of the services available and the role of rehabilitation in general. There was an overwhelming turnout for the hearing clinic and all reported the contact between the two community speech therapists and the clinic staff to have been a success.

- Planning: A prolonged meeting took place between the researcher, Mr Jikijela and Mrs Madikane. The purpose was to plan the assessment of the community's attitude toward disability issues. As the study was nearing its completion, however, the concerns of the TDC representatives enjoyed priority. Although both representatives agreed that it was understood that the research aim was to supply guidelines for integrating the PWD in Tsilitwa into the projects that the TDC was to develop, they felt that the researcher should find funding to initiate such projects. As the rest of the

CSIR team, because of funding problems, was still waiting to become involved they felt that the community would blame them if the recommendations could not be implemented soon. After lengthy negotiations it was decided to continue with the sub-project with the compromise that the researcher would present a workshop to the TDC on writing proposals for development funding. The final planning concerning the format of the attitude assessment was done. It was decided that a plenary session should set the objectives for the day and clarify the concepts, followed by small group discussions and ending in a feedback session; in the afternoon the PWD of Tsilitwa and their families would be invited to obtain their views on the subject and to clarify the outcome of the sub-project; Mr Jikijela would meet with the sub-headmen of the various zones, explain the purpose of the meeting and ask them to identify suitable representatives from their zones to attend the meeting; Mr Jikijela would organise a youth component from the school to represent the next generation; a maximum of 100 participants could be accommodated; Mr Jikijela would ask four teachers to assist the clinic staff and the research assistants in facilitating discussions in the small groups, bringing the total number of facilitators to 10 and allowing for 10 community members per group; the workshop on the writing of proposals as well as a workshop to train the facilitators for the small group discussions would take place a day before the community meeting; the questions to initiate the discussions in the small groups were discussed and Mr Jikijela agreed to finalise the wording to ensure that they would be well understood.

■ Job analysis: The two income generating projects were visited and video recordings were made of beadwork, machine sewing, bread baking and gardening for the job analyses. No leatherwork projects could be found.

Visit 8

Visit 8 was not spent collecting data for the study as such, but was the culmination of various meetings during previous visits with the rehabilitation team members stationed at Umtata hospitals. These meetings were used for

the investigation of the local resources in terms of vocational rehabilitation and possible adaptations that might be needed for successful work placement.

In preparation for the implementation of the recommendations following the study it was necessary to introduce the community to the services available and to establish direct contact with them.

During visit 8 the researcher brought the speech and hearing therapists from Umtata General Hospital on one day and the occupational therapists from Bedford Hospital on the following day to meet the clinic staff and explain their services and the referral lines that would bring them in contact with the clients from the area.

On both days the professionals provided services in the community for clients arranged by Mrs Madikane. The speech and hearing therapists did hearing tests and home visits were done by the occupational therapists to the homes of PWD.

Visit 9

Preparation

The content for the various workshops was researched and compiled. Handouts for the participants of the workshops were prepared as well as a resource file for the community with information on various types of funding agencies and their funding application protocols.

Visit

■ Attitude survey: Nine facilitators were trained instead of 10, it was decided that the research assistant with the language problem might have difficulties during the training and she was asked just to attend the meeting (see **Appendix V** for programme). Because of unavoidable delays, the meeting started late and many people had left already. The youth component did not materialise, possibly because of the school holidays. Four of the PWD, who were to attend the meeting arranged for PWD and their families that was to follow the attitude survey, had already arrived and

joined the meeting. In total there were 39 participants. After the introduction, in which a common understanding of the term physical disability was achieved and the objectives for the small group discussions were set, the participants were divided into four groups. One facilitator was assigned per group and each facilitator was given one trained facilitator as a scribe. This solved the possible problem of accurately recording the attitudes expressed in the meeting whilst facilitating the discussion at the same time. The ninth facilitator joined the researcher in making rounds and assisting the discussion in the groups. Lively discussions took place in all four groups, results were recorded (see **Appendix V** for forms) and reported back to the meeting. It was decided to combine the agendas for the two planned meetings of the morning (see **Appendix VI** for agenda of PWD and families' meeting). In the general discussion the PWD were given opportunities to express their individual views. From the discussion on the way forward the following decision was reached: two TDC members would call a meeting of all PWD in Tsilitwa with the purpose of establishing a committee that would address disability issues. A representative of this PWD committee would join the TDC. The PWD committee would include non-disabled persons from the community.

■ Job analysis: As no leatherwork/shoe repair project could be found in the area, the researcher videotaped the occupational therapy assistant at Bedford Hospital, himself a paraplegic, during leatherwork and shoe repair activities for the purpose of a job analysis.

■ Fundraising workshop: The workshop on how to approach fundraising and write funding proposals was attended by 12 persons involved in development projects in Tsilitwa (see **Appendix VII** for programme).

■ Planning: In an in-depth discussion on the process and the results of the sub-project with Ms Madikane it became clear that the TDC, in spite of their request for integration of the PWD in the village and all the awareness drives about the rights of PWD, still considered a separate workshop for PWD. In planning the following visit it was thus agreed that the format of the feedback to the TDC would include various scenarios for

implementation. Once again the researcher was asked to provide the necessary assistance to obtain funding for the implementation. A provisional date for the last visit was set.

4.5.2 Phase 3: Data analysis

■ Statistical analysis: The respective departments of the University of Pretoria did the data capturing and analysis. The SAS statistical package was used to identify persons with physical impairments from the screening survey for the assessment of activity limitations. All persons who had scored a 2 (see **Table 4. 3**) were included in Phase II of the survey. The same programme was used to establish frequencies from the data obtained in the functional assessment. The intention of the statistical data analysis was to obtain descriptive statistics in terms of frequencies, e.g. number PWD identified, percentage population PWD with physical impairments in Tsilitwa, number of lower limb functional problems, and averages of the degree of limitations. Some of these data were useful to describe the findings. However, because of the small number of PWD identified by the process it was decided in consultation with the statistician to use a single case study methodology to process and present the results.

■ Competency profiles: The scale developed for the assessment of the PWD identified in Phase I of the survey was used to draw up a competency profile for each of PWD identified in Phase II of the survey as having a physical disability (see **Table 4. 3**).

A recording design was developed for future use by community based health workers. In the design the relevant aspects of a human figure are represented on a chart to ensure that all aspects were considered in drawing up the profile. See example below.

Chapter IV Methodology
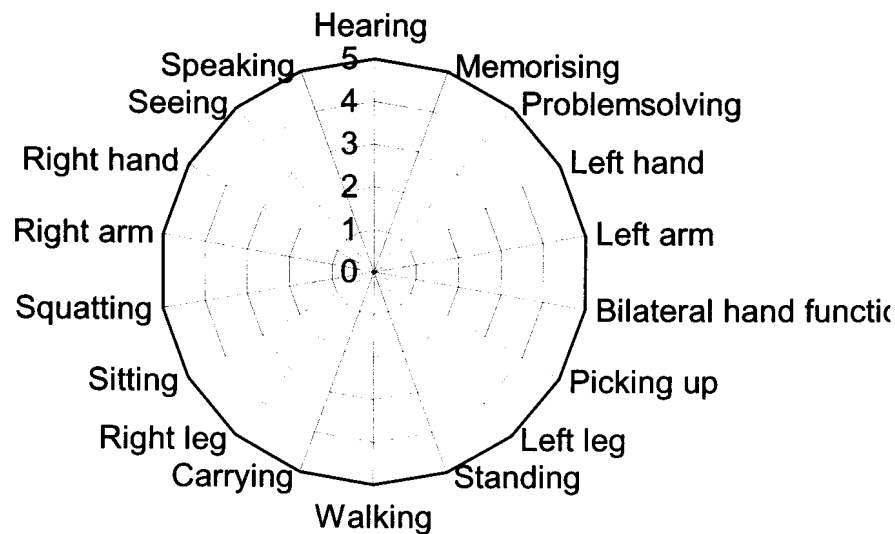
Figure 4.4 Example of profile

The design was used to provide graphic illustrations of the case studies.

■ Job analyses: The five types of income generating projects, requested by the community, bread baking, gardening, sewing, poultry and shoe repairs (see under Data collection **4.5.1.2 Visits 5** and **9**), were analysed from the video recordings to identify the following:

- Key tasks of the activity,

- Groups of tasks that would have to be carried out to make a meaningful contribution to the project,

- Requirements in terms of the aspects assessed for the competency profile to perform the tasks.

The assessment scale described in **4.4.2** was then used to quantify the requirements for successful completion of the tasks (see **Table 4.3**).

A matching design was used to record the data. The data of the functional analysis and the job requirements were then plotted on one web, the work ability web (WAW) to illustrate compatibility. The additional information from the Phase II questionnaire on aspirations and level of motivation as well as the WAW were used to arrive at a conclusion whether a job match could be made. The charts were used to illustrate the job analyses in the chapters on results and the job match.

■ Job match: The occupational therapy process of making the job match has not been analysed. It is described as a result of clinical reasoning with more emphasis on the models used to organise the information than on the process used to make the match.[148] The researcher presented the data to two experts in the field of vocational rehabilitation to make job matches. The process was then analysed and the following steps identified:

1. Investigate:

• Level of motivation – e.g. awareness of norms, ability to comply with norms, level of supervision if needed,

• Aspirations and work skills – e.g. interests expressed or already acted upon, previous work skills and experience, availability for training,

• Abilities – e.g. performance components, availability of adaptations, possibilities for reasonable access,

• Employment alternatives.

2. Select closest match according to aspirations and physical abilities to perform work tasks.

■ Needs and attitude analyses: the qualitative data from the investigations in terms of the needs and aspirations of the PWD as well as the attitude survey of the caregivers and the community was categorised, themes identified and quantified where possible.

The process used for this analysis followed Schön's reasoning that reflection in action can clarify tacit understandings that develop from repetitive experiences of a specialised practice. Reflection in action therefore can construct new theory from established practice.[199]

4.5.3 Phase 4: Feedback

A formal feedback meeting was scheduled for the last visit. A report on the completed research was handed over to representatives of the TCD at a meeting that included community members and PWD from the area.

Visit 10

Preparation

■ Report: A report containing relevant statistics from the statistical data analysis and three scenarios that the community could use in their deliberations on the use of the data. The three scenarios were full integration of PWD into the new projects, home industries for PWD or a separate workshop for PWD. Full job analyses were not yet available and were therefore not included in the report.

■ Funding proposal: Information on format, content and contact persons was collected to assist Mrs Madikane with a proposal to the Mbeki Development Trust for the implementation creating work opportunities for the PWD of the area.

■ Tsilitwa Committee of PWD: Mrs Madikane had called a meeting with the TDC, headmen of the community and PWD of the area and established a committee of three members that would look after the interests of the PWD in the area and be represented at development meetings.

Visit

■ Feedback to the TDC and the community: Mr Jikijela, TDC chairperson, had to officiate at a function at a neighboring school, but the rest of the

committee, several community members, the newly formed Tsilitwa Committee of PWD and the research team were present at the meeting. The report was presented with advantages and disadvantages for the three scenarios. The researcher used the opportunity to educate the audience on current policies and national and international trends on disability issues.

■ Closure meeting with research team: A final discussion of the feasibility of implementing the three scenarios took place with Mrs Madikane and the research assistants in which it appeared that the TDC would favor the establishment of a separate workshop for PWD.

■ Planning: The researcher agreed to assist the TDC with their application for funds and made the necessary arrangements for this with Mrs Madikane. It was agreed that both the TDC and the researcher would keep in contact on future developments concerning the study.

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The four phases of the MBR model described in **4.3.2.1** were applied. The final analyses will be reported back to the community on completion of the thesis.

The ownership created by the participation was felt throughout and contributed to the completion of the fieldwork. The results described in the next chapter are the result of this collaboration and provide new information that could guide professionals and communities to development that will benefit all.

Representatives of the Tsilitwa Community development committee with research assistants after training

Phase I of disability survey

Phase II Functional assessment

Community meeting for attitude survey

**Community projects
In the Umtata region**

The road leading into Tsilitwa
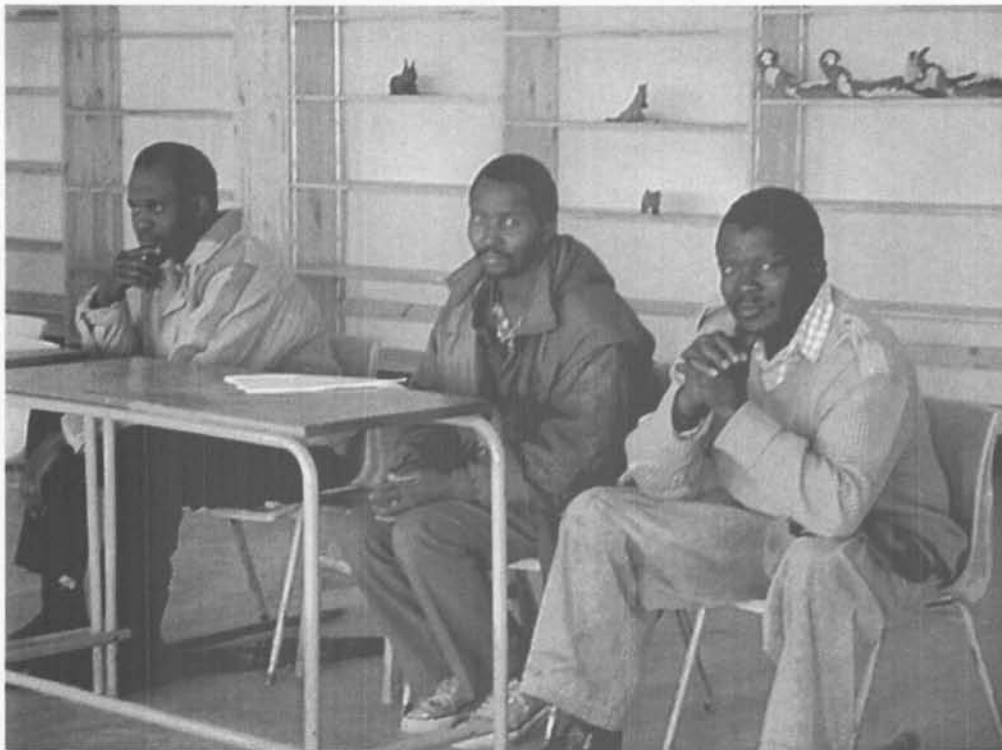
The Tsilitwa Committee of Persons with Disabilities

Chapter V

Results

Results from the disability survey
- Number of adults with physical disability
- Needs and aspirations
- Skills
- Case studies
- Attitudes toward disability

Results from the work situation analysis
- Job analyses
- Facilities
- Resources

5.1 Introduction

The community sense we strive for, is one in which there are shared perceptions of value of individual lives and a social commitment to protect them all equitably. Equitable recognition of needs is a prerequisite for community and equitable care for those needs is its goal. Larry Churchill.

To guide the development of a rural community to achieve such a goal one needs to understand the community and the barriers that stand in the way of equity. This study investigated some aspects of the social and physical complexities that prevent PWD from sharing in and contributing to community life.

This chapter presents the results of the survey to establish who the PWD are and what opportunities there are for them to be included in the development of employment opportunities in the community. The results of the data collection implemented to achieve the objectives of the study (see **Chapter VI 4.2.2** and **4.2.3**) will be presented per objective.

Descriptive statistical analyses are provided for the data of the quantitative investigations. Because of the small number of subjects identified, the data of the disability survey will also be assembled per individual and presented as case studies.

The data of the qualitative investigation will be summarised in the categories established. The insight gained will be used to give depth to the discussion of the results in the **Chapter VIII**.

The job matches generated are presented in **Chapter VI**.

5.2 Results

5.2.1 Objective 1: Draw up a community profile in terms of the adult PWD

The purpose of the household survey was to identify, by way of self-reporting, persons with physical problems for the disability assessment of Phase II.

A total of 475 households were visited in the three villages, Thombeni, Tsilitwa and Mtondela. The heads of household reported a total of 887 persons between the ages 16-40 years old living in the three villages of the area, of which 43 were reported to have a disability.

The following table illustrates the relevant figures from the Phase I survey.

Table 5.1 Demographics of population 16 - 40 years old in Tsilitwa

Households visited	Population (16-40 years)	Male	Female	Physical disability
475	887	363 (41%)	524 (59%)	43 (4,8%)

5.2.1.1 Number of adults with physical disability

In Phase II of the disability survey, the functional assessment was used to establish activity limitations that indicated physical disability. Of the 43 self-reported PWD, 31 persons could be followed up. The table below summarises the reasons for exclusion of 12 reported PWD from Phase I.

Table 5.2 Summary of persons excluded in Phase II of the disability survey.

Location of person with reported PWD	Reason for not being available for the assessment	Number of persons
Residing in a city (Johannesburg – 2 Cape Town – 2 East London – 1 Umtata – 1)	Living with family for the purpose of medical services, work	6
In neighbouring village	Being treated by traditional healer	1
Attending school (East London Pietermaritzburg)	Boarding at main stream schools	2
Elsewhere in the village (Collecting wood or visiting)	Independently mobile – were asked to come to the clinic for assessment but never arrived	1
Home (Over 40 years old, acute injury that should not cause long-term activity limitations)	Available for assessment	2

The results of the functional assessment identified 12 persons or 1.35% of the age group investigated as having physical impairments causing activity limitations.

The personal data from the questionnaire, collected during the functional assessment, can be summarised as follows:

■ Gender: - Male subjects made up 66.6% (8 men) final study population and female subjects 33.3% (4 woman).

■ Age: - The youngest PWD identified in the study age group was 22 and the oldest 38 years old, with 83% (10 persons) of the subjects in their thirties.

■ Disability grant: - Forty two percent (5 persons) of the PWD were receiving governmental disability grants; one person was supporting six family members with his grant; 58% (7 persons) of the PWD who were not receiving a disability grant had dependents.

■ Dependents: - Fifty percent (six persons) of the PWD in the area were responsible for family members; the highest number of dependents was six family members.

No formal diagnoses were provided. From information supplied by the clinic sisters, the PWD, their families and observations made by the researcher the following conditions were identified:

■ Traumatic injuries: - One spinal injury and three head injury caused by faction and social violence,

■ Cerebral palsy: - Two cases of birth trauma and one case that was reportedly identified at nine months,

■ Neurological conditions: - Two cases of unidentified neurological lesions,

■ Rheumatoid arthritis: - One case of chronic ailment resulting in activity limitations,

■ Lower limb injuries: - Two cases of miscellaneous injuries.

Although two cases of amputations were reported, one upper limb and one lower limb amputation, no persons with amputations were living in the village at the time of the study.

The table below summarises the type of movement problems these persons had as a result of their conditions.

Table 5.3 Summary of movement problems of PWD in Tsilitwa

Category	Number (% - N=12)
Hemiplegia	4 (33%)
Paraplegia	3 (25%)
Cerebral palsy – quadriplegia	1 (8%).
Pain and limited range of movement	2 (17%)
Other – abnormal movement patterns	2 (17%)

The effect of these movement problems on activity were limitations in terms of mobility, hand function and balance.

■ Mobility problems included moving about with assistive devices, such as wheelchairs, crutches, walking sticks,

■ Hand function problems included one-handedness, limited range of movement or reduced muscle strength and endurance,

■ Balance problems included difficulties to control postures and body movements without external support.

The table below summarises the results according to upper limb and lower limb activity limitations. Because of the combinations of upper and lower limb limitations (see **Table 5.3**) the table does not add up to a 100 percent.

Table 5.4 Summary of upper and lower limb involvement

Limbs affected	Number (% - N=12)
Upper limb	7 (58)
Lower limb	11 (92)
Both upper and lower limb	6 (50)

The high incidence of lower limb dysfunction indicates a high degree of mobility problems in the PWD in the area. Twenty five percent (3 persons) of the PWD found it difficult to walk over longer distances, while 50% (6 persons) made use of assistive devices to move around.

5.2.1.2 Needs and aspirations of the PWD and the community/care-givers for integration into the workplace

Aspirations

The qualitative data collected on aspirations was grouped under the following themes:

- Work related,

- Social,

- Rest,

- No aspirations.

The researcher recorded the aspirations as translated by the research assistant. The answers are thus not available in the PWD or caregiver's own words.

The following table provides an overview of the responses. Because the PWD could report more that one aspiration the table does not add up to a total of 100%.

Table 5.5 Summary of aspirations of PWD

Category	Number (% - N=12)
Work related responses (a desire to return to work, achieve a worker status, earn an income for a better life)	6 (50)
Social (be accepted by wider family, have a place in community)	2 (16)
Rest	1 (8)
No aspirations	5 (42)

Level of motivation and action

Their level of motivation could affect the aspirations of the PWD. To investigate this possible relation, the level of motivation was assessed according to the Vona du Toit Theory of Motivation and Action. Four of the five subjects who had no aspirations were under the levels of participation.

The following table illustrates the levels of Motivation and Action as assessed during the functional evaluation.

Table 5.6 Summary of evaluation of Level of Motivation and Action

Level of Motivation and Action	Number (% - N=12)
Active participation	4 (33)
Imitative participation	1 (8)
Passive participation	5 (42)
Self presentation	1 (8)
Self differentiation	1 (8)
Tone	0 (0)

Needs

Thirty three percent of the respondents (4 persons) reported more than one need. These needs had to do with assistive devices or equipment to improve their functionality; 58% (7 persons) reported one major need (see table below).

Table 5.7 Summary of needs assessment

Need	Percentage (N-12)
Assistive devices/equipment	4 (33)
Work	3 (25)
Money (by other means than work)	2 (17)
Other: transport/medication	2 (17)
None	1 (8)

5.2.1.3 Level of skills of PWD in the area

The situation did not allow for an in depth evaluation of work related skills. The information presented here is a summary of information gathered in the disability survey during Phase I and II.

The table below illustrates the PWD's level of education.

Table 5.8 Summary of level of education of PWD

Level of education	Number (% - N=12)
None	3 (25)
Primary school	5 (42)
Secondary school	3 (25)
Tertiary education – academic	0 (0)
Tertiary education – trade	1 (8)

Only one of the PWD had any formal training. However, five of the men had had in-service training, two as miners, one as farm labourer, one in a brick factory and one as electrician. None of the women had any training but had been involved in household tasks.

The following table summarises the work skills reported by the PWD. Because some PWD reported more than one kind of skill the table does not add up to a 100%.

Table 5.9 Summary of work related skills reported by PWD

Skills related to:	Number (% N=12)
Household tasks – including needlework	4 (33)
Agriculture	2 (17)
Animal husbandry	3 (25)
Mining	2 (17)
Brick making	2 (17)
Motor repairs	1 (8)
Shoe repairs	1 (8)
Electrical installations	1 (8)

5.2.1.4 Individual case studies

The 12 cases identified as PWD in the age group 16 – 40 in the Tsilitwa area are described as individual cases in this section under the following headings:

■ Personal data: - age, gender and education,

■ Condition: - self-reported diagnosis or according to clinic information and observation, cause and onset of the condition that caused disability,

■ Aspirations and needs: - reported by PWD or caregiver in the interview during the functional assessment,

■ Skills: - self-reported work related skills,

■ Profile: - abilities and disabilities identified in the functional assessment (see **Appendix III**).

The scale for the assessment as described in Chapter IV is briefly summarised for interpretation. See Table 4.3 for full details.

Table 5.10 Assessment scale

Level	Definition of functioning	
Level 1	Independent function	(normal)
Level 2	Independent function	(abnormal)
Level 3	Independent function	(with assistive device or activity adaptation)
Level 4	Dependent function	(with assistant)
Level 5	No function	(total assistance)

Case I

Personal data

Age: 34   Gender: Female

Dependents: 0   Disability grant: No

Education: Secondary school – Grade 8

Condition

Cerebral palsy identified at nine months

Epilepsy

Level of motivation

Passive participation

Needs

She reported that she had no special needs.

Aspirations

She would like to be a teacher.

Skills

She is responsible for cleaning tasks in the home and is involved in the local crèche.

General observations

Ms T was found alone at home and was initially apprehensive and withdrawn. She participated willingly with all requests but remained inactive and non-contributing when no instructions were given. She became more animated when the children in the crèche were discussed. From discussion with the research assistant it appeared that circumstances have led to a passive role.
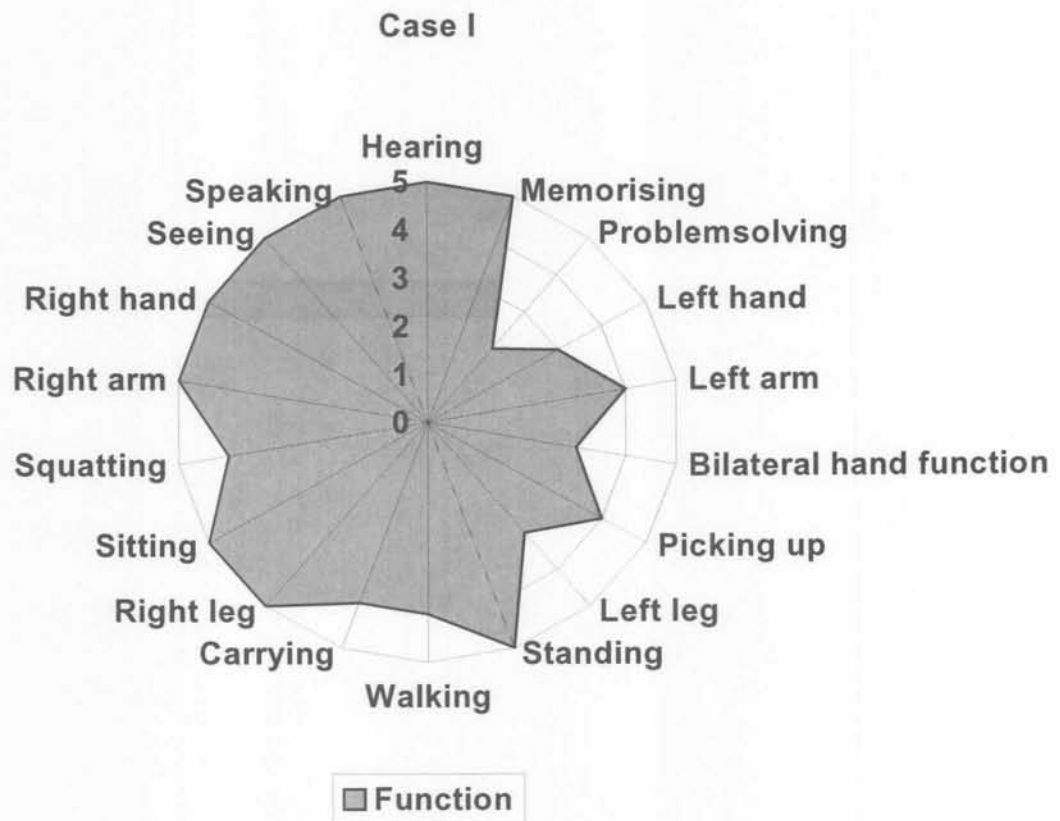
Case I

Figure 5.1 Profile of function: Case I

Ms N's movement patterns were abnormal and slow mainly because of increased muscle tone. She performed activities one-handed with the left hand performing support actions.

Case II

Personal data

Age: 22   Gender: Female

Dependents: 1   Disability grant: No

Education: Secondary school – Grade 11

Condition

Motor vehicle accident that caused loss of muscle in both lower limbs causing abnormal movement. The left leg is more affected than the right leg. The accident happened when she was 12 years old.

Level of motivation

Passive participation

Needs

She reported that she needed transport from and to within a distance that she could cope with. (The nearest stop for lifts to town was one km away – according to her mother she used to walk to school before the accident, approximately 10 km away.)

Aspirations

She would like to be able to do needlework.

Skills

She is not involved in tasks in the home. Her mother takes care of her child. She said pain prevented her from such activities.

General observations

Ms M did not show signs of pain during the assessment except during negotiating the steps outside the house. This seemed inconsistent with previous movements.

Case II
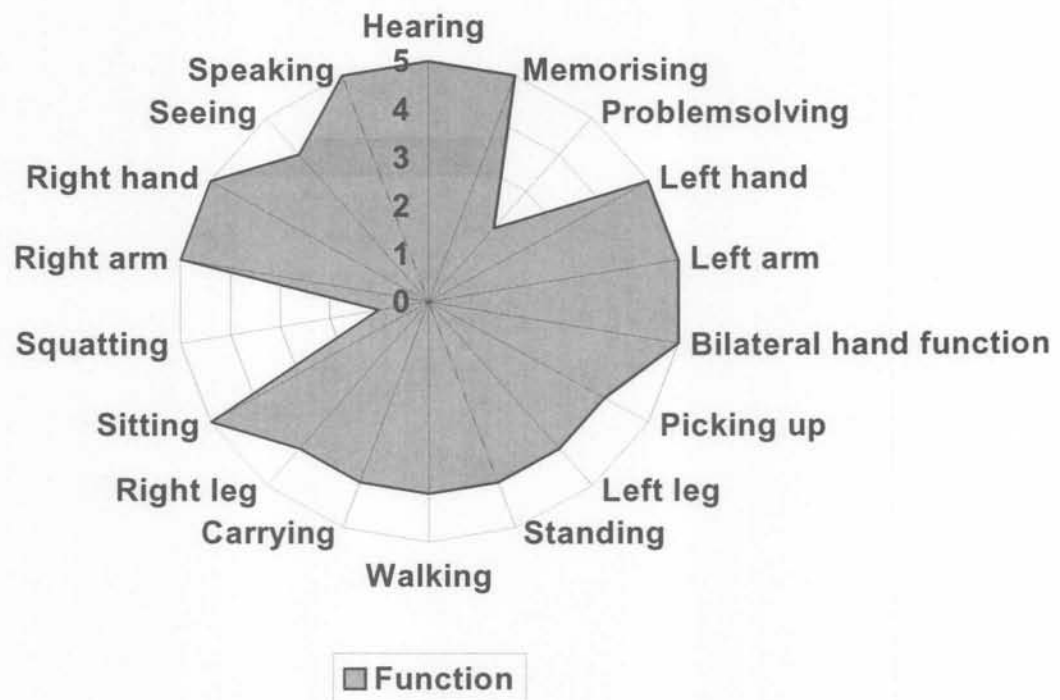
Figure 5.2 Profile of function: Case II

Ms M's visual problems would be followed up by the clinic from where she would be referred to an optician for glasses. She was mobile but walked with a limp (more weight bearing on the right leg that the left leg). She reported that she experienced pain after long periods of walking, standing and with squatting to pick up objects.

Case III

Personal data

Age: 31   Gender: Male

Dependents: 0   Disability grant: Yes

Education: None

Condition

Cerebral palsy – severely disabled since birth

Epilepsy

Level of motivation:

Self differentiation

Needs

The mother reported that he needed orthopaedic shoes and a wheelchair.

Aspirations:

None

Skills

None – mother takes care of personal management activities.

General observations

Mr G had severe difficulties carrying out the tasks of the functional assessment. He could not fasten the buttons and needed assistance with the activities that required mobility and is usually assisted in activities of daily living by his mother.

Chapter V Results
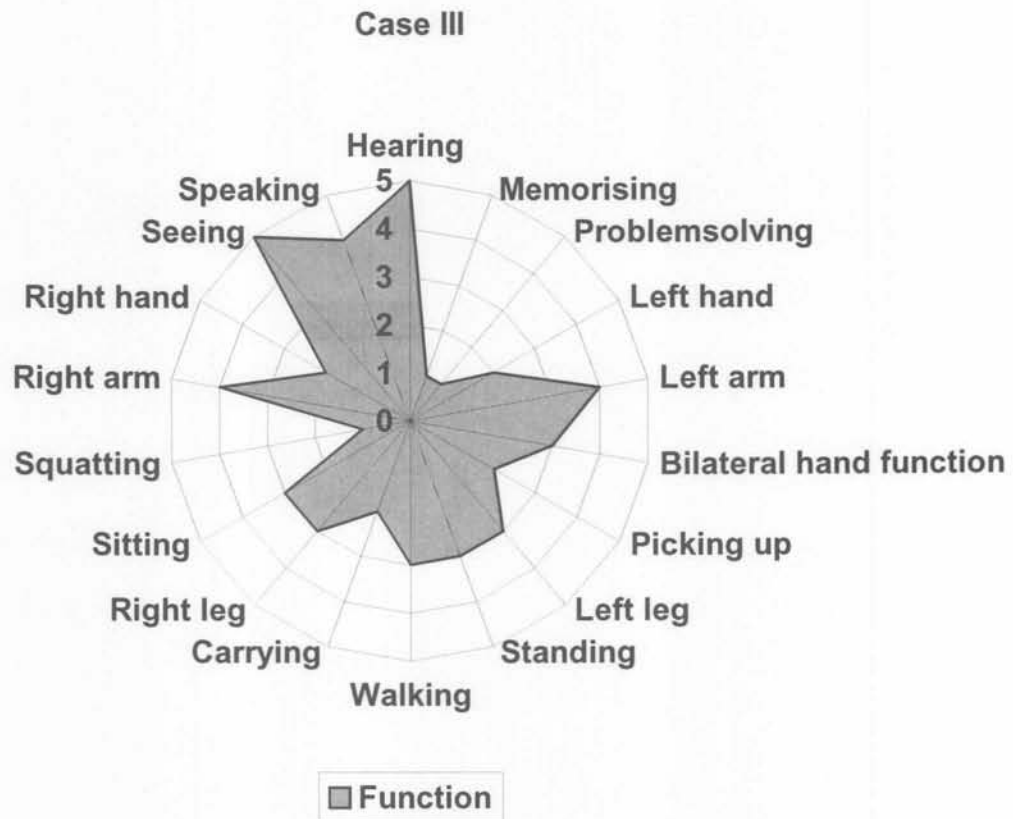
Case III

Figure 5.3 Profile of Function: Case III

Mr G used severely abnormal movement patterns caused by abnormal muscle tone. This affected the accuracy and speed of his activity performance and speech. Walking down the two steps from his house, for example, was a difficult task, which took a long time and a lot of effort. Fine co-ordination to fasten buttons could not be achieved.

Case IV

Personal data

Age: 38   Gender: Male

Dependents: 1(Mother)   Disability grant: Yes

Education: None

Condition

Cerebral Palsy identified shortly after birth – mild quadriplegia

Level of motivation

Passive participation

Need:

His mother felt he was fine and had no special needs. She then thought he might benefit from training. She could not say what kind of training.

Aspirations

To rest

Skills

The mother involves him in tasks like brick making otherwise he joins the boys in cattle watching. He appears to be able to follow instructions and contribute to a collective task.

General observations

Mr S has been cared for by his mother since birth. He is neatly dressed and well mannered. She takes him with her to family and social gatherings where he plays a passive role. He is not independent and functions only under supervision.
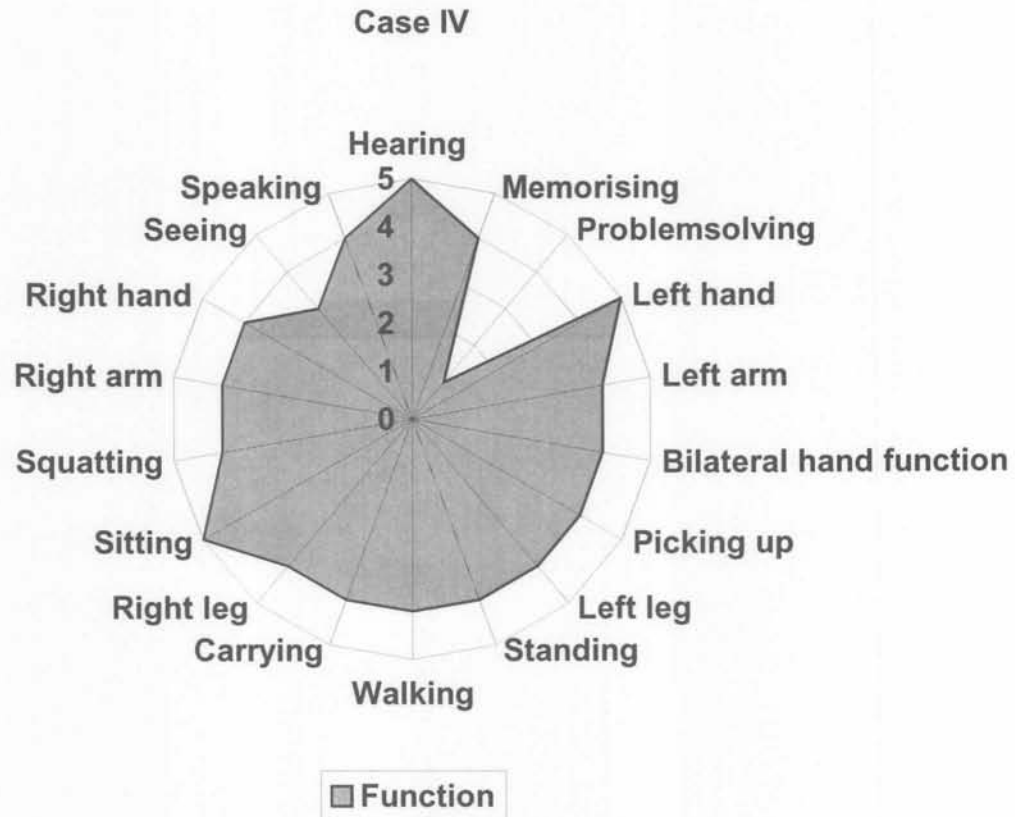
Case IV

Figure 5.4 Profile of function: Case IV

Mr S's visual problems might be improved with glasses and would be followed up by the clinic. His hearing was functional if he was addressed from the right. The abnormal movement patterns and the speed of his movements were affected by abnormal muscle tone. He demonstrated some balance problems in walking on uneven surfaces and in squatting. Associated reactions appeared in resisted movements.

Case V

Personal data

Age:	36	Gender:	Male
Dependents:	4	Disability grant:	No
Education:	None		

Condition

Incomplete spinal injury caused by a fight two years ago.

Level of motivation

Active participation – he showed initiative in carrying out the suggestions to make his house more accessible and to use his time more productively.

Needs

A toilet and a path to it.

Aspirations

In the interview he only mentioned he would like to walk again. However, in other discussions he explained plans to procure an income through repairs of radios and shoes for friends.

Skills

After some exposure in leatherwork in occupational therapy at the Bedford Hospital he made himself tools and developed skills for shoe repairs.

General observations

Mr B was seen on various occasions during the study. Initially he appeared depressed and did not leave his bed. He reacted well to suggestions to improve his situation but because of the uneven surface around his house he was limited to a small area in which he could negotiate his wheelchair.
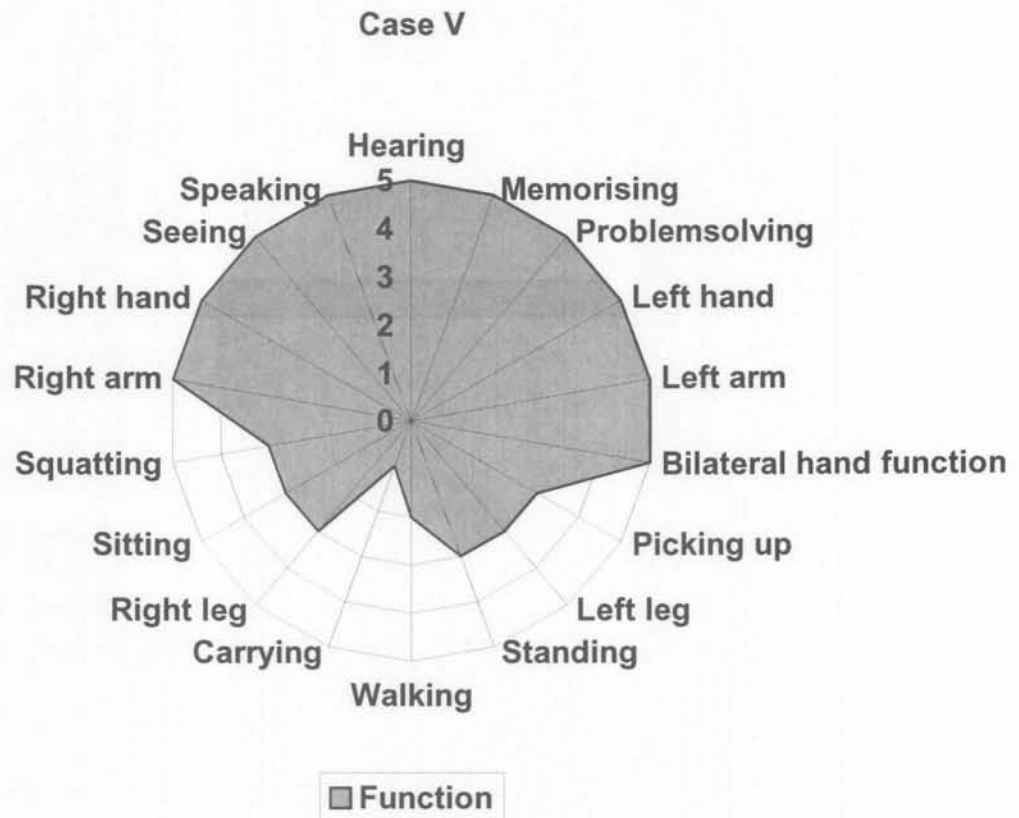
Case V

Figure 5.5 Profile of function: Case V

Mr B's skills to handle his wheelchair were affected by some balance problems but were slow mainly due to the long period of not using his wheelchair before the researcher's first visit. He walked between the parallel bars his friends had helped him to erect. The right leg had more movement than the left. Because of poor dorsi flexion at the feet and hip movement only small shuffling steps could be taken.

Case VI

Personal data

Age:	38	Gender:	Male
Dependents:	2	Disability grant:	No
Education:	Tertiary level – trade: Motor mechanic N3		

Condition

He sustained an injury to his legs in a motor vehicle accident six years ago causing difficulties with mobility.

Level of motivation

Active participation

Needs

He expressed the need for tools to effectively carry out motor repairs for people in the village.

Aspirations

He would like to establish his own workshop for motor repairs.

Skills

He uses his formal training to repair motor vehicles in the village and volunteers as teacher in the local high school in the auto shop.

General observations

Mr M is often seen walking in the village, to school, meetings or friends. He participates actively in the community. When he was given a lift on one occasion it was observed how much effort and time was spent on reaching his destination.
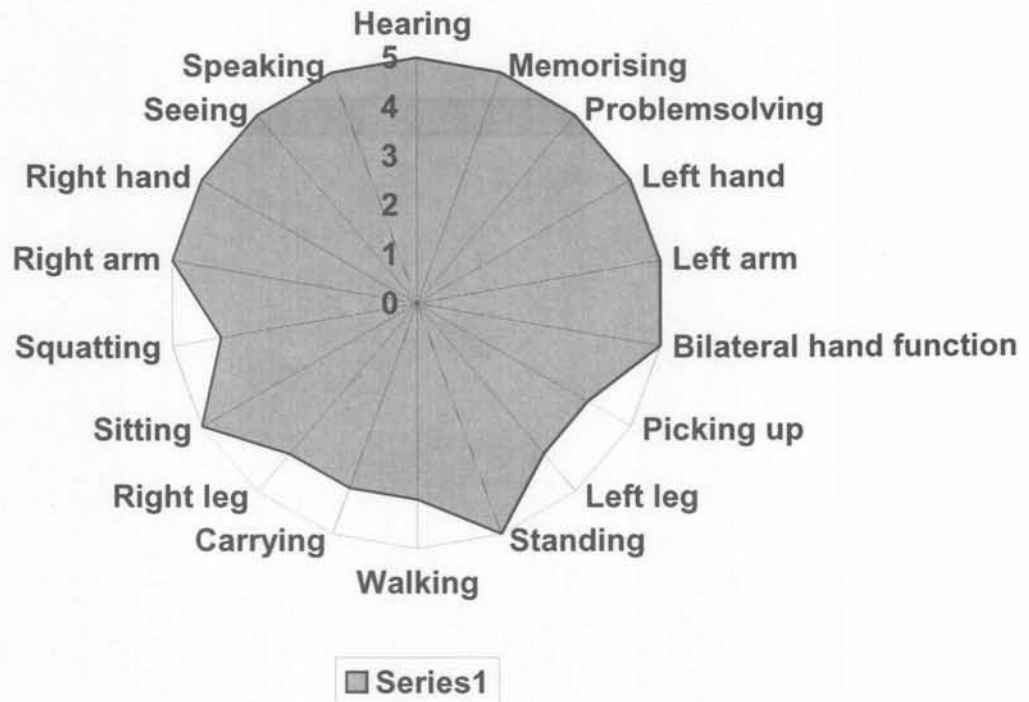
Figure 5.6 Profile of function: Case VI

The right knee and both hips had normal movement. The lack of dorsi flexion of both ankles affected his gait especially over uneven surfaces.

Case VII

Personal data

Age:	38	Gender:	Male
Dependents:	5	Disability grant:	No
Education:	Secondary school		

Condition

He sustained an injury to his legs during a blast in a mine 13 years ago. According to Mr J he was injured because of a curse – this interpretation suggests possible traumatic brain injury.

Level of motivation

Active participation

Needs

An income

Aspirations

He expressed that he would like to be able to work again.

Skills

He worked the pumps in the mines. However, he does not have any special skills that he learned as a miner. He has been taking care of his neighbours' goats and has some knowledge of animal care.

General observations

Mr J is dependent on the generosity of his family and appeared grateful for the opportunity to care for the goats. He spends most of his time during the day sitting in front of his house.

Chapter V Results
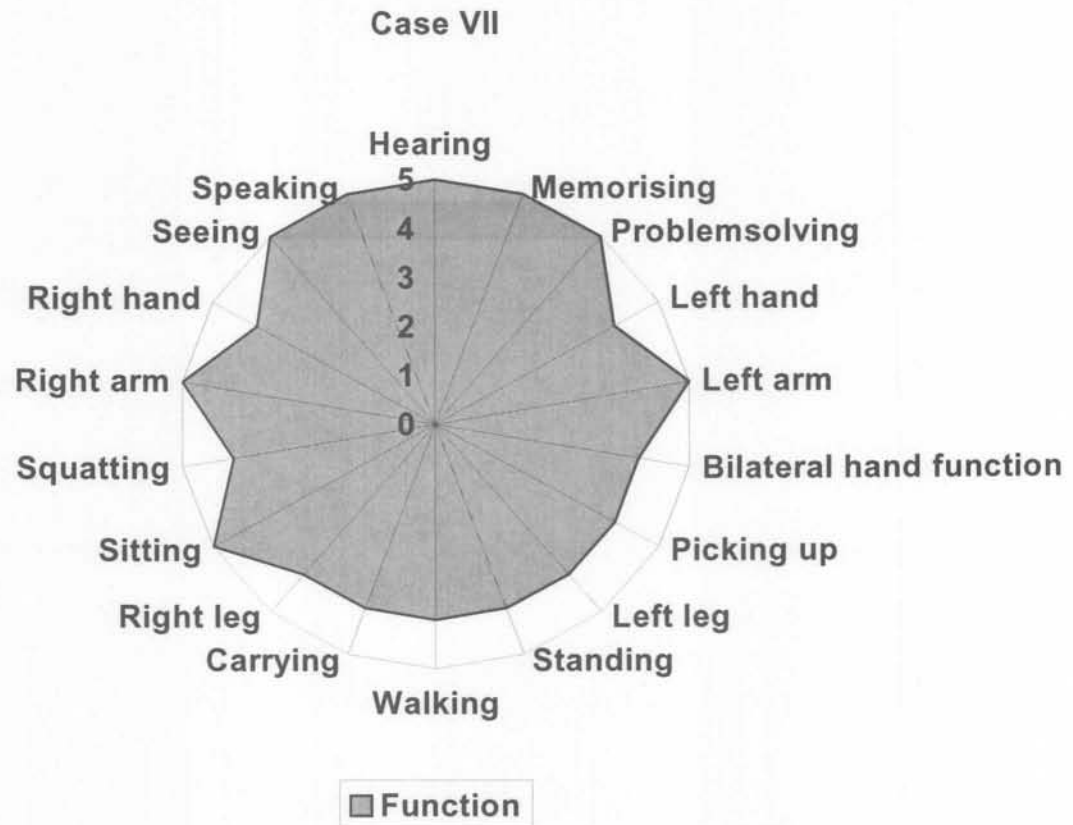
Case VII

Figure 5.7 Profile of function: Case VII

Pain appeared to affect Mr J's function in terms of range of movement and speed. He also appeared to have some proprioceptive fall out, which was observed in the hand function and reported by him in his feet. He walked with an unilateral external support.

Case VIII

Personal data

Age:	36	Gender:	Female
Dependents:	0	Disability grant:	Yes
Education:	Primary school		

Condition

Rheumatoid arthritis - reportedly since her late teens.

Level of motivation

Passive participation

Needs

She expressed a need for a reduction in pain caused by her condition.

Aspirations

None

Skills

She assists with light household tasks, but has no specific responsibilities.

General observations

Ms S expressed that her long-term suffering justified her not having to participate in household activities and that she was not interested in work related activities that might be planned.

Case VIII
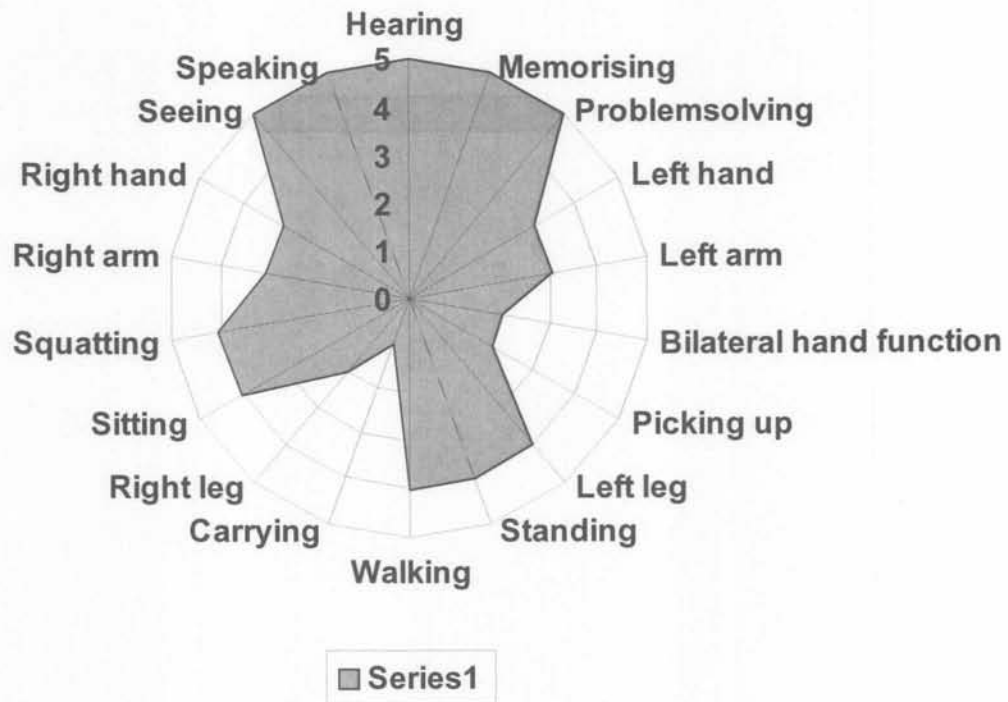
Figure 5.8 Profile of function: Case VIII

Ms S's chronic condition had affected the range of motion throughout, but more in the upper limbs that the legs. She also experienced the same pattern with pain. Both these factors affected her posture and to some extend her balance.

Case IX

Personal data

Age:	28	Gender:	Male
Dependents:	0	Disability grant:	Yes
Education:	Primary school		

Condition

Traumatic brain injury sustained during a violent strike eight years ago

Level of motivation

Self presentation

Needs

His mother said that she did not know of anything he might need, except some advice.

Aspirations

Mother said that she did not know of any.

Skills

He had worked in a brickyard and planted trees for a nursery, in both instances as a labourer with no special training.

General observations

Mr F reacted inappropriately to the situation and appeared surprised at being able to complete the tasks given in the assessment. He does not carry out any tasks except personal management, which he appears to do under supervision.
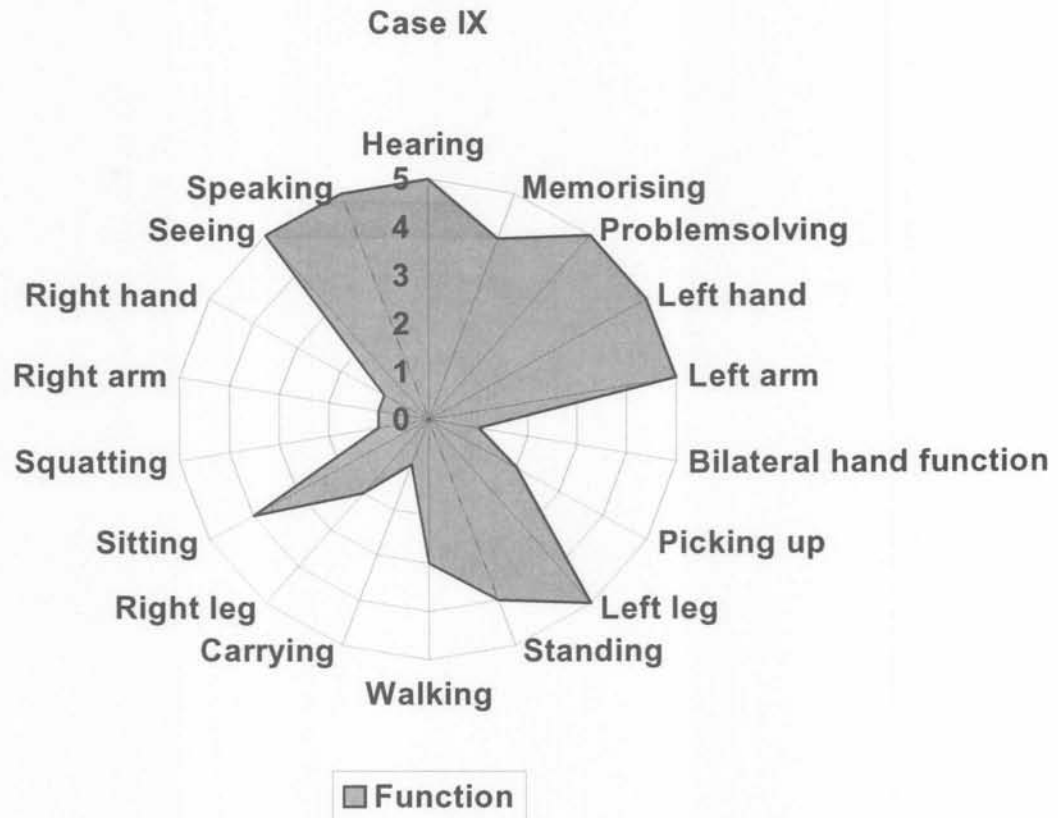
Figure 5.9 Profile of function: Case IX

The slight expressive aphasia slowed down communication and the accuracy of the memory assessment. Increased muscle tone was the main reason for his mobility and postural problems. He had difficulty with weight bearing because of clonus in the right foot and walked with a hemi gait pattern supporting himself with a crutch. The use of the crutch with his good side and the balance problems affected his ability to carry objects.

Case X

Personal data

Age: 39 Gender: Male

Dependents: 6 Disability grant: Yes

Education: Primary school

Condition

Traumatic brain injury caused by a gunshot during faction fighting three years ago

Level of motivation

Imitative participation

Needs

He expressed the need for work, which he could do sitting down.

Aspirations

To work again

Skills

He received in-service training at a firm that installed alarms in Germiston and thought he might be able to remember how to do electrical wiring.

General observations

Mr S was interested in the various tasks given in the assessment and enjoyed the attention. According to his wife he played a passive role in the household. He was later voted into the Tsilitwa Committee of PWD.
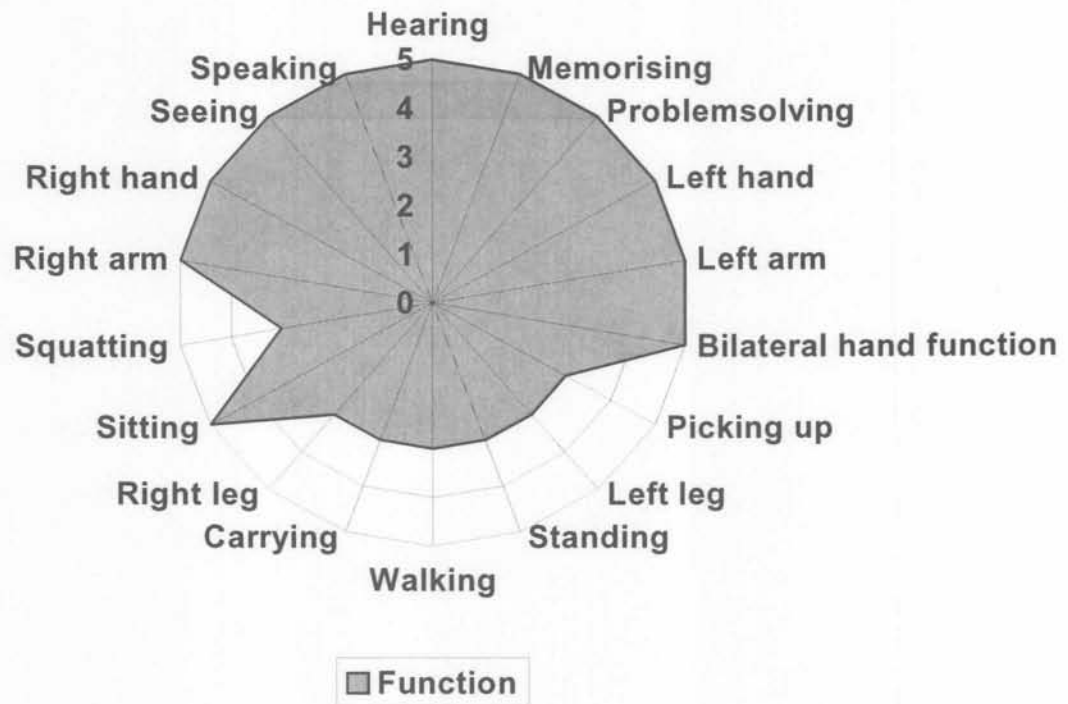
Figure 5.10 Profile of function: Case X

Mr S needed external support to stand up, walk and carry an object. A lack of postural control and control over leg movements demanded the use of a walking stick and caused him to prefer turning around backward rather than forward.

Case XI

Personal data

Age: 37   Gender: Female

Dependents: 0   Disability grant: No

Education: Primary school

Condition

Hemiplegia – arm more affected than the - leg since birth

Level of motivation

Active participation

Needs

She reported that she needed money.

Aspirations

None

Skills

Skills involved in performing household tasks

General observations

Ms L appeared to have adapted to doing tasks with one hand. Although she appeared withdrawn during the assessment she was observed to interact well with others socially and participated fully in activities.

Case XI
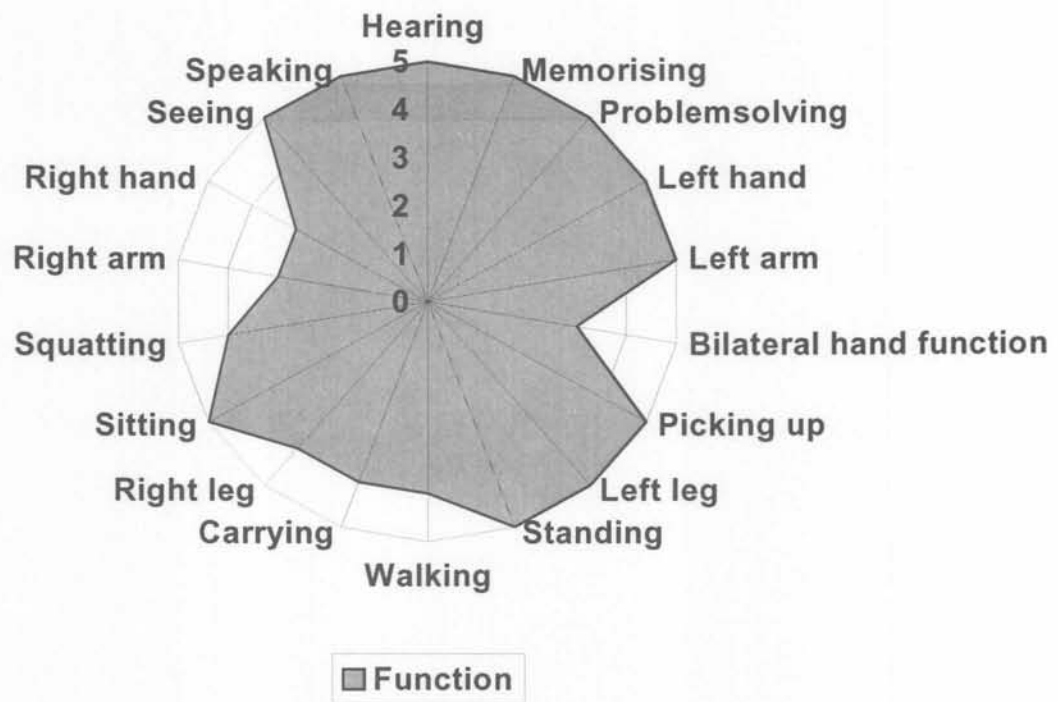
Figure 5.11 Profile of function: Case XI

Ms L had adapted to functioning one-handed. Abnormal muscle tone affected her movement patterns, the speed of her gait and balance during tasks like squatting and walking.

Case XII

Personal data

Age:	39	Gender:	Male
Dependents:	0	Disability grant:	No
Education:	Secondary school		

Condition

The family reported a sudden onset of problems with an unknown cause, three years ago – the researcher considered the possibility of a stroke.

Level of motivation

Passive participation

Needs

He said he needed a fowl run.

Aspirations

He would like to farm with poultry to procure an income.

Skills

He was a miner erecting supports in new tunnels for which he had in-service training. He felt he had the necessary knowledge and skills for the poultry farming.

General observations

Mr J was passive during the assessment and the interview with an apathetic attitude to the tasks given. He suddenly became vocal and interested when discussing his past.

Case XII

Figure 5.12 Profile of function: Case XII

Abnormal muscle tone and associated reactions affected the speed, and accuracy of Mr J's movements. It also was evident in his posture and gait and affected his balance. He performed activities one-handed with decreased accuracy and speed.

Attitudes of the PWD, caregivers and community to equal employment opportunities for PWD

Of the 100 persons expected at the community survey meeting about 50 arrived (see **4.5.1.2 Visit 8 and 9**). The final number of participants in the survey was 39 persons. Two of the 43 reported to have disabilities in the Phase I survey attended the meeting as well as family members of some others. The rest of the group were ordinary residents of the area.

The responses from the attitude survey can be summarised in the following three themes for each of the two aspects surveyed (attitude toward the role of the PWD in the family and in the community):

- Value of the person to the family or community,

- Function of the person in the family or community,

- Burden on the family or community.

The scribes summarised the points on which the group reached consensus. Therefore no statistics can be given on how many persons in the group voiced a specific attitude or whether a response reflects the attitude of a PWD, family member or community member.

The following tables summarise the responses of the four groups. The responses will be quoted verbatim in the chapter on discussion of results to give depth to the interpretation of the results.

Table 5.11 Summary of attitudes to PWD's position in the family

Category	Attitude
Value of the person to the family	The PWD: ■ Belongs in the family ■ Is loved and respected ■ Should retain his/her status in the family
Function of the person in the family	The PWD: ■ Can be a contributing member according to ability ■ Should receive support for further treatment, and training to further abilities
Burden on the family	The PWD: ■ Need to be cared for, for their personal and financial security ■ Need sheltering because of their vulnerability

Table 5.12 Summary of attitudes to PWD's position in the community

Category	Attitude
Value of the person to or community	The PWD: ■ Are valued for their experience ■ Should be treated equitably
Function of the person in community	The PWD: ■ Should be included in meetings ■ Can contribute economically with training
Burden on the community	The PWD: ■ Need protection ■ Need special facilities

5.2.2 Objective 2: Investigate the planned job creation projects in the IRDM for suitable integration of the PWD

5.2.2.1 Job analyses of planned projects

The job analyses were done according to the scale developed to match the functional assessment (see **4.2.2**). The scale reflects the assistance needed to complete a task safely and successfully.

The analyses reflect the requirements to perform a task normally. Level 3 indicates whether an aspect would be used in an alternate position or following an adapted method, which in normal performance would not be required to perform the task. This information will be used to make the job match when adaptations are required.

The evaluation of the PWD's ability to solve problems examined the integration of insight, judgment and abstract thinking. Requirements of these higher cognitive functions were combined under the aspect of problem solving.

The analysis process was as follows:

- Identify tasks involved in the work process,

- Determine requirements for completion of the task for each of the aspects evaluated in the functional assessment in each of the tasks,

- Apply scale,

- Identify highest performance level required to complete all the tasks in the work process.

The results of the analyses of the five projects will be presented according to this process.

Leatherwork

No local leatherwork projects were operational at the time of the study. The leatherwork analysis was then carried out in the occupational therapy department at Bedford Hospital by video recording the occupational therapy assistant in a variety of leatherwork activities which he performed from a wheelchair because of his spinal lesion.

The request to include leatherwork in the study was mainly for shoe repairs as a project. To extend the request to include other types of leatherwork needed the inclusion of only one task, namely the punching of holes. The analysis presented here includes this task so that there is wider application and the work process thus includes the making of leather articles like belts and bags.

The following table illustrates the requirements for the various tasks that need to be executed for the leatherwork process.

Table 5.13 Summary of leatherwork tasks

Task	Cutting	Sewing Lacing	Gluing	Nailing	Sanding	Punching
Hearing	1	1	1	1	1	1
Memorising	4	4	4	4	4	4
Problem solving	5	4	4	5	5	4
Left hand	5	5	4	4	5	5
Left arm	5	5	4	4	5	4
Bilateral hand function	5	5	4	4	5	5
Picking up	3	3	3	3	3	3
Left leg	1	1	1	1	1	1
Standing	1	1	1	1	1	1
Walking	3	3	3	3	3	3
Carrying	3	3	3	3	3	3
Right leg	1	1	1	1	1	1
Sitting	5	5	5	5	5	5
Squatting	1	1	1	1	1	1
Right arm	5	5	5	5	5	5
Right hand	5	5	5	5	5	5
Seeing	4	4	4	4	4	4
Speaking	1	1	1	1	1	1

The following figure illustrates the highest levels of requirements for leatherwork.

Leatherwork
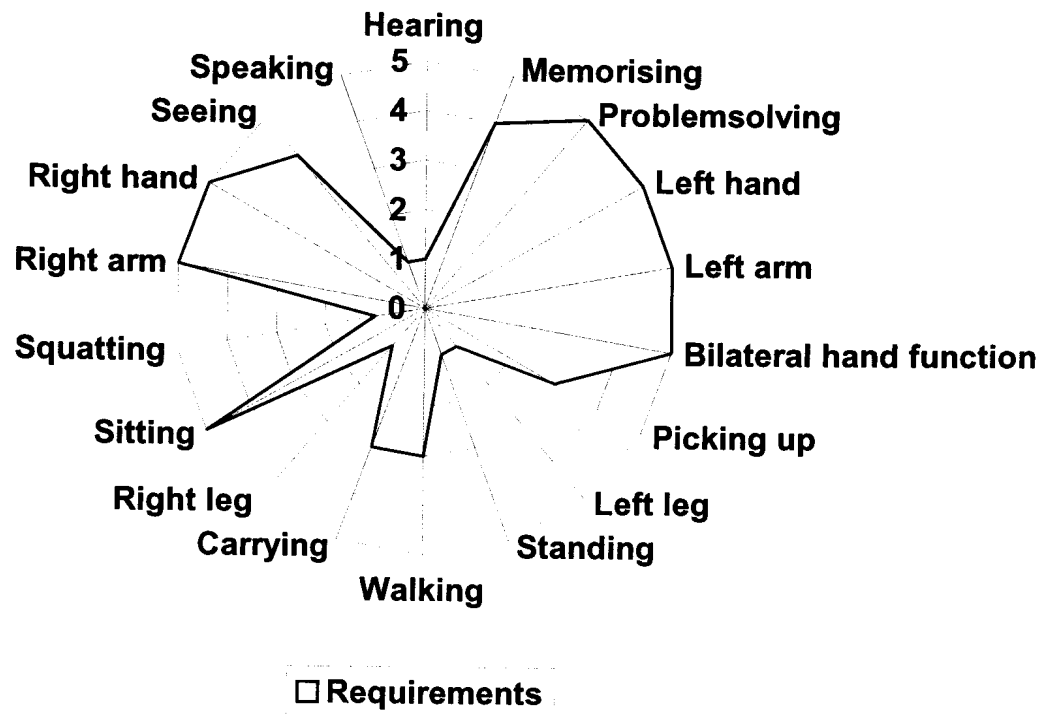
Figure 5.13 Profile of requirements for leatherwork

This profile illustrates that leatherwork is mainly carried out as an upper limb function. It is a bilateral activity, which can be carried out in sitting. Adapted methods can be used for walking and carrying. For finer detail, vision is essential but routine work can be done by compensating with touch.

Problem solving ability and insight are important in repair work. Routine manufacture of leather articles would not demand as much memory as intricate craftsmanship of a variety of articles.

Needlework

At the needlework project visited, the women were also doing traditional beadwork. The actions of the beadwork were analysed. It was found that the requirements could be compared to those of hand sewing and were included in the analysis as such.

The following table illustrates the requirements for the various tasks that need to be executed for the needlework and beadwork processes.

Table 5.14 Summary of needlework tasks

Task	Cutting	Pinning	Hand sewing/ beadwork	Hand machine sewing	Electric machine sewing
Hearing	1	1	1	1	1
Memorising	5	4	4	4	4
Problem solving	5	5	4	5	5
Left hand	4	5	5	4	4
Left arm	4	5	5	4	4
Bilateral hand function	4	5	5	5	4
Picking up	3	3	3	3	3
Left leg	1	1	1	1	1
Standing	1	1	1	1	1
Walking	3	3	3	3	3
Carrying	3	3	3	3	3
Right leg	1	1	1	1	4
Sitting	5	5	5	5	5
Squatting	1	1	1	1	1
Right arm	5	5	5	5	5
Right hand	5	5	5	5	5
Seeing	5	5	5	5	5
Speaking	1	1	1	1	1

The following figure illustrates the highest levels of requirements for needlework and beadwork.

Needlework

Figure 5.14 Profile of requirements for needlework

Needlework is an activity that requires mostly upper limb function. It is a bilateral hand activity that can be carried out in sitting. If structured correctly, once the position has been taken up, no further mobility is needed. Adapted methods can be used for walking and carrying. Vision is important for safety in cutting, pinning and machine work. One lower limb should be functional for machine sewing.

Higher cognitive functions, especially judgement, are important to deliver a marketable product.

Gardening

Food production projects like vegetable gardening are one of the first projects in most rural development programmes. There are many documented methods for such projects. The one analysed was typical for co-operative gardening projects in the region, in which traditional methods are favoured.

The following table illustrates the requirements for the various tasks that need to be executed for gardening.

Table 5.15 Summary of gardening tasks

Task	Digging	Planting	Weeding/ hoeing	Watering	Harvesting
Hearing	1	1	1	1	1
Memorising	4	4	4	4	4
Problem solving	4	4	5	4	5
Left hand	5	5	5	4	5
Left arm	5	5	5	4	5
Bilateral hand function	5	5	5	4	5
Picking up	5	5	4	5	5
Left leg	5	5	5	5	5
Standing	5	5	5	5	5
Walking	5	5	5	5	5
Carrying	5	5	5	5	5
Right leg	5	5	5	5	5
Sitting	1	1	1	1	1
Squatting	4	5	4	4	5
Right arm	5	5	5	5	5
Right hand	5	5	5	5	5
Seeing	5	5	5	5	5
Speaking	1	1	1	1	1

The following figure illustrates the highest levels of requirements for gardening.

Gardening

□ Requirements

Figure 5.15 Profile of requirements for gardening

Gardening is an activity that requires comprehensive physical functioning, strength and endurance. The gardener needs to be mobile especially over the local hilly terrain. He/she needs bilateral hand function and strength to operate the heavy traditional tools, carry water in the local conditions and manoeuvre the harvest.

Judgement and problem solving skills are important to ensure a good crop but routine could compensate for less functional memory.

Poultry farming

Poultry farming, as it is practised in the rural area visited, can be described as free-range farming. The chicks are kept indoors for the first week and then join the adult chickens. The chickens are kept in a fowl run overnight and roam free in a fenced area during the day. The chickens are sold live, thus no slaughtering tasks have been included.

The following table illustrates the requirements for the various tasks that need to be executed for the poultry farming process.

Table 5.16 Summary of tasks involved in poultry farming

Task	Handling chicks	Feeding	Collecting eggs	Selling
Hearing	4	4	4	5
Memorising	4	5	4	5
Problem solving	5	5	4	5
Left hand	4	4	4	4
Left arm	4	4	4	4
Bilateral hand function	4	4	4	4
Picking up	5	5	5	4
Left leg	4	4	4	4
Standing	5	5	5	4
Walking	5	4	5	4
Carrying	4	5	5	4
Right leg	5	5	5	5
Sitting	1	1	1	1
Squatting	4	1	5	1
Right arm	5	5	5	5
Right hand	5	5	5	5
Seeing	5	5	5	5
Speaking	1	1	1	5

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The following figure illustrates the highest levels of requirements for poultry farming.

Poultry farming
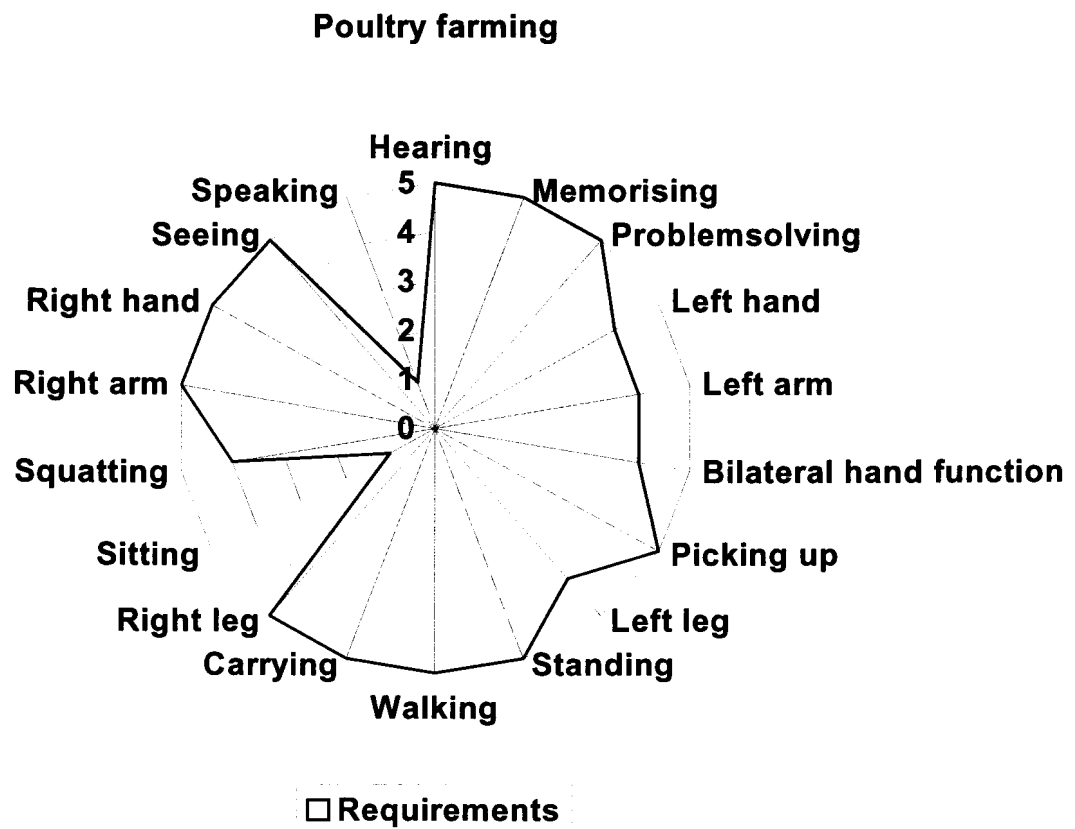
□ Requirements

Figure 5.16 Profile of requirements for poultry farming

The profile indicates that many of the tasks for poultry farming do not necessarily require bilateral hand function. Walking and carrying, however, are necessary for the rounding up of the chickens and the collecting of eggs which in the local nesting areas could require walking over uneven terrain. Vision is important to ensure that the chickens are well and to find them in the free- range farming style. Speech is a requirement for the buying and selling process of the activity.

Memory, judgement and problem solving skills are important for farming with poultry and livestock.

Baking

Bread was the most profitable baking product during the study. No skills for cake decorating have been included; the analysis focuses on bread baking only. Although the project analysed used a wood-fired clay oven, the tasks involved in heating the oven have been left out as the project in Tsilitwa will be using electric ovens.

The following table illustrates the requirements for the various tasks that need to be executed for the bread baking process.

Table 5.17 Summary of bread baking tasks

Task	Mixing ingredients	Kneading	Dough handling	Pan handling	Baking
Hearing	1	1	1	1	1
Memorising	5	4	4	4	5
Problem solving	5	4	5	5	5
Left hand	4	4	5	5	5
Left arm	4	4	5	5	5
Bilateral hand function	4	1	4	5	5
Picking up	4	1	4	5	5
Left leg	4	5	1	5	5
Standing	5	5	1	5	5
Walking	5	1	1	1	5
Carrying	5	1	1	5	5
Right leg	4	1	1	5	5
Sitting	1	1	3	5	5
Squatting	1	1	1	1	5
Right arm	5	5	5	5	5
Right hand	5	5	5	5	5
Seeing	5	4	5	5	5
Speaking	1	1	1	1	1

The following figure illustrates the highest levels of requirements for bread baking.
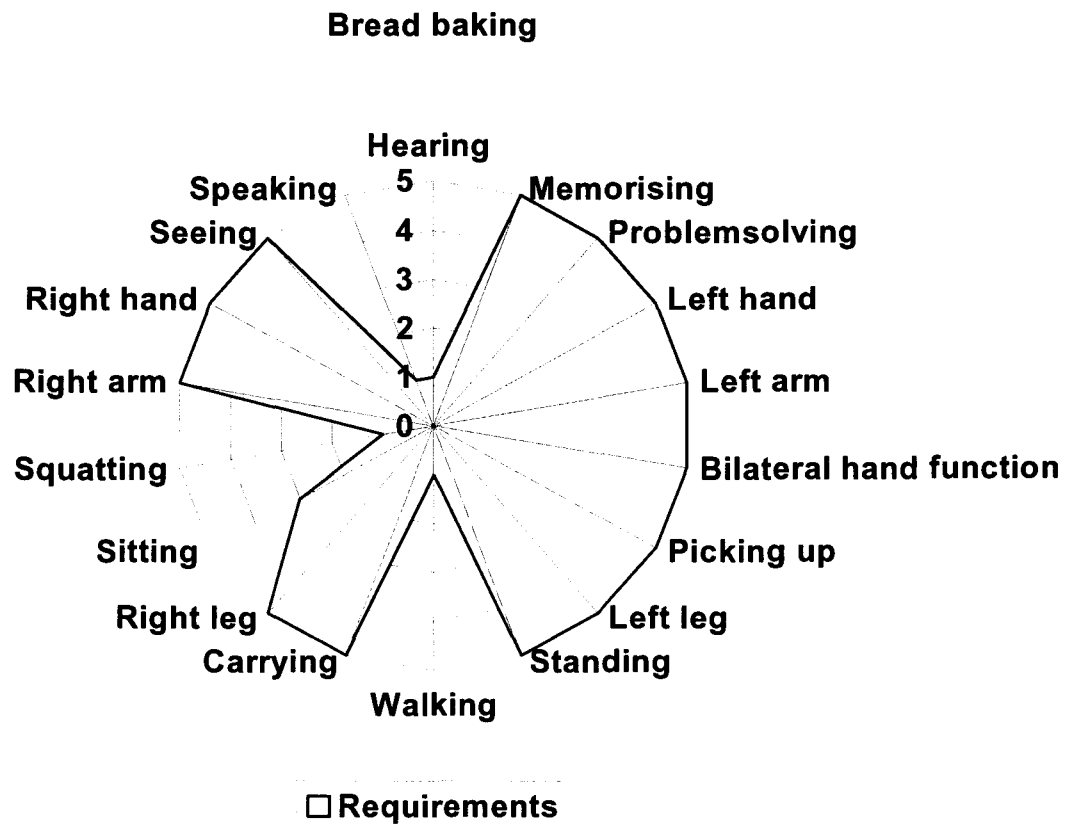
Bread baking

Figure 5.17 Profile of requirements for bread baking

Baking is an activity that requires mainly upper limb function. It is a bilateral hand activity that requires strength and endurance for the preparation of the dough. Mobility is needed in the mixing and the baking tasks. Speech is a requirement for the buying and selling process of the activity.

For successful and safe completion of the activity the baker needs good memory, judgement and problem solving skills.

5.2.2.2 Facilities

None of the projects mentioned by the committee in the first stage of the research study were in existence by the end of the study.

The fowl run used for a poultry project had collapsed in a heavy rainstorm and was no longer in existence. The sewing project had been run from the home of one of the committee members but she had moved away and the project was dormant. The plans for the baking project were progressing with the donation of a building.

The TDC had erected the facilities for the baking project at the school in the later stages of the study. The facility was built as an income-generating project for the whole area.

The site and the facility were examined to assess the accessibility for PWD to allow them to be fully integrated as prospective participants in the project.

Site

The building was erected within the school grounds, which are central to the Tsilitwa village. Accessibility was considered in terms of the following:

■ Position: - the position at the school is suitable because of its central location and the security that is provided by the school board. The building is the first building just inside the main gate (± 30 meters from the entrance).

■ Roads: - the major roads in the area are deeply rutted; they are passable by motor vehicle (preferably a light delivery vehicle (LDV) as the tracks have the width of such vehicles), on horseback or on foot; the smaller roads are uneven, often overgrown and in many places have deteriorated to footpaths; footpaths cross the hills from all direction to provide more direct routes for pedestrians.

■ Transport: - no formal or informal transport system exists in the area. There are pick-up points at which people gather and wait until some one passes and offers a ride. With the rare exception of a sedan, the passing vehicle is a light delivery vehicle (LDV) and people sit under a canopy on the back, amidst the goods being transported. PWD thus need to be able to reach the pick- up point and board the vehicle. Drivers do accommodate wheelchair users if they can fasten the wheelchair to the roof of the vehicle.

■ Surface: - the school is built on a hillside and the surface surrounding the buildings is roughly evened out with level paths along the classrooms.

■ Toilets and water supply: - the toilets are positioned at the edge of the school complex (±250 meters from the new building) and access to them is by a narrow footpath; the only current water supply is a tap on the school grounds centrally positioned in a grassed area.

Building

■ Entrance: - There is a concrete strip (wide enough for a wheelchair) and one small step to the entrance of the building (±20 cm); at the time the concrete strip started level with the ground.

■ Doors: - the entrance door is wide enough for all wheelchairs; some of the doors to office and storeroom spaces would only allow narrow adult wheelchairs to pass.

■ Floor surface: - the floor surface is a level concrete surface throughout.

■ Lighting and ventilation: - adequate windows allow for good daylight and ventilation; the building has been wired and there are electric fittings for use once the village has been connected to the national power supply network; the building is constructed from metal transport containers which will cause it to be hot in summer and cold in winter.

- **Size:** - the work area is spacious and can house a variety of equipment and people without becoming too cramped for wheelchair users to manoeuvre inside the building.

- **Work surfaces:** - no work surfaces had been acquired by the last visit and could therefore not be assessed.

5.2.2.3 Resources in terms of training and adaptations needed by PWD

The investigation into local facilities for vocational rehabilitation was carried out at a local, district and central level.

Clinic

- **Facility:** - the Tsilitwa Clinic provides primary health care for the three villages included in the study; it lies on a hill next to the road to Thombeni and is about 2 km from the main road that leads to Tsilitwa; the clinic is not accessible for PWD with severe mobility problems (location, transport, six steps at the entrance), the sisters attend to them at their homes.

- **Personnel:** - the clinic sister has no rehabilitation training, but is aware of the plight of the PWD in the area; no referrals for further rehabilitation and vocational training were made in the past; the purpose of the visits from the rehabilitation professionals was to inform the local personnel what services could be provided at a tertiary level (ie. Umtata Hospital) and to establish contact and a referral system.

District Hospital

- **Facility:** - Sulenkama, the district hospital, is about 30 km from Tsilitwa; no rehabilitation services are provided at the hospital; the matron passes on referrals for specific services from the clinics; the patients are transported to Umtata per ambulance if an appointment at the required services has been obtained; the hospital does not have an outreach programme to the clinic because of transport problems; transport to Sulenkama Hospital has to be arranged by the family of the PWD.

■ Personnel: - the matron in charge of this service was informed of the purpose of referral for vocational rehabilitation; she assured the researcher that referrals from the Tsilitwa Clinic would be forwarded if there was space in the ambulance.

Provincial Hospital

■ Facility: - Bedford Hospital in Umtata has well equipped occupational and physiotherapy departments; patients are discharged as soon as conditions stabilise and not in accordance with rehabilitation targets that would allow them optimal independent functioning; the discharge is often too early for the provision of disability grants, wheelchairs and other assistive devices; a speech and hearing therapy department is located at Umtata General hospital; co-ordination of rehabilitation services did not seem to be a priority.

■ Personnel: - the rehabilitation personnel of the various disciplines are well trained according to national standards, but expressed frustration with their internal referral systems and the lack of outreach programmes; this attitude appeared to cause them to focus on acute care rather than long-term goals; the purpose of the visits to Tsilitwa with the rehabilitation teams was to motivate them to extend their services to include vocational aspects and to establish contact with local clinic personnel and PWD of the area; the occupational therapy personnel assured the researcher that they would attend to needs in terms of assessment, job matching, additional rehabilitation and adaptations as long as it was within their means to do so; the referral system to the community and from the community to the provincial professionals was formalised.

National services

There are no funds available to refer PWD to tertiary institutions that offer specialised vocational rehabilitation services. If the family can afford the transport and accommodation near such services these institutions provide vocational rehabilitation services to clients from the provinces with which the hospitals have agreements.

The MODE (Medunsa Organisation for Disabled Entrepreneurs) was planning to extend their services into the Eastern Cape in the foreseeable future. This organisation provides:

■ Empowerment opportunities by motivation PWD to discover their abilities and assist them to use them to gain access to the workplace,

■ Vocational rehabilitation including pre-vocational skills, work performance skills and problem solving skills,

■ Work placement, job creation and business placement in the formal as well as in the informal sector,

■ Environment-enabling solutions to overcome physical and social obstacles in the work place.

The community was provided with a contact person and contact details for the purpose of training and assistance to establish individual enterprises[200].

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The above described results will be used to make job matches in the following chapter to further investigate the opportunities for PWD to be integrated into the development programme of the local community.

Chapter VI

Job match

Introduction

Job match for individual cases

Summary

6.1 Introduction

A job match for a PWD is a complex problem solving process. The level of functioning of the person is the most important factor to consider in the match. If the level of motivation and action is not addressed correctly, the person will not use his/her abilities and skills effectively. The level of motivation and action is thus also matched to the job requirements. If there is not a complete match the possibilities to compensate with supervision and structure are investigated to establish a match.

Secondly, the person's aspirations are considered to ensure job satisfaction, which is of the utmost importance to ensure that the worker will be able to maintain a reliable, consistent performance.

The person's abilities and skills are then matched to the job requirements. If there is not a complete match, the possibilities to compensate with other performance components or adapt the method, workplace structuring and equipment is investigated to ensure a complete match.

This chapter presents the possibilities to match the PWD identified in Tsilitwa to the work opportunities within the community development projects the TDC requested to be included in the study. This process is the fulfilment of Objective 3 of the study.

6.2 Job match

6.2.1 Objective 3: Assess the placement possibilities for integration of the PWD into the workplace developments

The individual job matches were made according to the process explained in the introduction. The data presented in the results chapter (**Chapter V**) were integrated to come to a conclusion.

The format for the individual job matches is as follows:

- ■ Match between abilities and requirements of the work activity,

- ■ A short discussion of all the factors considered for the recommended job match, including the person's aspirations, abilities and skills, and the level of motivation and action,

- ■ Adaptations required for successful implementation of a placement,

- ■ Training required to perform the tasks involved in the work activity.

6.2.2 Case I – Ms T
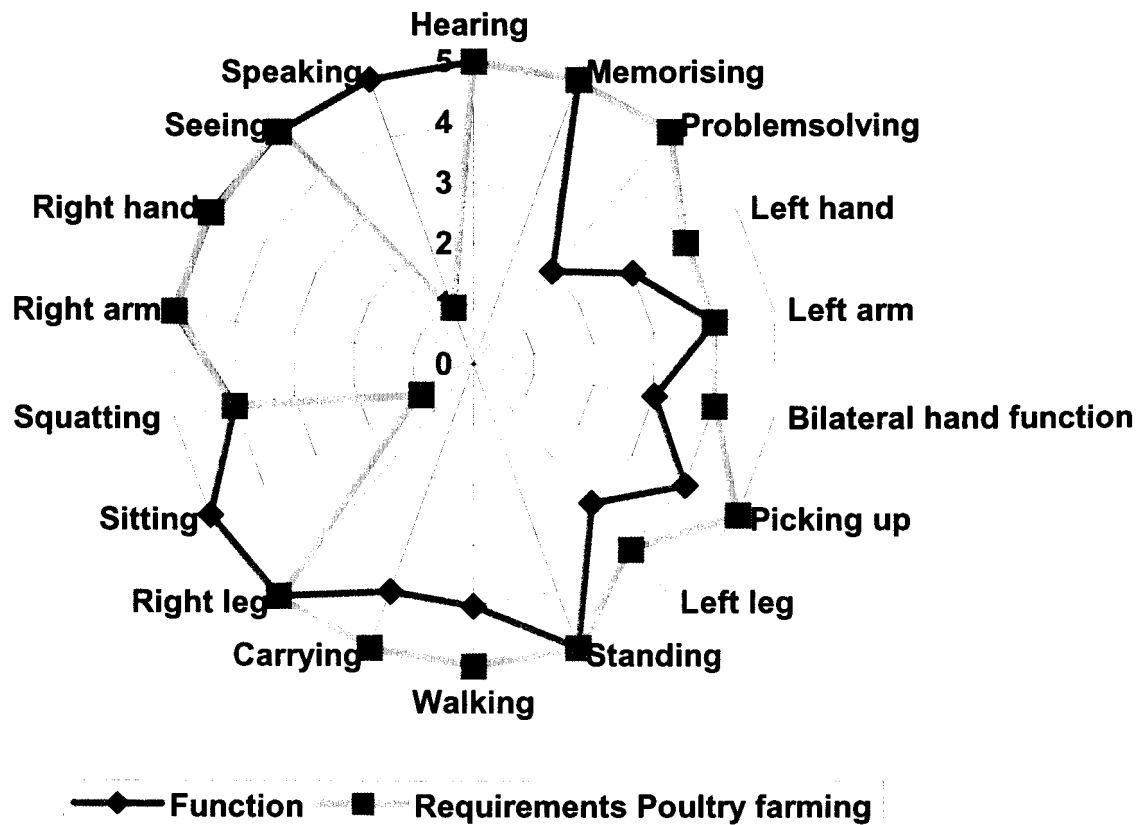
Figure 6.1 Job match: Poultry farming – Ms T

Discussion

■ Level of motivation and action: - Ms T functioned on a level of passive participation, which indicates that she could participate in a work situation but not independently.

■ Aspiration: - She aspired to be involved in teaching, which would make poultry farming a less suitable project for her. The suggestion was, however, not put to her and she might have an interest in animals that would make involvement in poultry farming meaningful for her. There were no opportunities to include her formally in the teaching system.

■ Abilities and skills: - Although the activity does not require a high level of bilateral hand function her abilities scored lower on five of the aspects, which indicates that a limited number of tasks could be performed independently without adapting the activity to a large extent. Her ability to solve problems was considerably lower than required, which also indicates the need for a major adaptation. No chickens were observed at her home at the time of the assessment and she did not report being involved in the care of chickens. No information on skills in this regard is thus available.

Adaptations

■ Abilities: - Her reduced speed of walking and picking up would possibly affect the rounding up of the chickens. The reduced bilateral hand function could affect the handling of the chicks and eggs. The reduced ability to solve problems would mean that she could not be left to make decisions on the health status of the chickens or sales aspects. As an assistant she would, however, be able to perform tasks at a reduced speed, as the speed of actions and her abnormal movement patterns would not affect the growth of the chickens or the production of eggs.

■ Level of motivation and action: - Because of the passive nature of her actions she would require supervision to ensure that tasks are performed at the right time and no important aspects are left undone.

Training

Ms T has observed the care of poultry around her as one of the activities in many of the households in the village. None of the tasks require the learning of technical or highly specialised skills. In-service training would be sufficient for an assistant's position in a poultry-farming project.

Conclusion

Ms T could be involved in poultry farming as an assistant under supervision if she showed sufficient interest in the project.

6.2.3 Case II – Ms M
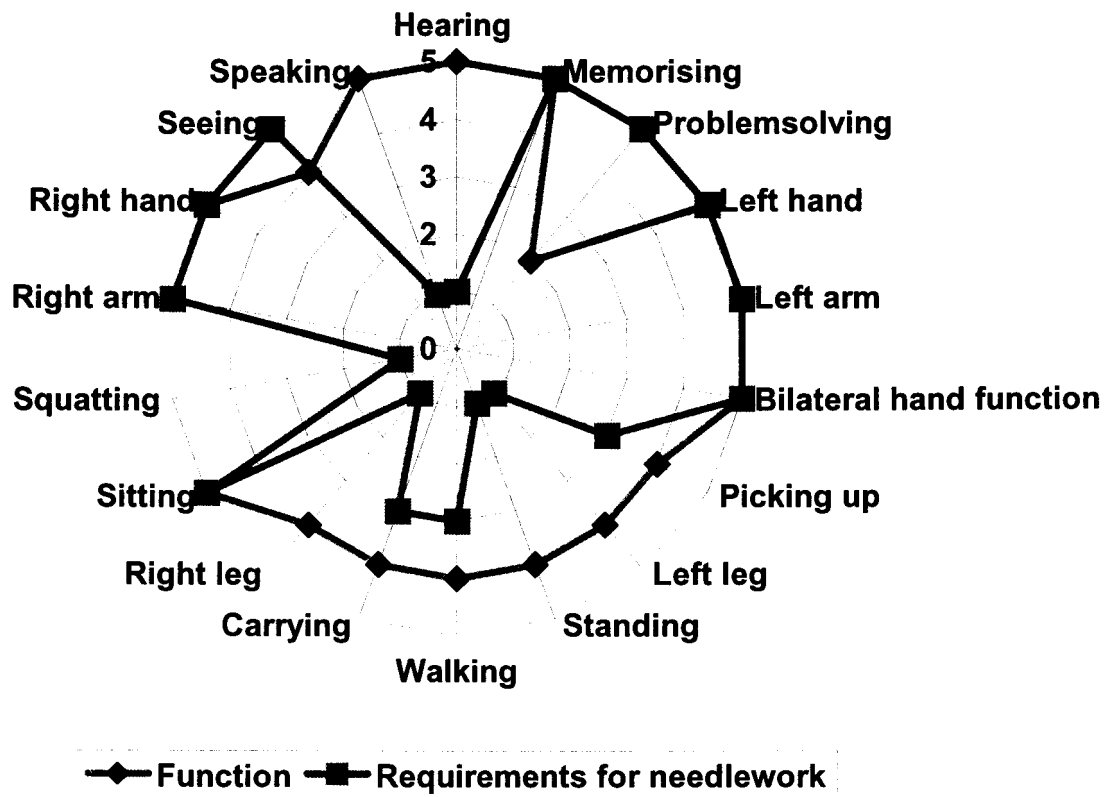
Figure 6.2 Job match: Needlework – Ms M

Discussion

■ Level of motivation and action: - Ms M functioned on a level of passive participation, which makes it necessary for her to join a project rather than performing the activity as a home industry.

■ Aspiration: - Ms M reported that she would like to do needlework.

■ Abilities and skills: - Her abilities match the requirements for needlework well. The only aspect on which she scored below the required level was problem solving. This is to be expected on her level of motivation and action. She reported having skills in sewing, which would probably not be on a level for producing marketable goods. The activity is carried out in

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sitting which is ideal for her because of the reported pain with extended walking and standing.

Adaptations

The fact that she is mobile makes it unnecessary to provide special structuring. She would require no adaptations to complete all the tasks involved in needlework independently and safely.

Training

Ms M would need further training in needlework. She could attend a course in needlework presented for community projects, but would require funding and accommodation as these courses are mainly presented in bigger towns and centres.

Conclusion

Being involved in a needlework project would suit Ms M's aspirations, abilities and skills. Training in the field would empower her and would probably lead to a higher level of functioning in terms of her level of motivation and action. She could be a productive member of such a project, delivering quality work at a normal speed.

6.2.4 Case III – Mr G

Discussion

Mr G was severely disabled. He functioned on a level of self-differentiation which meant that he was not ready to hold his own in a group, he did not have a task concept and could not conform to norms. Although he certainly could be involved in activities with an assistant, his abilities were too limited for employment. The speed and accuracy of his movements would result in an unacceptable production speed and he could not be a productive member of a work project. The fact that he had regular epileptic episodes complicated the matter further.

Adaptations

Because of the low level of motivation and action even the highest level of adaptation, that of having an assistant, would not enable Mr G to perform according to the required norms for a work environment.

Training

He was not ready to be exposed to formal training.

Conclusion

Mr G could not be involved in one of the projects. No job match could be made for him.

6.2.5 Case IV – Mr S
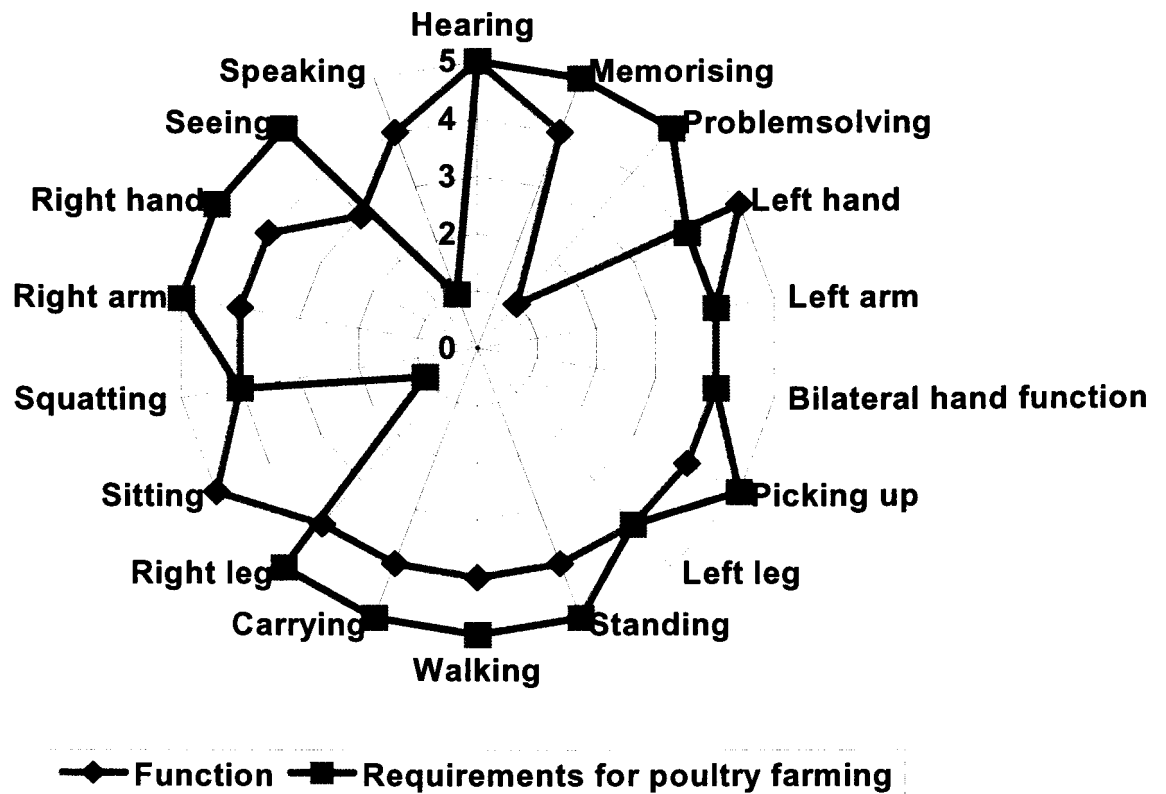
Figure 6.3 Job match: Poultry farming – Mr S

Discussion

■ Level of motivation and action: - Mr S was functioning on a level of passive participation. He participated in activities with the encouragement of his mother. The fact that he reported a wish to rest was an indication that the demands of some of the activities his mother involved him might have been too much for his level of functioning.

■ Aspirations: - He expressed the wish to rest. This suggests that he would participate in work activities only if encouraged by his mother.

■ Abilities and skills: - Mr S performed consistently with some abnormal movement patterns and reduced speed. Except for the rounding up of the chickens he would be able to perform all the tasks at a reduced speed.

The visual problems could be improved with glasses. His poor performance in the problem solving assessment would present problems in situations where he would have to use his judgement.

Adaptations

No adaptations would be needed for the physical aspects of the tasks. Mr S would, however, only be able to function under supervision because of his level of motivation and action, and the reduced speed of his physical performance.

Training

Mr S's reduced score for memory suggest that he would best learn through a repetitive routine. In-service training over an extended period of time would be required to ensure a good grasp of his duties.

Conclusion

The researcher's impression after the interview was that Mr S could be effectively involved in routine activities. Gardening, leatherwork and baking would all result in associated reactions because of the resisted movements in the tasks, which would further reduce the functionality of Mr S's movements.

The best match for Mr S would therefore be poultry farming. The variety of tasks in poultry farming might demand too much of him, even though he could physically perform the tasks. He could be involved as an assistant in a poultry-farming project, although he would best be accommodated in process work in a production line.

6.2.6 Case V – Mr B
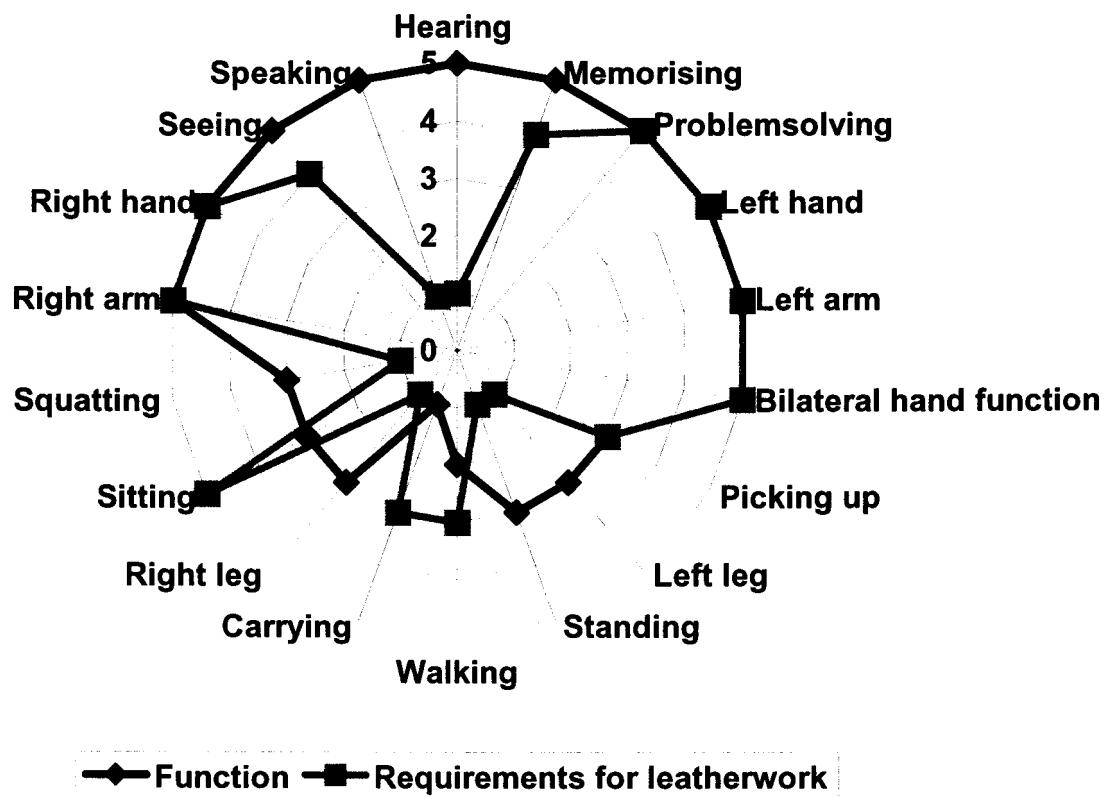
Figure 6.4 Job match: Leather work – Mr B

Discussion

■ Level of motivation and action: - Mr B functioned on a level of active participation. He demonstrated initiative and the ability to initiate actions according to his own drive.

■ Aspirations: - He expressed during several discussions the wish to build up a small shoe repair business. He started making his own tools and was actively working towards the fulfilment of his wish.

■ Abilities and skills: - The only aspect in which he scored below the requirement for leatherwork was sitting. He was only able to perform dynamic balance in a small range of movement. His exposure to

leatherwork in occupational therapy provided knowledge of the tools needed and he proceeded to make himself some needles out of wire found in the vicinity of his house. On one visit he was busy repairing shoes with his new needle. The quality of work was below market related norms. He also showed good problem solving skills, not only during the assessment but in his tool making and attempts to repair a radio that was brought to him.

Adaptations

The only adaptation needed is the provision of a solid work surface at the correct height for his wheelchair, which will also provide external support for his balance problems.

Training

Mr B needs further training in shoe repairs, which he can obtain from the occupational therapy assistant at Bedford Hospital. A referral, transport and accommodation for the period would have to be arranged through the referral system.

Conclusion

Involvement in a leatherwork project would afford Mr B the opportunity to achieve his goals. He would not only be a productive member but his drive could contribute greatly to the success of such a venture.

6.2.7 Case VI – Mr M

Discussion

Level of motivation: - Mr M was functioning on a the level of contribution, both through his teaching and motor repair activities.

Aspirations: - His aspiration was to build up his own motor repair shop in the village. He was already doing repairs for which he had tools available. His physical problems should not interfere with the performance of the tasks involved in motor repair. He experienced problems with walking, especially over uneven terrain and for long distances.

Abilities and skills: - No judgement could be made on how skilled he was at his work and whether he could perform a variety of repairs without supervision. He was teaching some aspects of repairs at the local high school, which might suggest that he had the knowledge for basic repair work.

Adaptations

No adaptations are needed for motor repair work. A workshop near his home or transport to the workplace would, however, reduce the time he needs to reach his destination and the energy expenditure involved in getting there.

Training

Whether further training is needed to operate a workshop independently would have to be established in a thorough assessment of his mechanical and administrative skills.

Conclusion

Because of Mr M's aspirations, skills and current activities none of the projects investigated would make an ideal match. Mr M should be able to work in the open labour market. The area he lives in offers no formal work opportunities

for a man with his skills. He would be a good candidate for inclusion in a project that involves motor repairs.

6.2.8 Case VII – Mr J

Figure 6.5 Job match: Poultry farming – Mr J

Discussion

■ Level of motivation and action: - Mr J was functioning on a level of active participation, demonstrated in the way he took responsibility for the goats.

■ Aspirations: - He expressed a strong wish to work and earn a living. He said that he did not know what he could do because of his balance problems.

■ Abilities and skills: - Mr J demonstrated abnormal movement patterns and reduced speed in the performance of movements, which would affect his ability to round up the chickens. During the assessment he suddenly

got up and chased the goats he was taking care of out of the neighbour's vegetable garden. The speed he demonstrated in that action, which he performed with the help of his walking stick, would be adequate to perform similar tasks with chickens. The proprioceptive fall out might influence the handling of the chicks and eggs. His problem solving ability and good communication skills ensured that he could deal with decisions that would have to be made in the care and selling of the chickens.

Adaptations

In handling chicks and eggs Mr J would have to compensate with vision for the proprioceptive fall out. Because he uses external support for mobility he could use a cart to transport food etc around instead of carrying it.

Training

He appears to have the motivation and abilities for further education. Training in a community poultry farming course would be beneficial to ensure economic success of such a project.

Conclusion

Because of Mr J's current involvement with animal care and his apparent pride in the work he is doing for his neighbour, poultry farming was considered as a match. Mr J could contribute toward the success of a community poultry farming project especially if it was more structured and the chickens housed in chicken runs instead of roaming freely.

6.2.9 Case VIII – Ms S

Discussion

Ms S's level of motivation and action was that of passive participation. She did not report a wish to work and would thus not be motivated to become involved. Her widespread pain and limited range of motion allow only for light work with encouragement and assistance. Kneading dough, the static positioning of sewing and the high physical demands of gardening are contraindicative for her condition.

Adaptations

Adaptations for joint conservation and splinting for more functional positions or to assist in the case of subluxations would be of assistance if the condition had not been as debilitating as it had become. These should be of help in her activities of daily living but would not be enough for the demands of more strenuous work.

Training

None

Conclusion

No job match could be made with the projects investigated. Ms S is not a candidate for a work project.

6.2.10   Case IX – Mr F

Discussion

Mr F was functioning on a level of self-presentation. He had no aspirations and could not express any needs. He had an abnormal posture, and balance problems aggravated in walking by clonus. He used abnormal movement patterns, which affected the accuracy and speed of his performance. He had an expressive aphasia. His behaviour was inappropriate but he did offer a workable solution to the problem posed during the evaluation. All these factors would affect his ability to contribute towards the success of a work project.

Adaptations

The injury had occurred eight years earlier and he could benefit by adaptations for activities of daily living (ADL) but they would not be enough to compensate for the lack of function in a work situation.

Training

None

Conclusion

No suitable job match could be made for Mr F with the projects investigated. Mr F could not be included in an economically viable venture.

6.2.11   Case X – Mr S
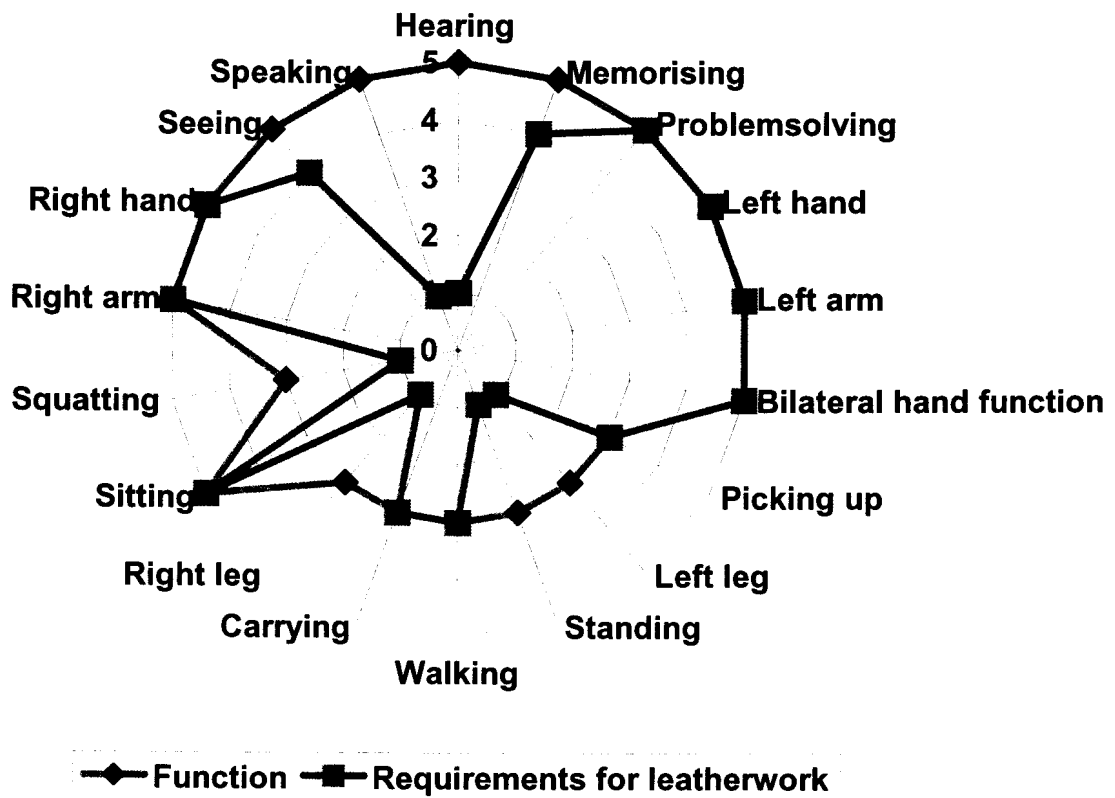
Figure 6.6 Job match: Leatherwork – Mr S

Discussion

■ Level of motivation and action: - Mr S functioned on a level of imitative participation, which means that he would be able to work according to the norms set in training and by examples provided.

■ Aspirations: - He reported wanting to be gainfully employed but did not have any specific preference although he thought he might be able to remember how to do electrical wiring. The villages are not yet connected to an electricity network, his physical abilities would prevent him from doing the installations when it should happen and the type of wiring he did

was for alarms only, not general installations. Electric installations would thus not be a suitable employ for him.

■ Abilities and skills: - His physical abilities match the requirements of the tasks involved in leatherwork. He is mobile enough to position himself at a workstation. The lower score for memory might need compensating for.

Adaptations

The memory deficit could be compensated for by routine in the manufacture of a small range of articles. He could use a kart to move objects from one area to another to compensate for the problem with carrying, as he is not wheelchair bound and won't use his chair to transport things.

Training

Mr S would need training in leatherwork, which can be provided by the occupational therapy assistant at Bedford Hospital. The training might have to be adapted if it is affected by his memory deficit.

Conclusion

The best match for Mr S is that of leatherwork. It is an acceptable work activity for a man of his culture and can be performed with his abilities. The training and the worker status he would achieve through involvement in a project would positively affect his functioning and might assist him to break out of the passive role he had assumed.

6.2.12   Case XI – Ms L
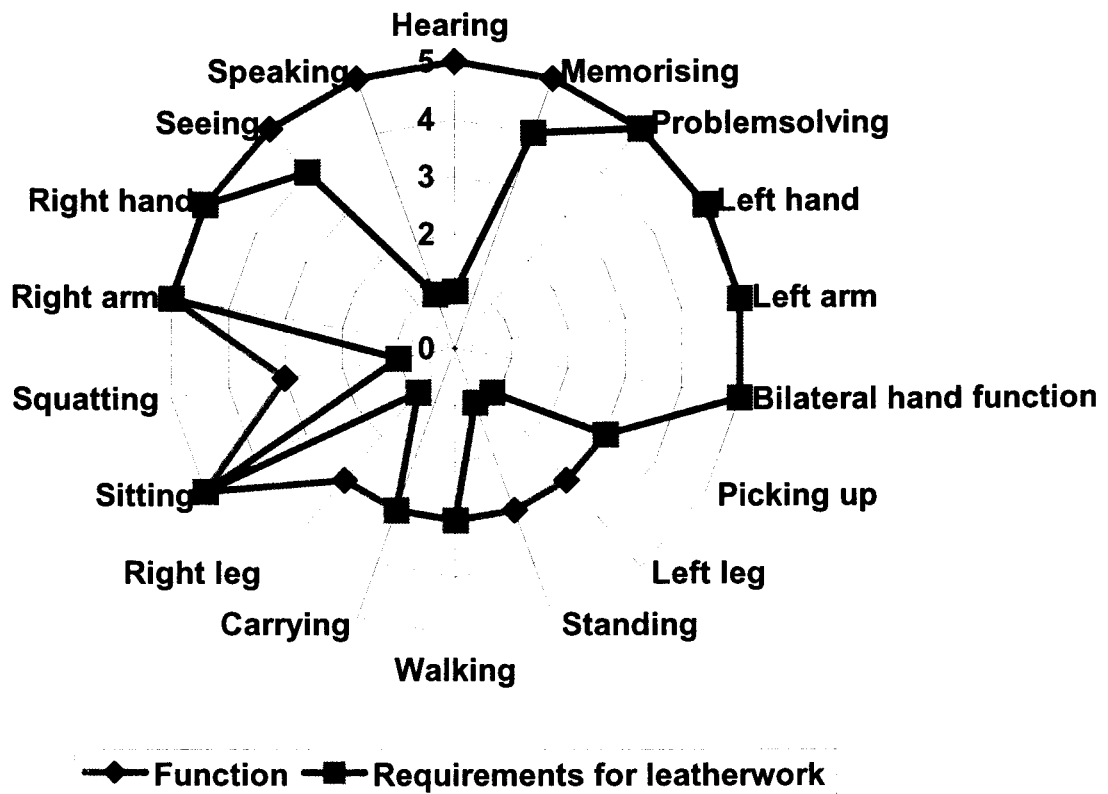
Figure 6.7 Job match: Needlework – Ms L

Discussion

■ Level of motivation and action: - Ms L functioned on a level of active participation observed in her interaction with the neighbours and showed some initiative and insight in the problem solving assessment.

■ Aspirations: - She had no aspirations. From observations of the family interactions it appeared that it was never expected of her to move beyond the home. She played the role of assisting her mother without assuming any responsibility.

■ Abilities and skills: - She was adept at performing activities one handed and had found her own methods of compensating because she never had full use of her right hand. Her gait is functional and she moves around freely over the uneven terrain. No needlework skills were recorded but she had been involved in a variety of household tasks.

Adaptations

Beadwork would probably be the most suitable needlework activity for her if she were shown how to make a knot one-handed. Cutting can be done one-handed if the material is weighted down. Pinning, hand sewing and electric machine sewing could be performed one-handed by a person adept at handling materials one-handed.

Training

Ms L would need to attend a course in sewing as offered for community projects. She could be taught beadwork by someone in the village who practises the traditional activity.

Conclusion

Although needlework is a bilateral hand activity there are ways of compensating for the lack of Ms L's right hand functioning and needlework can therefore be a suitable job match for her. Ms L could be a productive member of a needlework project if the family is convinced of the benefits for her.
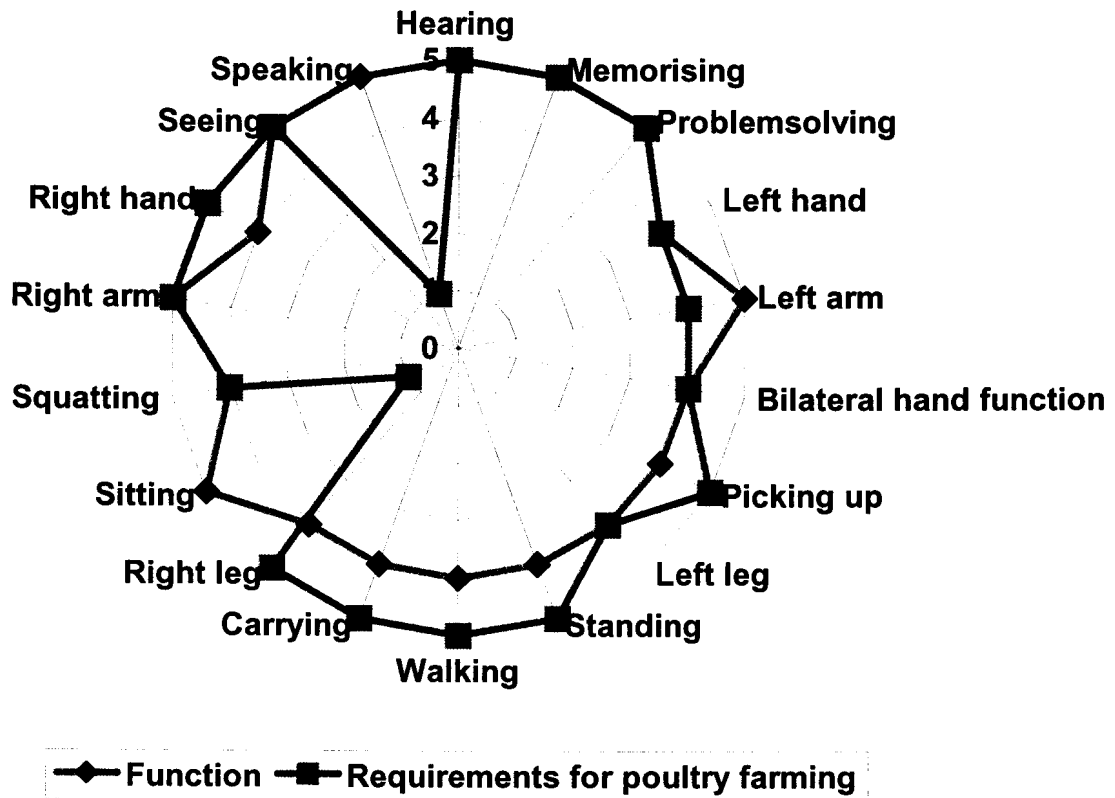
6.2.13   Case XII – Mr J
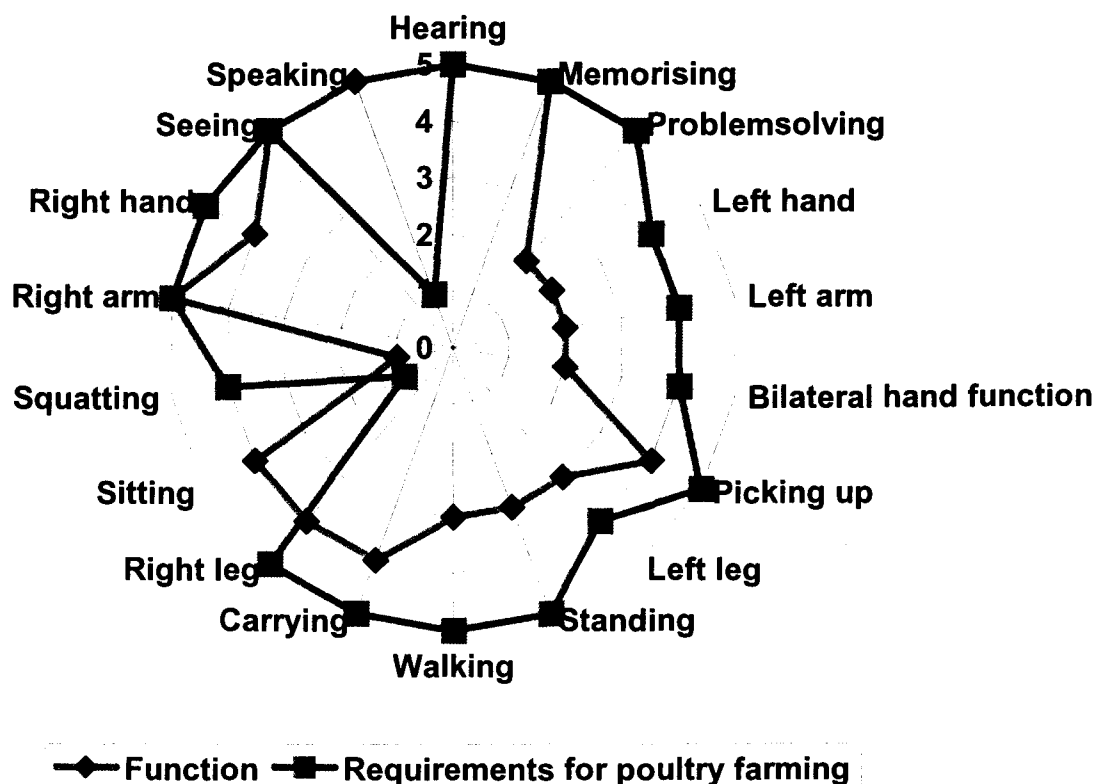
Figure 6.8 Job match: Poultry farming – Mr J

Discussion

■ Level of motivation and action: - Mr J was assessed to be functioning on a level of passive participation. This might have been influenced by the situation, because it does not seem to be consistent with his successful adaptation to his situation.

■ Aspirations: - He reported wanting to farm with chickens and that he needed a fowl run. He appeared to have given it some thought but had not acted on any of it.

■ Abilities and skills: - Mr J's abilities fall short on 12 of the 18 aspects assessed. The low score of problem solving was an indication of a lack of insight and judgement. He had adapted to one-handed functioning and made use of a horse for transport. He seemed to have established through trial and error ways and means to live his life as close as possible to the way he always had.

Adaptations

Mr J would only be able to farm with chickens with the help of an assistant because of the many aspects that scored below the required level and those aspects that the assessment identified as needing adaptation.

Training

None

Conclusion

Mr J might be able to farm with chickens with the help of his extended family as part of the family's activities of subsistence farming or even as a home industry. He would, however, not be employable in an economic venture of a larger scale in the community.

6.3 Summary

6.3.1 Summary of job matches

As in any community, disability of various levels was found. Most communities have severely disabled in their midst who can not be integrated into the workplace even with assistance, as well as PWD who can compete in the open labour market with or without reasonable accommodation by industry. The remaining PWD would need professional intervention to determine their ability to perform tasks, compensatory techniques, appropriate workplace adaptations and level of assistance where needed. This study investigated opportunities for PWD to be integrated in rural development programmes. The result of the data is thus presented in terms of possible inclusion in community projects in Tsilitwa.

Number of positive matches

Fifty eight percent of the PWD included in the study could be integrated in community projects planned by the community.

Sixteen percent of these however would require supervision and would only be able to be placed in the role of an assistant. The main contributing factor to this level of employment was their level of motivation and action.

One person could not be accommodated in the projects investigated, because of his particular aspirations and skills.

Type of work project

The following table summarises the spread of projects into which the PWD could be integrated:

Table 6.1 Summary of job matches per type of work project

Work project	N=12
Leatherwork	2
Needlework	2
Gardening	0
Poultry farming	3
Bread baking	0
Other	1
None	4

Gender

Needlework is an activity that is more acceptable for women in the local culture and therefore matches with this type of work were only made for women.

Leatherwork is an acceptable activity for men of the culture and especially the shoe repair work was thus suitable for matches for the men.

Gardening is traditionally carried out by the women of the culture but is suitably related to farming to make it acceptable for men to participate in this activity and could thus be recommended for both genders.

Women also carried out the baking in the projects visited. Because it is common knowledge that in the formal sector men are involved in the baking industry and because of the scarcity of work opportunities in the villages, it might be a suitable placement possibility for men with the right abilities.

Exclusions

The reasons for not being able to accommodate 33% (3 persons) of the PWD in the study were the severity and complexity of their disability.

Case I had multiple conditions and was severely disabled. Case VIII's chronic condition caused widespread pain and limitations. Case IX was complicated by cognitive problems in addition to severe physical disability. Case XII was severely physically disabled.

In all cases the level of motivation and action was below a level of participation because of these disabilities, except in Case XII where the severe disability prevented him to compete with able-bodied applicants for participation.

6.3.2 Summary of adaptations

Two of the PWD for whom successful job matches were made would need no adaptations. Only minor physical adaptations for work would be required, except for accessibility issues like transport and building access. Adaptations for cognitive aspects and a lower level of functioning were needed by three of the PWD.

The following table summarises the need for adaptations for successful and safe execution of the work activities.

Table 6.2 Summary of adaptations needed

Adaptation needed	N=8
Physical adaptation	2
Supervision	3
Both	0
None	2

6.3.3 Summary of training

Three types of training were identified for successful participation in the work projects, namely:

- ■ In-service training – for which a knowledgeable person should be available who is able to convey information and develop skills in employees.

- ■ Community development courses – which are offered by various NGOs nationwide; the community would need information about details.

- ■ Vocational rehabilitation – as part of vocational rehabilitation, occupational therapists offer skills and adapted skills training; the referral system would need to operate effectively for PWD requiring further rehabilitation.

The following table summarises the need for further training to ensure competitiveness in the workplace.

Table 6.3 Summary of training needs

Training	N=8
In-service training	2
Community development courses	3
Vocational rehabilitation	2

Formal tertiary education is not necessary for participation in the projects investigated. If one of the PWD were to assume leadership of a project business training would be advisable.

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The results presented in the last two chapters were derived from the data collected during the two phases of the disability survey and the analyses of the requested work projects.

The data collection was kept simple with the intent of developing a model for data collection that might be carried out by community-based rehabilitation workers in the future. The results reflect this level of information.

Chapter VII

Discussion of results and methodology

"It is neither wealth nor splendour but tranquillity and occupation, which give happiness." *Thomas Jefferson*

Results

- The disabled people of the Tsilitwa area
- Work opportunities for the disabled people in the Tsilitwa area

Method

- The participatory model
- The method of assessment
- The method of analyses

7.1 Introduction

The lack of statistics on the prevalence and needs PWD in South African rural areas necessitated an in depth investigation into the type and severity of disability as well as the skills, needs and aspirations of PWD before job opportunities for PWD in rural development programmes could be determined. The results gave insight into circumstances under which the PWD live and emphasised the many barriers they face to achieve full integration into their communities.

In this chapter the results described in the previous chapters are interpreted and the factors which influenced them discussed. Where appropriate the discussion integrates the quantitative and the qualitative results.

The discussion of the results of Objective 1 are discussed in subsection **7.2.1** and the results of Objectives 2 and 3 in subsection **7.2.2**.

This chapter also includes a discussion of the research methodology that was followed.

7.2 Discussion of results

7.2.1 The disabled people of the Tsilitwa area

7.2.1.1 Community profile of adult disablement in Tsilitwa

The focus of the disability survey was on physical disability found in the age group 16-40 years of age.

The national disability survey found the highest prevalence of disability in the country among the African population in the Eastern Cape. It was reported that this province had a 3.1% higher average prevalence than the rest of the country. The national survey found a disability prevalence of up to 7.9% higher in the age group investigated compared to all age groups of the total population[201].

Based on these statistics, it appears that the prevalence in the Tsilitwa area was lower than the Eastern Cape average and the expected rate for the age group. This correlates with the findings of the national survey, which indicated that disability prevalence is lower in rural areas than in urban areas.

The final figure of identified PWD was affected by the following factors:

- ■ Perception of disability: – The list of PWD identified in Phase I included persons with recent injuries, which would not have a long-term effect on their activity performance, as well as persons who functioned according to

norm in spite of an impairment, e.g. the loss of a finger or a stature slightly shorter than the norm.

■ Financial need: - Because of the lack of employment opportunities in the rural areas many families are solely dependent on subsistence farming for survival. The possibility of obtaining a disability grant, if someone was identified as a PWD, seemed to have influenced some of the reports of disability in Phase I of the survey. Over reporting like this is a common occurrence especially in poor communities and regularly described in the literature[202]

■ Lack of services: - Although the heads of household were asked to supply information on persons living in the villages at the time, 20% of the PWD identified in this phase were living in urban centres because of a lack of local services (see **Table 5.2**). The reasons for reporting these persons were linked to financial need of the family left behind or a hope that if services and opportunities improved their family members could return and be included.

The PWD in the area included a number of retrenchees and persons who had worked outside the community before their disablement and were the breadwinners of their families. This is seen as the explanation for the percentage ratio of 66.6% (8 men) male to 33.3% (4 women) female PWD in spite of a generally reversed pattern in rural populations.

Of the five who were receiving disability grants three had been awarded these as children. The other two had received rehabilitation in urban centres where the procedures of assessment for grants had been followed through. The lack of financial aid for PWD in the area is caused by a breakdown of the system put in place to assist PWD who have special needs and are unable to earn a living. The PWD not eligible for a grant and who should be able to find employment are prevented from doing so by the lack of employment possibilities for PWD in rural areas. As a result of the absence of grants and the lack of work opportunities the PWD and their families are the poorest of

the poor in these areas and dependent on the generosity of family and community.

Due to their condition, the ability of all the PWD to move around in the village was restricted and they experienced even greater difficulties in moving beyond the area. The reasons for this were:

- The most common cause of permanent disablement (eight PWD) was found to be of a neurological order with resultant abnormal movements and instability.

- Half of the PWD had upper and lower limb involvement indicating a high level of disablement.

- The lower limb dysfunction of ten of the PWD affected mobility.

The physical barriers of the environment compounded the problems and resulted in isolation from the community. The physical barriers present in the area were:

- Hilly countryside,

- Uneven surfaces,

- Narrow pathways and poor roads,

- Distances,

- Lack of transport,

- Inaccessible buildings,

- Lack of assistive devices.

These barriers prevented the PWD from moving around freely and on their own in the community Only four of the PWD in the study were able to move around independently in the villages. The rest were dependent on their families or even the community, with its limited transport resources, for assistance.

7.2.1.2 Aspirations and needs of the disabled people in Tsilitwa

Aspirations

Fifty percent of the PWD reported aspirations regarding a return to work or to gain the status of worker. This emphasises their need to improve their grave financial position and is linked to an associated need to be recognised and accepted as members of their community. Through involvement in a workplace they would achieve a place in society outside their family and be respected for their skills and contributions instead of being a burden on the family and community. This need for acceptance is highlighted by the fact that two of the respondents also reported a wish to be afforded a place in their community.

The remaining six reported no aspirations or "rest". This exceptionally high percentage of aimlessness is affected by the following factors:

■ Culture – The attitude of the Tsilitwa community toward PWD appeared positive (full discussion follows in the next sub-section) yet it seemed that in practice due to underlying traditional beliefs PWD were expected to accept their situation. The community was satisfied to leave them in the care of family members and special care organisations. The PWD seemed to feel powerless to change this situation and could not foresee a different future for themselves.

■ Depression and low self-esteem – The PWD experienced additional stressors to those already present in current rural situations. The isolation within their homes because of the physical and social barriers, the often-incomplete rehabilitation and their financial situation on top of their disability, further induced depression and low self-esteem. Depression and a lowered self-esteem are characterised by feelings of helplessness and pessimism and this leads inter alia to a loss of ambition[203].

■ Level of motivation – Eighty percent of the respondents who reported no aspirations were functioning at low levels of motivation (assessed according to the Vona du Toit Theory of Motivation and Action). The above

psychological factors as well as the person's personal characteristics and the disability itself contribute to the level of functioning. This leads to the deduction that 20% of the PWD had aspirations, but did not expect their situation to change sufficiently for them to be realised.

■ Lack of information – The PWD, their families and the community did not have knowledge of services that could enhance the quality of life of the PWD or of solutions they could find within their community to improve the situation. This lack of information forced them to accept the status quo unquestioningly and affected the PWD's aspirations.

The initiative to improve the situation for the PWD came from the TDC. During discussion with the TDC and the interviews with PWD and their families more concern about the situation was mentioned by the community leadership than by those directly involved. The impact of disablement and the physical and social barriers that prevent rural PWD from full participation in community life appear to leave them apathetic and powerless to strive for a better future.

Needs

Although 11 of the PWD could be more functional with appropriate assistive devices they did not possess, only four felt they had a need for such. Increased functionality would accordingly improve their employability.

The three PWD who reported work related needs indicated some insight into how they could realise their aspirations to work again.

Only four of the PWD reported more than one need. Taking into consideration the plight of PWD in their area these short lists, in one instance none at all, support the deduction that they feel hopeless.

Their needs would have been affected by:

■ Aspirations – The general low level of motivation and the resultant lack of aspiration would directly affect the needs perceived by the PWD.

■ Lack of knowledge – Needs are defined as requirements in order to solve problems. A need can therefore only be expressed if one is aware of a solution. Most of the PWD had inadequate rehabilitation, in which they were not informed about appropriate solutions to their problems. None received vocational rehabilitation. Their knowledge of work opportunities was thus non-existent. Because of their general lack of knowledge about services available to them they were incapable of expressing and listing the needs that would improve their quality of life.

The needs identified by the researcher correspond to those found in other developing countries[204].

The most compelling being the need to:

■ Improve the everyday life of the PWD in terms of basic necessities, including medical care,

■ Create an awareness of their needs and rights in the community,

■ Alleviate poverty among the PWD through employment opportunities and social services.

The inability of PWD to express their needs and aspirations presents a dilemma that is experienced globally[49]. It emphasises the passive roles PWD play in their families and communities. They are often managed by authorities who decide for and on behalf of the PWD and their communities as to what their needs are and what services can be developed for them. This does not take into account the rights of the people involved to decide on their own priorities. The best way to address this dilemma is by providing information on services available and the rights of PWD, and by raising the awareness of the situation of the PWD within a community. Informed decisions by the community, inclusive of the PWD, will ensure that their specific needs can be met and appropriate services provided.[49,205]

7.2.1.3 Educational and skills background

Both schooling and previously learned skills are important for effective participation in a work situation and as a basis for the acquisition of new skills. The PWD interviewed lacked both.

Education

The extremely low level of education, only three having attended some high school and one having received some further education, contributed to the PWD's inability to influence and control their future. Most showed poor problem solving skills and none had any knowledge of how to use local or national systems to their advantage. Only one PWD could converse in English, which might be a problem if further training is considered.

Skills

One of the PWD had some formal skills training from which he could no longer benefit. Another one had some training post-injury in skills that would be appropriate for income generation under present circumstances. Nine reported some traditional skills, which may be useful as basic knowledge in the projects.

The low levels of education and skills are not unique to the PWD in the local population. To ensure that income-generating projects are sustainable and economically viable the workers involved have to deliver quality goods or services consistently. Not every member has to be involved in the management of the project, for which business skills are essential. They would, however, all need access to all training that is planned if they are to have equal opportunity to compete for a work-place. Training for all community members would have to take their mother tongue into consideration for effective communication.

7.2.1.4 The attitude to disablement in the Tsilitwa area

The participants took the discussions, which took place in small groups during the attitude survey, seriously. Everybody was involved in a lively debate and they made sure that the scribe recorded their opinions accurately.

The attitudes expressed reflected an awareness of the human rights of the PWD mixed with more traditional views on ways of dealing with disability. The awareness of disability issues could have been affected by talks the researcher was asked to give on the purpose of the study on various occasions. The purpose of the attitude survey was to establish whether the community would be willing to accept PWD as co-workers in their development projects. The talks were meant to prepare the community for this and it was considered appropriate to measure the attitude at the end of the study, as the next phase in the process would be the implementation of integration into the workplace.

The results from the semi-structured interviews are arguably limited because of the small number of participants on the day, fact that all opinions were formulated by the facilitators and translated for interpretation.

However, the recorded responses gave a good insight into the community's attitude at the time and could be used during further discussions with the TDC regarding this step.

Examples of the attitudes recorded on the day illustrate the mixed feelings that existed in the community at several levels.

■ In terms of their place in the family:

Many comments demonstrate that the community felt the family and the community should accept the PWD, as illustrated by "Disabled people should be accepted in the family and in the community so that they can feel that they belong somewhere" or "Mother should remain mother". Comments like "They should not be isolated, locked in their houses" and "His/her family must not feel shy about him/her" described an awareness

of such practices and indicate a open attitude towards the PWD in their midst.

Traditional beliefs, that the PWD should accept her/his disability were reflected by comments like, "They should not have self-pity and should involve themselves in minor duties so that they don't relapse" and "They must take part in the domestic work, e.g. making tea for their parents."

The comment "He/she must not be isolated from other people. Their need shelter" shows some contradiction. It demonstrates that although the PWD's rights have been noted, the community still feels that they should have separate facilities.

■ In terms of community involvement:

The contradiction found in the comments on the PWD in the family is continued in the comments on their position in the community in "Need love, respect and protection" and "They must be protected against taking harmful substances e.g. alcohol successively". These comments contain elements of control by the community rather than by the PWD about their lives.

The willingness of the community to move toward integration by PWD into full community participation was illustrated by expressions like "They must attend community meetings and their views must not be looked down on", "She/he must be elected in the committee" and "Disabled people can use their skills to improve the economy of our country. They must be organised and thought skills that they use."

The recordings of the discussion also revealed a need for assistance to achieve such integration, through comments such as "If they could be build a school for their special education so that they come back with their skills to the community" and "If they can get assistance or training to start small business for themselves. They can also be included in projects where they will be able to fund raise".

Social development theorists, in studying the transition from traditional to modern societies emphasise the values and norms that operate in these two types of society. [206]

It is argued that the transition from limited economic relationships of traditional society to the innovative, complex economic associations of modernity depends on prior change in the values, attitudes and norms of the population.

During the survey it became clear that the community under investigation is in a transitional phase. The vision of empowerment and upliftment for all its inhabitants – PWD included – is a sign of the leaders' empathy. Empathy is seen by social scientists as an indicator for the intervening stages that take place in the development from a traditional to a modern society.

Observations made during the survey that indicate the transitional stage were:

■ In terms of the *value* of the person to the family and the community the following attitudes were recorded - the PWD are loved, deserve respect and should participate in family and community activities according to their social position.

■ In terms of the *function* of the person in the family and the community the following attitudes were recorded - they participate in household duties according to abilities and should have opportunities in the community in terms of work and social participation.

■ In terms of the *burden* of the person to the family and the community the following attitudes were recorded - they need support, shelter, special facilities and continued treatment if necessary.

The phrasing of the comments, recorded in the community attitude survey, e.g. should, deserve etc. indicate an awareness of modern norms and not necessarily an implementation of these norms. The fact that all groups indicated, to some degree, an attitude that PWD should be taken care of and the community decide for them, once again points out that norms have not consistently changed.

The community thus seems to be aware of the rights of the PWD in their midst but in practice still feels that they should control the extent to which they include the PWDs. These attitudes do not reflect intolerance to the same degree as those described in the national survey on disability where it was reported that PWD are subjected to intolerance and prejudice[44], but can rather be seen as evidence that change is taking place in South African rural communities.

An incident, which occurred at the meeting, further illustrates the conflicting attitudes. Mr B (Case V) was not at the meeting as had been arranged by the researcher. TDC members informed her that it would be better if he did not attend. His presence would remind the community that one of its members, as yet unpunished, had caused the injury that disabled him and his presence at the meeting would upset some participants. It thus appeared that some PWD would be integrated more readily than others.

During the final discussion with Mrs Madikane this attitude was noted again. Mrs Madikane mentioned that the committee would favour home industries as least disruptive to the community whilst still assisting the PWD. In follow-up telephonic conversations it transpired that the committee had indeed followed this route.

Global experience revealed the importance of providing appropriate information and instilling a feeling of optimism through the sharing of successes at public meetings and celebrations.[49] The empowerment of PWD in the community will also create awareness of their abilities and the contributions they can make, thereby advancing the necessary attitude change. [172,204]

7.2.2 Rehabilitation facilities

Rehabilitation in the region can only be offered to a few PWD as a result of limited facilities and incomplete professional teams. Only one of the PWD in the area had received occupational therapy during his stay in the Bedford Hospital in Umtata.

Because of short hospital stays the focus is usually on performance components. The occupational therapists often opt for a rehabilitation approach that attempts to improve occupational performance through adapted methods of activities of daily living. Except for a limited number of wheelchairs no assistive devices were observed in the hospitals or in use by the PWD of the community. Most of the treatment is concentrated on the personal care context with limited attention to the work and leisure contexts.

This fragmented approach and the often incomplete rehabilitation process have the effect that the PWD remain uniformed about their own potential, their rights and services available. The resulting lower than necessary level of functioning contributes to the low level of motivation observed during the study.

Despite the newly instated community service year for rehabilitation professionals, which should improve services in historically underserved and disadvantaged areas,[207] the Speciality Focus Group for the Modernisation of Tertiary Services, from their discussions, deduced that shortage of general and specialised comprehensive rehabilitation services is likely to increase over the next 10 years in South Africa.[208] The access to services in rural areas is thus not likely to improve in the near future.

7.2.3 Work opportunities for disabled people in the Tsilitwa area

The focus of this study was work opportunities for PWD within the planned development programme rather than investigating informal work related tasks within the households or social circles of the PWD. The discussion thus is also restricted to formal work opportunities within the community.

Unemployment in the area is high. Except for the schools, the clinic and family owned shops there are no employment opportunities. Most of the economic activity is centred around these structures, e.g. women selling fruit and refreshments. The other adults are involved in subsistence farming and household maintenance.

International research shows that income-generating projects, as part of rural development programmes, have had a 50% chance of failure.[18] The researcher's experience in the Eastern Cape was similar. Although this aspect was not included in the study it was observed that many projects were slowly declining. On a visit to the Lubisi and Umtata areas, people involved in projects there mentioned various reasons to the researcher for such collapsed projects, mostly to do with business and financial problems or a loss of motivation. The researcher also observed a lack of problem solving and marketing skills in the projects still running. All the projects seemed to have difficulties in producing a reasonable income for the participants involved, who often seemed to find social gratification out of participation rather than financial satisfaction. The same was found in the Tsilitwa area where the lack of funds to re-erect the collapsed building that had housed the poultry project and the lack of buying power for the products produced in the sewing project were cited as reasons.

The CSIR withdrew its involvement in the area during the course of this study because of funding difficulties. In the researcher's opinion the implementation of the IRDM could have been of great value to the community to ensure sustainability of their development programme. Without the support of an interdisciplinary team the projects planned by the community face the same problems that have caused the collapse of so many community projects. However, the commitment of the leaders in the community who initiated the Tsilitwa development programme is strong and this should ensure that the momentum is maintained.

Involvement of PWD in income-generating projects of development programmes is globally promoted by organisations such as the UN, WHO, ILO and various development agencies like Oxfam. Local policies, acts and strategies have initiated the process in South Africa.[82,95] The presidential Jobs Summit of October 1998 was aimed at furthering the economic empowerment of South Africans with disabilities. One of the targets set at the summit was that 5% of all economic development investments by public sector, small, medium and micro enterprises (SMME) promotion, training, micro and

industrial credit resources are to be targeted at people with disabilities[209]. In 1997 the Society for the Blind, the Association for the Physically Disabled and the Society for Mental Health in the Eastern Cape formed REHAB an organisation that acts as a resource for PWD to fulfil their potential. Their objectives are to:

- Build the capacity of PWD and people living with AIDS and their families,

- Facilitate an understanding of the concept for inclusive education,

- Facilitate the setting up of income generating activities in communities and

- Facilitate the placement of PWD in the formal sector.

The organisation is operating from East London with offices in Stutterheim and Butterworth. Although the aim of the organisation is to serve rural areas throughout the province, at the time of the study the organisation was not active in the Umtata region.

This study investigated the opportunities for implementation of employment equity in rural areas in South Africa.

The work opportunities for PWD in Tsilitwa were in the process of development. The discussion is based on information received at the end of the study and during follow-up conversations with Mrs Madikane.

Work opportunities are inevitably linked to opportunities to acquire the necessary knowledge and skills to execute the work activity and will therefore be discussed consecutively. Thereafter the barriers that need to be addressed to achieve access to these opportunities will be discussed briefly.

7.2.3.1 Opportunities

Work

The only work project initiated by the TDC by the end of the study was a bread-baking project. None of the PWD had expressed an interest in this type of employment. The analysis of a bread-baking project did, however, demonstrate suitability for involvement of PWD who have bilateral upper limb functioning. The planned electric ovens and the spacious work area of the new building would thus allow PWD who have the abilities and interest to participate in this project on equal footing with any other inhabitant of the area.

As requested by the TDC, the recommendations delivered to the community in the final report included three scenarios for job matching. Advantages and disadvantages for the development of a sheltered workshop and home industries were presented and a strong recommendation was made for the inclusion of PWD in the planned communal income-generating projects.

The TDC had after the completion of the study applied to the Thabo Mbeki Development Trust for Disabled People for financial support to develop a shoe repair workshop for PWD. The Trust's vision is to enhance the quality of life of PWD and promote their integration into mainstream society.

One of the PWD had expressed the interest to pursue this line of work and the TDC believed that other PWD might be involved in the project with him. From the last communication it was not clear yet where such a workshop would be housed.

Work opportunities thus currently remain scarce for PWD and the direction the TDC has taken indicates that they are favouring separate rather than integrated work opportunities. This would exclude PWD from further development projects of the villages.

The analyses of work projects have shown that with the right structuring and, if necessary adaptations, PWD with physical problems could be included

according to ability and interest in all the projects. This probably also applies to other projects not analysed in this study that the community might consider.

International literature confirms that these opportunities exist by virtue of the fact that no projects are excluded on grounds of unsuitability for PWD. Full integration is thus globally deemed possible for PWD.

Training

Through appropriate knowledge and skills, PWD can be empowered to support themselves and to overcome poverty and deprivation. Global experience shows that in spite of changed legislature, policies and guidelines it still remains difficult to enable rural PWD, particularly those with elementary schooling. [204]

Training opportunities are generally scarce and often of an inferior standard in rural areas. The lack of adequate training needs to be addressed in planning on a national and district level to remove this barrier to employment. McLaren and Zungu recommend the setting up of databases of training offered in the districts, facilitate the setting up of skills training courses and to investigate the work opportunities for PWD in their communities.[202] The government has made bursaries available to PWD who have completed school.[210] This, however, implies that access to schooling should be available even in rural areas so that PWD can benefit from this opportunity.

Training in Tsilitwa is provided on various levels and through a variety of institutions. There are two primary schools and one technical high school in the villages studied. Tertiary education for those who have access to financial aid is provided in Umtata or other national centres. Various NGOs and development agencies provide ad hoc training for community development projects in the area. Information about when and where such training takes place is difficult to obtain and costs in terms of transport and accommodation often prevent participation.

For the PWD of the Tsilitwa community the following levels and avenues are relevant:

■ The first step in the providing of training should be access to mainstream schooling, where appropriate, and adult literacy programmes. The key skills for further training in South Africa are reading, writing of English and arithmetic. Although some community courses are presented in local languages more formal education is mostly provided in English and communication with suppliers and clients might necessitate the use of English.

■ Mainstream tertiary education is a logical consequence for suitable candidates, which would equip them to compete on equal footing in the job market.

■ PWD should be considered as candidates when the community can send inhabitants to training programmes for development projects.

■ Vocational rehabilitation in the area is carried out as part of occupational therapy programmes and provides basic skills training for a limited number of income generating activities. However, the occupational therapy department in Umtata needs to develop this aspect of their services by further training of the therapists to provide adequate pre-vocational and vocational skills training. The department also needs to develop a referral network for training of PWD who have needs they cannot meet. For example, a link could be established with the soon to be introduced MODE programme in the Eastern Cape[211], which offers entrepreneurship development, support and training for the setting up of a small business or workshop, placement in the formal sector and assistance with structuring of a workshop to accommodate the various needs, as well as consultations on business and financial structuring of the venture.

The importance of work and business skills training cannot be over-emphasised as a basis for both sustainable community development projects as well as the empowerment of PWD to afford them employment equity. The need for implementation of training strategies is stressed in many publications across the world in developed and developing countries.[49,161,172,212,213,204]

In developing countries training is broadly defined as any instruction, advice or other type of purposeful activity that advances the capabilities of targeted individuals and/or groups through the provision of relevant knowledge and the development of specific skills, including indigenous knowledge.[214]

The importance of the training in rural areas of developing countries is by no means greater than in other circumstances, but because of the lack of opportunities for accessible training it needs special attention in strategies to provide equal opportunities for all.

7.2.3.2 Barriers

Globally and especially in rural areas of developing countries, many PWD do not have the opportunity to participate in the workplace. What prevents them from taking part is often more the result of barriers than the disability itself. Examples of these barriers are:

■ The attitude and assumptions of non-disabled people, including employers,

■ The way in which employment is structured and organised,

■ The built environment,

■ Laws and regulations relating to employment.[215]

PWD are not a homogenous group. The various disabilities and combinations thereof have different needs and face different barriers to integration in the workplace. In advancing a "Society for All" the ILO has drafted a code of managing this diverse group in the workplace to act as guide for governments and service providers.

Member states of the OAU are encouraged to address barriers to integration of PWD during the African Decade of the Disabled by active support for training, adaptations to workplaces to allow access to PWD and assistance in work placement.[98]

General environmental barriers have been mentioned briefly before. This sub-section will address both the physical as well as the social barriers PWD in Tsilitwa face regarding employment.

Physical

The physical barriers in terms of getting to and from a community project are the environment and the lack of suitable transport. Both can be addressed if they are taken into account when budgeting for a project.

The community is in the early phase of development and all buildings that are erected can without extra costs be designed and built according to national guidelines for accessibility. Awareness of the need for access for PWD has been instilled in the community through this project. It would now depend on the willingness of the TDC to implement suggestions so that no future adjustments and changes will be necessary.

Adaptations to work areas will need to be considered for each PWD on an individual basis. The costs of alterations to accommodate an individual might prevent equal opportunity to compete for a place in a project. The willingness of the community to spend the extra money will thus finally influence the involvement of the PWD in community projects.

As a group project the physical problems can be addressed more economically than on an individual basis. The physical barriers thus become more limiting when an individual workshop or home industry is established. Obtaining supplies and reaching the target market in this remote isolated area in which the PWD, because of the area and their current financial state, have no access to telephone and transport facilities contributes to the difficulties of ensuring a viable income from a home industry.

Social

Social barriers, which could affect the PWD's access to employment opportunities, are the attitude of the community towards them as a group and

the general lack of employment opportunities, which would intensify the competition for work places in the projects.

Both the committee and the community have indicated a tendency to want to keep the PWD separate. The community through reported attitudes like

"They should not have self-pity and should involve themselves in *minor duties* so that they don't relapse."

or the more ambivalent attitudes like

"If they can get assistance or training to start *small business for themselves. They can also be included in projects* where they will be able to fund raise"

"If they could be build a school for their *special education* so that they come *back with their skills to the community.*"

(Emphasis added)

The TDC has put motions in action to develop a separate workshop, which does not exclude them from future involvement in projects, if the PWD and national guidelines prevail with promoting their rights.

Another indication that PWD were not afforded equal opportunities in the community is the fact that Case VI had been teaching at the technical high school for years without being considered for a post. The involvement was seen as charity towards him, an attempt to make him feel appreciated. The fact that his work was not worthy of compensation put emphasis on his disabilities rather than on his abilities.

Probably the most important social barrier is the strong competition for work in the community because of the general lack of employment opportunities within the area. As both the PWD and the other inhabitants are in the same position with regard to suitable business and work skills, it remains to be seen who will be afforded the opportunity for training and therefore the best positions in the projects.

As both the physical and the social barriers depend to a great extent on the attitude of the community toward disability issues the situation is flexible. One successful involvement of a PWD in a community project could change attitudes positively as experience has shown in other parts of the world.[49]

7.2.4 Employability of the PWD in Tsilitwa

Fifty-eight percent of the PWD included in the study could be integrated in community projects. The empowerment achieved through training and the recognition as equals in the community, would have the effect of reducing depression and functioning on a higher motivational level. This means that they would perform better with time and might be able to take on more tasks or more responsibility in the projects.

Any community, like the one in Tsilitwa, will have a percentage of severely disabled persons who will have to be supported. However, if the majority of PWD can contribute economically the burden will not only be lifted for their families but the community as a whole will benefit.

There are no doubts in the minds of global and national policy makers that it is not only possible but highly desirable to achieve employment equity in all communities. Few studies were found about employment opportunities for PWD in rural areas in developing countries.[172,204,213] No published studies were found on involving them in general development programmes of communities. This is thus a relatively new development and will need attention to ensure that rural communities do not lag behind in the implementation of employment equity. The great challenge lies in the timing of intervention. In the researcher's opinion a multi-disciplinary approach like that of the IRDM of the CSIR would be ideal to illustrate the possibilities of integration, assist in the implementation and support the community in following through with the provision of access to all its inhabitants.

At this point in the development of the Tsilitwa community the timing to integrate the PWD appears to be perfect. By including them in the planning for the development programme about to be launched, accessibility issues can

be addressed from the start. In this way the PWD could participate from the beginning as equals with minimal extra costs involved. However, the community's transition from a traditional to a modern society is not complete and it is necessary to aid and promote social change to assimilate the new philosophies.

If the PWD in Tsilitwa follow the route of self-employment they are by no means unique. The literature shows that in rural areas self-employment appears to be the most common form of employment for PWD globally.[171,216] Such information implies the lack of implementation of integration policies in community projects worldwide.

If there had been employment opportunities in the open labour market in the area one of the PWD would have been able to rejoin the open market with the encouragement of the new policies and laws of the country.

The study has shown that more than half of the PWD in the villages are employable. The reasons they have not been able to rejoin the labour force were personal and societal attitudes, the lack of opportunities and the environmental barriers in the area.

7.3 Discussion of research method

7.3.1 The participatory research approach

The participatory research approach was selected for three reasons:

- ■ Theoretical reason - Participatory research, based on ecosystemic human rights and development frameworks is directed at human, political, economic and social emancipation. It is a suitable approach for use by social scientists and health professionals to enhance the full human development of disempowered people.

- ■ Political reason: - Many disadvantaged South African communities have in the past experienced no benefits from the results of research. They feel they have been abused by researchers for their own gain and

have no improvement in their situation to show for it. A request for research has thus to be initiated by the community or its leadership so that it will be meaningful for them. In this study a request was made by the TDC to investigate the employment possibilities for PWD in their community.

■ Personal experience: - The researcher had developed a research model based on the theory of Rifkin[178] and Whyte[181] during a previous study in a rural community and had found the participatory process to be beneficial to all participants.

In applying the approach the researcher experienced similar difficulties to those described by Doherty and Price,[217] e.g.

■ Concluding the project in the predetermined time – The researcher only had one year in which the study needed to be brought to a conclusion. This implied that awareness of the issues had to be raised, the community educated in terms of PWD rights and their attitude determined at the same time. The community's attitude could not be investigated before and after the input on these matters because it was not possible to mobilise the community as a whole to participate in the research at the beginning. The research process activated an interest in the issues as demonstrated by the reasonable attendance at the attitude survey. The process thus needed to be adapted to fit the time frame.

■ Protecting the independence of the research project findings given the political agendas of the participants – The initial agreement helped to keep the study on track instead of turning it into the development of a home industry project in spite of considerable pressure from participants with such agendas.

■ Inconvenience of distance – This impediment could only be overcome by careful planning and by obtaining the participation and support of the community members who made up the participatory research team.

■ Need for good research skills by team members - The training of community members and careful follow-up checks were needed to ensure acceptable findings.

■ Cost implications – The withdrawal of the CSIR team from the area put serious constrains on the implementation of the study. This resulted in fewer visits than planned in the protocol and resulted in more pressure to complete the study within the predetermined time.

However, In spite of these difficulties the researcher, in agreement with Doherty and Price[217], believed that the advantages of the approach outweighed the problems, namely that participants:

■ Had the opportunity to participate in the design and implementation of the research study,

■ Improved the quality of the information,

■ Assisted in transparent planning and consensus realisation,

■ Expanded their knowledge and skills.

The process generated commitment and ensured that the community acted upon the findings.

The TDC approved the approach and remained committed to the study throughout the year. The committee members assigned to participate devoted freely of their time, shared their knowledge and experience, and worked well together as a team with the researcher. The assistants from the community were enthusiastic and completed their work with pride. They went far beyond their duties to ensure that the researcher could complete her part of the investigations and proved to be valuable members of the team.

Isolated negative remarks from community members indicated that not all members considered such a study beneficial and that they would prefer more tangible results from outside interest. The majority of the members, especially

the families of the PWD, gave their full co-operation and were open to the ideas presented in open meetings about disability issues.

The most important aspect of the participatory approach was found to be the shared planning. On each visit the next step was discussed and agreement reached among the team members. The researcher is convinced that this was the main reason why the execution of the study progressed according to the mutual plans. The needs of the various members had to be accommodated and as a result there were small changes as the study continued, e.g. including the speech and hearing therapists in the planned visits of rehabilitation professionals because the clinic sisters wanted to screen the school children for hearing defects, although this was not the focus of the physical disability survey undertaken.

Because individual needs were accommodated within the agreed upon plan, as long as they did not divert the study from its objectives, everybody felt recognised as a worthy member of the team. Making absolutely certain that all team members understand the objectives of the joint study from the very beginning is essential. Early agreement on what was to be done and mutual respect prevented the study from derailing near the end when financial support was expected from the researcher for the implementation. It had been agreed in the first meeting that the disabled people would be integrated in the general development projects, therefore, no additional funding for them would be needed to provide work opportunities.

The withdrawal of the rest of the CSIR team complicated this issue. The community now had to find another development agency to support their development plans. In the spirit of participation the researcher presented a training course in fund raising to the TDC and put them in contact with some development agencies. This again ensured goodwill from their side and the study could be completed.

This incident illustrates the importance of co-operation and insight into the factors that affect participation. Such insight can only be gained through a

close working relationship, an openness to the various value systems and good communication.

The MBR model was applied through all its phases and as expected led to the next cycle. As agreed, the researcher ended her involvement in the community on completion of the study and could only act as advisor for this step. She was not able to accompany them through another cycle but followed the process through telephonic consultations and by supporting their applications for funding to the Thabo Mbeki Development Trust.

The contrast between a participatory approach and the customary research practices was illustrated by the involvement and withdrawal of the rest of the CSIR team. In a customary research situation, when the researcher scouts for a suitable situation for his research, the focus of the research is his own goal. If a community-initiated request is addressed through a participatory research approach, the desired end result is to provide answers to the community. The commitment entered into is ethically binding in both approaches. However, it appears to be easier to break this commitment if the researcher elects a community on his own accord and decides for a one-sided reason that another location is more suitable for reaching his goal.

In this study the CSIR had become aware of the community through work in a different community in the Eastern Cape. They investigated the Tsilitwa community to establish whether they could apply their IRDM. The community then made the request for this study and the researcher was brought on board. The researcher was free to select her own approach for the study and chose a participatory approach because of previous experience of research on community level. The agreement between the researcher and the management of the CSIR team was that the information supplied by this study would be used by the team and her recommendations in terms of integration into the development programme would be implemented by the team in the community's development programme.

The discussions of the CSIR with the community created certain expectations, which could not be met by the researcher after their withdrawal. This left the

researcher in the awkward position of being a representative of the CSIR but only addressing a small fraction of the community's needs. It meant that the recommendations of this study could not be implemented after completion of the research. This was a great disappointment and diminished the value of the study.

Notwithstanding the above, the researcher is of the opinion that the study could still be completed because of the collective agreements reached in the planning of the study. Furthermore, the process provided the community members with knowledge and skills with which they can proceed to implement the recommendations in their own way.

7.3.2 The method of assessment

A two-phase survey was conducted. In the first phase the self-reporting method was intended to identify the households in which PWD were residing. The questionnaire was based on questionnaires used in similar studies by Concha[79] and McLaren[78]. The questions were phrased in the positive (e.g. Can ...... use his right hand?) to emphasise abilities the person has, whilst gathering information on disabilities. The questionnaire was designed for use by the research assistants. The layout proved to be user friendly and the scoring method effective as shown in the inter-rater reliability test described in **Chapter IV**.

All persons who had reported difficulties or a lack of use were then followed up in the second phase for more in-depth assessment. The functional assessment was designed with a view to its future use by community health workers. Instead of formal assessments of various performance components, observations are made in function of how these components are used. Abnormal patterns and the speed of execution are noted but the focus is on the occupational performance, i.e. whether the activity can be performed effectively.

The functional tasks posed in the assessment were found to be appropriate for the community and can be used in other rural communities. However, the

researcher did find that she made extensive use of her knowledge of the performance components needed to execute the tasks and her experience of assessing disability in her interpretations. If community workers are to use such assessment in the future it would have to be included in training programmes.

The dressing and eating activities were effective for observing hand and upper limb function and the range in which the activity could be performed if the objects were positioned appropriately. The picking up and carrying of the brick had to be adapted and interpreted according to the highest position in which the person was functional, e.g. in sitting for a wheelchair-bound client.

The functional assessment was also found to be very effective in eliminating pretended disability because clients focus on the task and are inclined to forget the pretence. The following case illustrates such an incident. Respondent No. 13 entered the room complaining of pain in walking and sat down groaning with pain. The movement patterns he displayed did not fit with the problems he reported to have retained from a motor vehicle accident. He demonstrated no problems in performing the tasks. He enjoyed the attention and started to show off his strength as a man, throwing the brick into the field instead of just picking it up, and jogging to fetch it and return it to the researcher. When it became clear that he had no disability the family confessed that he had developed serious addiction problems since his convalescence and was not working, they did not know how to handle the situation and thought he might be eligible for a disability grant.

Another advantage of the functional assessment was that it could be carried out in a relatively short time. Because the various performance components are integrated in the tasks they can be observed simultaneously. This however does complicate the assessment again for inexperienced fieldworkers.

The various items of the kit were easily obtainable and could be substituted by local materials, e.g. a rock of a comparable weight instead of the brick, own shirt. It was also easy to transport the kit while walking from house to house.

The researcher thus found the functional assessment to be effective to use in the circumstances.

7.3.3 The use of the ICF in the study

The usefulness of the data for comparison on an international level is restricted by the limited use of the ICF and the small sample size of the study. The ICF was used as a conceptual basis for the study was. The further classification of the qualifiers of the limitations was felt to be too complex for the level worker for which the system of assessment was designed. Although the classification was certainly culturally applicable the system is cumbersome in the field. The comprehensiveness of the classification, designed to address the complexity of the study and documentation of disability in itself appeared to be a disadvantage in fieldwork with community level workers in developing countries.

Other researchers have found the lack of a standardised definition for disability and measuring instrument problematic. The meeting at a workshop on Disability Statistics for Africa held in Kampala Uganda (2001) recommended the use of global questions for the screening of disability in a population based on activity limitation, which should record severity, a time frame and use of assistive technology. The use of such global research tools would make data comparable.[218]

Another reason for restricted value is the transitory nature of the findings. As discussed earlier the community in which the study took place is in transition. Developing and developed communities are constantly changing as the paradigm shift in the global perception of disability demonstrates. Such changes affect the barriers PWD face and therefore their level of functioning. Unless detail of the environmental factors is taken into account comparisons are unscientific.

The researcher therefore used the global tools for background information to begin the development of a strategy for integration which could have wider application after refinement.

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7.3.4 The method of analyses

The analysis formats were designed with community workers as intended users in the future. The researcher developed a uniform scoring system for both the functional analysis of the PWD and the work activity, based on the levels used in the FIM, so that the two analyses can be directly compared to make a job match. The comparisons between the client's functional abilities and the job requirements are thus on a functional level instead of the traditional performance component level used in occupational therapy analyses and job matches.

The web type recording system was designed to give a visual image of the corresponding abilities and the shortfalls, which either make a match impossible or can be corrected through adaptations. The match was done on a computer but can be plotted on forms where such facilities are not available.

The system and the visual illustration of the web, the WAW, were found to be effective but once again the researcher used her knowledge and experience extensively in the final conclusion for the job match. Scoring is complicated if a person uses a different position to work in than the average worker will, e.g. working in sitting rather that in standing, although the activity can be equally successfully performed in that position. Normal requirements were scored but in a variety of positions. This was the reason why an average score for a task could not be assigned and alternative scores for some components had to be made.

A final conclusion of a suitable job match is a complex integration of physical, psychological, cognitive and motivational components with the requirements of the work activity, taking into account environmental and social barriers as well as the possibility of appropriate adaptation where necessary. Whether this can successfully be carried out, even with training, on a community level will need further investigation.

The analysis of the clinical reasoning that is applied in the job match was the first step in formalising this decision making process. According to
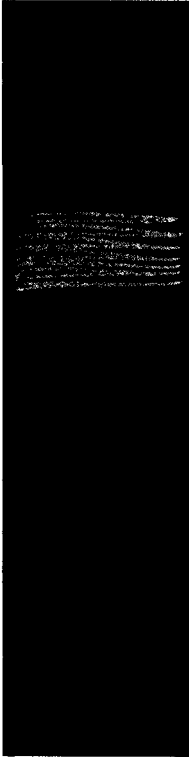
Hammond's six modes of enquiry it advanced the practice from intuitive judgment (Mode 6) through peer-aided judgement (Mode 5) to developing a system for the system-aided judgement of Mode 4, along the cognitive mode from intuition to analysis.[219] Further research is thus needed to test this system by trials and experimentation to achieve the highest level of clinical expertise of Mode 1.

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Information of disability prevalence on its own does not provide the impetus needed for implementation of the global policies and national strategies that can lead to full integration of PWD in their communities in all corners of the world. This study aimed at investigating the possibilities of achieving integration in rural communities where the situation is even more complex because of remoteness from the driving forces and the lack of services and facilities. The discussion in this chapter illustrates the complexities of both disability studies and research in such rural communities. The effectiveness of this work depends on whether the conclusions are meaningful to the community studied and others in the same situation, and whether the recommendations for further study and implementation find application.

Chapter VIII

Conclusions and recommendations

"I am concerned about the whole man. I am concerned about what people using their government as an instrument and a tool, can do toward building the whole man, which will mean a better society and a better world." - *Lyndon Johnson*

Conclusion and recommendations

- ■ **Opportunities for integration into the workforce in development projects**
- ■ **Research in rural communities in South Africa**

8.1 Introduction

A thousand opportunities invite us to a new life. Christian Morgenstern

This study was part of a community-driven development programme in three villages in a remote rural area. The conclusions drawn in this chapter are specific to this area and not necessarily applicable to all rural areas in South Africa. The recommendations cover both recommendations for the Tsilitwa area, as well as recommendations to address the aspects studied on a national level.

This chapter firstly provides the conclusion on achieving the research aim and secondly a conclusion on the suitability and effectiveness of the research

methodology. Recommendations on both these aspects follow directly after the respective conclusions.

8.2 Opportunities for integration of PWD in development programmes.

The conclusions reached through the results and the discussion of these in the previous chapter will be discussed per objective and the final conclusion given in the sub-section on the actualisation of the aim.

8.2.1 Conclusions

8.2.1.1 Actualisation of objectives

1.   Draw up a community profile in terms of the adult PWD

The conclusions on the various points agreed upon in the first phase of the participatory process for this objective are as follows:

■ Identification of adults with physical disability

The percentage of physical disability was 1.35% in the age group of 16-40. The incidence of lower limb impairments was high (91%) and appeared to be the most disabling because of environmental barriers.

The burden of disability in poor rural areas, with high unemployment rates and inadequate services, is severely felt by the whole community. The economic burden reduces families with PWD in rural areas to being the poorest of the poor in the country. The inadequate medical and rehabilitation services and transport and training facilities leave rural PWD and their families isolated and in despair. Social and cultural isolation aggravate the situation, rendering the PWD powerless and despondent. This results in low self-esteem, depression and inactivity as illustrated by the PWD's low level of motivation, with 58% at the level of passive participation or lower.

■ Needs and aspirations of the PWD and the community/care-givers for integration into the work place

The needs expressed and observed in the community are typical for under-serviced rural communities in developing countries. The poverty, lack of knowledge about their rights and the services that could assist them, together with the social and physical barriers to an active community life, have resulted in depression and a lack of motivation. In this state the PWD foresee little hope for improvement and cannot formulate what they need in order to better their situation.

The strongest need was for financial assistance or a means to procure an income. This emphasises the importance of implementing employment equity policies and strategies, as well as addressing the problems in the local system to obtain disability grants for PWD who are not able to work.

■ Level of skills of the PWD in the area

Only 8% of the PWD had tertiary training that could be used if a suitable project was initiated. The general lack of schooling and formal skills training, especially of the women, stresses the importance of access to mainstream schooling and the equal access to training programmes that the community is planning for their projects. Although the traditional, indigenous knowledge will be useful the PWD will need to develop their skills to be competitive in the job market.

■ Attitudes of the PWD, caregivers and community to equal employment opportunities for PWD

The Tsilitwa community was found to be in a transitional phase of development in which traditional norms and beliefs are being replaced by modern philosophies and guidelines. Community leaders are committed to change and are attempting the implementation of government directives. An example is the founding of the Tsilitwa Committee of PWD, through which the PWD of the area have obtained a voice and will be involved in future planning for the community. The committee members will need

support and encouragement to ensure that this step will effect the necessary changes to achieve full integration.

2. Investigate the planned job creation projects in the IRDM for suitable integration of the PWD

Conclusions of the investigation of the work opportunities cover the following three aspects:

■ Planned projects

All previous community projects had stopped functioning by the beginning of the study. The TDC reported to be interested in developing bread baking, gardening, sewing, poultry farming and shoe repair projects in their community. By the end of the study the implementation of the bread-baking project had begun. Involvement from development agencies and the commitment of the TDC and the community should result in sustainable projects which will benefit all in the community.

After the final report on the study the TDC decided to develop a shoe repair workshop for PWD in Tsilitwa.

■ Facilities

The present workshop is accessible for PWD. Professional help will be needed to adapt personal workstations according to individual needs. The contact with the professionals in Umtata was created by the study to ensure the referral line for such adaptations.

Awareness of physical accessibility issues was created in discussions with the TDC and through the report on the survey delivered to the community in November 2000, and should positively affect all future planning, ensuring that facilities will be made accessible.

The main roads in the villages were levelled at the end of 2000 making them accessible to wheelchair users. The distances, lack of transport and

the hilly nature of the environment remain barriers that do not allow PWD full access to facilities in the area.

■ Resources in terms of training and adaptations needed by PWD

Contact was established with the regional rehabilitation team and awareness created of the services they provide. The referral network has been restored and all the role players have been made aware of the importance of this in the lives of PWD and their families.

The community has been provided with contact names and telephone numbers of people who could provide vocational rehabilitation and training for PWD, as well as development agencies that provide training for community projects.

Resources remain scarce, however, in terms of training and adaptations for PWD as well as for community projects in the area.

3. Assess the placement possibilities for integration of the PWD into the workplace developments.

None of the identified PWD was interested in the first project the TDC initiated, a bread-baking project. That will hopefully not exclude interested persons outside the investigated age group and persons with physical problems who are functional, as identified in Phase I of the disability survey.

The planned poultry farming and sewing projects will provide further employment opportunities for many of the PWD.

The shoe repair workshop for PWD that has been initiated by the TDC will provide a work opportunity for the most destitute PWD in the area and might provide opportunities for more. The scope for growth of the workshop will depend on the local demand for the service. It is, however, limited by the remoteness of the area in terms of reaching a wider market.

8.2.1.2 Actualisation of aim

The aim of the study was to investigate the opportunities for the integration of PWD into rural development programmes. The aim to study opportunities has been achieved only on a theoretical level since the promised opportunities failed to materialise when the CSIR withdrew.

The area in which this study took place was typical of many rural areas in South Africa where development efforts have taken place but with little evidence of success to be seen. Until recently various projects had been initiated and run by individuals in the area. These efforts did not actually constitute a development programme. The formation of the TDC and mobilisation of the community by the committee had started the process of a co-ordinated development programme, with the income generating projects still having to be realised. Therefore, opportunities had to be deduced from investigations of community projects in general.

The study was initiated by a request from the TDC and carried out at the time to fulfil their request. The advantage of doing the study at the beginning of the community's development programme was that they could take disability issues into account from the beginning. The disadvantage was that it was impossible to implement an integrated work placement which would provide a model for further placements. Although the agreement with the community was for the necessary information about work opportunities and not the implementation of the recommendations, an example of successful employment would have provided a convincing argument for the integration of PWD in the development programme, especially at the stage of social transition in which the community was in terms of disability issues.

The WAW was found to be effective in illustrating a job match on functional aspects and could be used by community health workers with some additional training. The method could be used in situ for uncomplicated cases, thereby providing a local service, reducing the cost of transport and hospitalisation/accommodation for vocational rehabilitation purposes and decreasing the workload of professionals. For complex cases the referral

network can be used to obtain the services of professionals for analyses, matches, adaptations and guidance on workplace structuring. A flowchart for the process is provided as **Appendix VIII**.

The disability survey, the analyses of projects and the theoretical job matches have shown that persons with physical disabilities could be integrated in all community projects the community wants to implement according to interest and abilities, if the following process can be performed:

■ Assessment of abilities and aspirations – A discharge assessment after a completed rehabilitation programme, vocational assessment by an occupational therapist, or a functional assessment as used in the study by a trained community health worker is needed to provide a complete functional profile of the PWD. This should include the motivational level of the client.

■ Job analysis – A professional job analysis or an analysis performed by a trained community health worker using the format developed in this study is needed to clarify the requirements for effective and safe performance of the work tasks.

■ Job match – A professional opinion on a suitable match or the use of the WAW developed in this study is necessary to investigate a match and the need of adaptations for successful placement.

■ Placement – The necessary access, structuring and adaptations have to be implemented. This includes a supervision or assistance structure where applicable.

8.2.2 Recommendations

The community needs assistance and guidance in the development process it has undertaken. Financial support on its own will limit the pace and scope of development in spite of the remarkable dedication of the leadership and the potential for growth that exists in the community.

To achieve full integration of the PWD in the villages' development programme the transition from the traditional norms and beliefs to acceptance of modern philosophies and guidelines must be completed. The awareness created on disability issues needs to be followed up with further education and successful implementation, so that the theory can be assimilated into the community's own history and culture. The community will then be ready to incorporate the legislature and strategies for equal opportunities into their development programme for the benefit of the community as a whole.

To implement the integration of PWD into the workforce of the development programme the following issues need to be addressed:

■ Inclusion in the planning – Either the TDC or the development agency should involve the regional rehabilitation professionals as consultants to ensure that legislation and strategies are put into operation.

■ Tsilitwa Community of PWD – The local committee of PWD needs to be empowered to act in their own interests and ensure that their needs are considered by the TDC in the development programme for the area. Active involvement by the PWD themselves will ensure sustainability of the initiated process of integration.

■ Local process for assessment, job match and work placement – Local community health workers need to be trained in the job placement process, described in the previous sub-section, for uncomplicated cases. The training should include identification and assessment of disability and should place emphasis on observation skill especially of motor components needed for work, like range of motion, or sensory and cognitive components, like perception or proprioception. Community health workers should refer the complex cases via the network (Tsilitwa Clinic, Sulenkama Hospital, Bedford Hospital) to professionals at the regional centre. Referrals to professionals should include information on the work opportunities available at the time and environmental barriers in the area. The community workers should follow up on placements to ensure that the

match was successful, the adaptations are functional and that optimal work relationships are maintained.

■ Professional rehabilitation support network – Occupational therapists at Bedford Hospital should receive further training in vocational rehabilitation to perform assessments and job-matches for the complex cases referred to them. Their services should include the provision of assistive devices and guidelines on adaptations to work activities. A follow-up service should include enquiries on a successful match and advice on necessary changes that could improve access, structuring or relationships. Outreach visits are important to maintain the referral network, identify problem placements or develop further work opportunities. Regular contact should be maintained with the Tsilitwa Committee of PWD to support their efforts and provide them with new information on disability issues.

■ Training network – A network of training providers in the Eastern Cape needs to be developed for both specialised training as well as mainstream training to ensure that PWD have equal opportunities to develop their skills so that they become and remain competitive in the job market. Information in the form of a database needs to be made available to professionals working in the region and the communities they service.

Primary health care services are available in all areas of South Africa. Referral lines are established for all these local areas to regional centres. The recommendations for Tsilitwa could thus be applied in any rural area under the right circumstances.

Ideal circumstances would be an integrated development approach, a sustainable development programme, committed leadership, involvement of PWD, trained health workers at all levels and effective referral systems.

To achieve ideal circumstances in rural areas in the country the following steps need to be taken:

■ Create awareness of disability issues with development agencies and communities – Information to development agencies on disability issues

and international and national guidelines for implementation of employment equity is the first step to ensure that disability issues are addressed in development programmes. Development agencies globally assist in developing countries where local government is unable to address all the needs of the inhabitants in their areas. Rural areas, because of their remoteness and often sparsely populated vast spaces, are often the last to be serviced. Because of the legacy of Apartheid there are many such areas in South Africa and many development agencies and NGOs at work in them. If they could address disability issues as an integral part of development for all inhabitants of a community, integration of rural PWD in work projects and their communities could be applied nation- wide. Information could be presented by addressing development conferences, and training modules could be introduced in programmes designed for local developers like the Ecogrow Foundation, an organisation involved in developing a national developers' training programme to be presented by all technikons in the country.

■ Training of CHW – The creation of a post classification for community rehabilitation workers is still being debated. Although three provinces, Gauteng, KwaZulu Natal and Limpopo, trained and employed such workers few rural communities in the country enjoy such services. To assist the communities which do have community rehabilitation workers a module on the method of assessment and job matching used in this study could be included in their training. In areas where there are no such services an occupational therapist could present a course to community workers from NGOs, DPOs, health workers or clinic personnel on identifying activity limitations, screening the complexity of the case for referral to professionals, functional assessments, basic job requirements and making a job match with the WAW developed in this study. Even in developed countries rural areas are understaffed with professional rehabilitation personnel. It is thus not foreseeable that South Africa will be able to provide enough professional personnel to offer all PWD in the country professional services. By selecting the most complex cases for

professional intervention and assisting the uncomplicated cases from within the community more PWD can be served.

■ Postgraduate vocational rehabilitation training focused on the needs of rural areas – Postgraduate vocational rehabilitation courses, such as the Postgraduate Diploma in Vocational Therapy presented by the University of Pretoria, provide excellent training in this field. However, the courses include assessments carried out with expensive, high-tech equipment and the knowledge and skills learned are more applicable in centres where services and economic opportunities abound. These courses could include modules in which the focus is on appropriate knowledge and skills for under-resourced areas. Alternatively, special courses should be developed for therapists working in provincial centres that service rural areas.

■ Development of the referral networks – An effective referral network, utilised by well-trained persons from both the community and the tertiary levels, is the key to providing an appropriate service for the circumstances. Provincial health planners have provided the referral lines. Knowledge and experience will build and strengthen the network to include the various role-players a community requires to address its needs. The importance of such a network and the basic role-players needed to start a network should be taught in courses for community workers and professionals alike.

■ Development of training networks – The local school system and local governmental training facilities should form the basis for the training network. Involvement of development agencies who are aware of the rights and needs of rural PWD should expand the network, by providing access to training courses they offer. Vocational rehabilitation services provided by government and private enterprise need to address the needs for training that cannot be met in mainstream education. As the development process progresses the community will have formed more ties and gathered further information on appropriate training available, and the network will expand.

The social acceptance of PWD's rights and the willingness of local communities to address the issues are the key to implementation of the global guidelines to full integration of and employment equity for PWD. Disabled People's Organisations and health professionals should co-ordinate their efforts to create awareness and support local PWD to find their place in their societies.

8.3 Research methodology

8.3.1 Conclusions

The research methods selected were effectively applied to achieve the aim set for the study. Through involvement with the community some additions were included, but all the aspects agreed upon for the study during the planning phase with the community could be investigated and processed in the given time frame. Both the research approach as well as the WAW method was found to be useful in the community setting. The conclusions on these follow.

8.3.1.1 Participatory research

The participatory approach and the participatory model through which it was applied proved to be effective for research in a community setting, for the following reasons:

■ Research approach - Given the distance the researcher was based from the community studied, the lack of communication facilities (cell phones could only be used from a hill outside the village, thus only pre-arranged calls could be made from the researcher's side) and the withdrawal of the rest of the team, the successful completion of the study can be accredited to the commitment from both parties through the participatory approach. A strong bond was forged between the representatives of the TDC assigned to the study, the research assistants and the researcher, through planning and working together. The participating community members received recognition from the

community, as observed in the community meetings in which plans, progress and results were presented, and were proud to be presented as examples of community builders by the chairperson of the TDC during closing ceremonies for the various stages of the study. This approach creates ownership of a research study and its results, not only by the researcher but by the community as well. The community thus receives something they can use instead of feeling used for the benefit of strangers only.

■ The participatory model – The phases of the MBR model were applied as described. The use of the model ensured that the participatory approach was followed throughout. Criticism from an advisor that the feedback phase should also involve the community is well founded. In this study there was no opportunity to first share the results as a team and then present it to the community together. The format of the feed-back session had been planned together during the previous visit and was presented to the community accordingly. Questions were dealt with as a team, involving the members of the Tsilitwa Committee for PWD as well. The same comment was made about the analysis phase, which is commonly left to professionals outside the team. If community members share in the presentation to the community it would enhance the feeling of ownership and would make the presentation more appropriate for the community. Similarly, if simple statistical calculations are involved, a shared analysis process might shed light on this research step for persons who have not been involved in research before. This new knowledge would empower community members and could encourage and aid further enquiry into the effectiveness of customary activities and improvements thereof.

8.3.1.2 Work Abilities Web

The WAW used in the study can only be seen as a prototype. The assessments as well as the web were designed with community workers as intended users, in order to widen the service reach of vocational rehabilitation personnel. The comparative scoring scale of the functional assessment and the job analyses provided a means of superimposing the two onto one type of

graphic illustration The depth of the analyses on a functional level was considered effective so as to make a match, and feasible so as to be carried out by persons without the equipment, knowledge and skills for in-depth performance component assessments. However, as illustrated by the discussion in the previous chapter, the researcher had relied on her professional knowledge and skills to draw conclusions from her observations, e.g. in the functional assessment of activity limitations when observing the integrated performance components and deciding on a scoring level in the job analysis if the client used an unusual work position. This leads to the conclusion that the method cannot simply be applied by any category of community health worker. The same conclusion can be reached for using the WAW as an instrument for applying the general process described in **8.2.1.2**, i.e. that only trained personnel would be able to use the web effectively.

8.3.1.3 Contributions of this study to the accumulated knowledge of the scientific community

The final stage of the research was the report back to both the community as well as the scientific community. New findings and developments of research enrich both. The feedback to the community was described in **Chapter IV**. This thesis constitutes the feedback to the academic community.

Although the global guidelines and national policies, accepted by the local DPOs, were applied, the size of the study limits their use on an international level. The experience of research in a rural community could be of value for other communities and researchers and will be reported in relevant journals.

The study contributes the following innovations to the knowledge base of health and social sciences theory, in terms of disability and development issues:

The Mutual Benefit Research Model

The participatory research model, developed in previous research and refined during this study, has proven to be useful in meeting the needs of the various members of the team participating in the research. The shared experience not

only meant shared ownership but also increased the knowledge and skills of all the persons involved.

The frustration experienced by the researcher and the community because of the restricted involvement by the researcher in the community emphasises the value of a long-term relationship with a community. Credibility and good relationships with community members before embarking on research ensures that research undertaken truly meets communal needs. Long-term involvement allows for implementation of findings and follow-through in new cycles. Continued participation can also develop the knowledge skills participants acquired in the process to maximise the empowerment. Sustained capacity building combined by formal training opportunities, where appropriate, would consolidate various inputs and result in true enablement. Collaborative research as this study started out with the CSIR team thus poses a danger of exploitation if team members are brought in without consideration of the effects of short-term contact with a community.

It can be concluded therefore that the MBR model would be most useful for professionals, of various disciplines, involved in long-term community work.

The assessment format

■ The questionnaires – The questionnaire for Phase I of the survey was adapted from existing questionnaires to make it serviceable for the use of non-professional personnel in disability surveys. By phrasing the questions in the positive the interviews with community members and PWD stressed abilities, thereby contributing to the awareness of PWD's abilities to participate in a variety of social and work activities.

■ The functional assessment – The functional assessment compiled for this study can be used not only by professionals but also by community health workers after some basic training. It is practical for assessment in community settings where sophisticated equipment is not available. The researcher is convinced of the method of assessment as a tool to distinguish between real activity limitations and feigned disability.

The analysis method

■ The scoring system – The comparative scales for the analysis of abilities of PWD and job requirements are unique. Although many systems exist for both aspects, the use of a scale that can be used for direct comparison has not been described in the literature before.

■ The Work Abilities Web – The purpose of a single scale was to develop a comparison system for use by community rehabilitation workers (CRW). However, the method as demonstrated in the results chapters could be developed into a computerised system with further research.

The job match process

The job match process is described in the literature as an occupational therapy clinical reasoning process. The described process in this study is an attempt to analyse the process. It has triggered the interest of specialists in the field who will no doubt develop this line of thought further.

The study and the academic theory provided are an attempt at demystifying the integration process of PWD into the work place. The researcher saw the invitation to participate in the investigation not only as an opportunity to assist PWD in a rural community in a remote corner of the country, but also as a challenge to develop a clear method to open doors to PWD elsewhere.

8.3.2 Recommendations

Recommendations in terms of the methods used include the following two aspects:

■ Participatory research – Community members should be drawn into participation during all phases of the model. After receiving analyses from statiscians the researcher should involve the members of the team in the interpretation of the results and the development of the feedback report. In the current development stage of the country this will contribute to the general education and upliftment of community members. Specific team members can

be assigned to the task as with certain planning aspects of the study. As full community members PWD should be considered as community participants and should be included in planning and recommendation of research that concerns them.

■ Work Abilities Web - The focus of the study was to investigate work opportunities. The researcher used the opportunity to simultaneously explore methods for vocational assessment and the placement process that could be applied at the community level. The development of the WAW was intended to find a solution to the shortage of professional personnel in the area and the country as a whole. The conclusions indicate that although it was used effectively in the study, the method needs refining and an application system developed. As a spin-off from the actual study it will therefore need further development.

■ Recommendations for the comparative web include the following:

- Further research to investigate whether the assessment and analyses are comprehensive enough for universal implementation,

- Further research to establish the reliability of the scoring system,

- The development of a computer programme and manual format for wider application,

- The development of appropriate training programmes for community health workers,

- Research to establish whether community rehabilitation and community health workers can be effectively trained to apply the model to make suitable job matches.

- An investigation into the effectiveness of such a placement system using international guidelines for the development of health systems.

It is hoped that when this method is thoroughly researched it will contribute to the implementation of policies and achieve integration in the workplace for all PWD in the country, even those in the remotest rural areas of South Africa.

8.3.3 Final deductions

The situation of the PWD in rural areas is desperate. Global philosophies and national policies and strategies have not yet delivered the desired results for them. The solution to the PWD's plight lies in the development of a strategy which will reach into these areas.

The most obvious change occurring in the communities is driven by development programmes, which because of constraints in terms of finances and experts at a local level are mostly facilitated by NGOs and development agencies. A logical deduction is thus to include disability issues into the repertoire of aspects addressed in sustainable rural development, so that the necessary attitudinal changes are achieved in the general social development of the communities, and the needs of all citizens are taken into account in the planning for development. This would open the way to full integration for PWDs into their communities, including work opportunities.

A strategy developed with input from representatives of rehabilitation disciplines, DPOs, community development committees and development agencies should thus include:

■ Enlightenment of development agencies in terms of global guidelines on disability issues and disability prevalence and needs of PWD in local communities,

■ Guidelines for an integrated, multi-disciplinary approach to sustainable rural development,

■ Well-defined indicators to measure sustainable development of these issues,

■ Guidelines for the evaluation of the implementation of the national disability policies in development programmes.

Work opportunities for PWD in rural areas are affected by the general scarcity of work and the attitude of the communities they live in. Although there are signs of changes in rural communities, specialised workshops and more enlightened attitudes to integration in the workplace are currently only found in larger centres. Financial constraints and shortages of professional services in the country will affect services and opportunities in the rural areas for an undetermined time to come. Isolated efforts have often not been sustainable or have resulted in duplication of services in some areas and neglect in others. These inconsistencies add to the frustration of PWDs, their families and professionals attempting to co-operate with projects, alike.

This study is an attempt to gather information from the local communities about their needs and attitudes so that it can be assimilated in the accumulated scientific knowledge. This knowledge base needs to be extended and brought to the attention of agencies that could utilise it to the benefit of the people on the community level. Wider application of such knowledge could lead to sustainable co-ordinated efforts at applying strategies for full integration.

Effective implementation, instead of the fragmentation by which efforts have been plagued so far, thus depends on mobilising both ends of the spectrum – the global agencies and the local communities.

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Appendices

Screening Questionnaire

Names: Name of head of household: ------------------- -------------------												
1. Age (Years) 7-26												
2. Sex (Male = 1, Female = 2) 27-36												
3. Position in the family (See codes) 37-46												
4. Level of education (See codes) 47-56												
5. Can ----------- see? 57-66												
6. Can ----------- hear? 67-76												
7. Can ----------- speak? 77-86												
8. Can ---------- feel his/her body?	Left arm 87-96											
	Right arm 97-106											
	Left leg 107-116											
	Right leg 117-126											
9. Can ---------- move his/her limbs?	Left arm 127-136											
	Right arm 137-146											
	Left leg 147-156											
	Right leg 157-166											
10. Can ---------- use his/her hands?	Left hand 167-176											
	Right hand 177-186											
11. Can --------- walk?	187-196											
12. Does -------- have good breathing?	(Yes=1,No=2) 197-206											
13. Does -------- have a problem with his/her body or mind, which we have not discussed yet?	Specify 207-216											

Appendices

Appendix I   Questionnaire Phase I

CSIR – University of Pretoria
Disability Survey – 2000

Mninimzi Obekekileyo

Sileliqumru lingentla sicelwe luluntu lwenu ukuba sincedise kwindawo yenu kwicala laba Khubazekileyo.

U CSIR ne University yase Pretoria unqwenela ukuba khe siqondisisane Sibonisgne ngabantu abakhubazekileyo Kuluntu ngokubanzi.

Kwindibaniselwano yethu nabantu abakhubaze Kileyo, Intsapo zabo noluntu lonke sinqwenela ukwakha indlela esiyakubaphuhlisa ngayo. Ukuze sikwazi ukubonisana nani sinqwenela ukwazi ababantu abakhubazekileyo nendawo abahlala kuzo.

Akunnyanzelekanga ukuba uthathe inxaxheba kule mfunalwazi xa ungaboni nyato. Kodwa uncedo lwakho lungalulutho kuwe.

Imfunalwazi engu:-----------------------------------iza kubuza imbuzo ngaye wonke umtu omdala apha ekaya ukusuka kwilbukaya kwi 40 yeminyaka ubudala emva kwalendibono abantu abakhubazekileyo baza kutyelewa emakaya ukuza kubonisana Nabo.

Uyabulelwa Kakhulu ngenxaxheba yabo.

Codes

Question 3:

Father	1
Mother	2
Grandfather	3
Grandmother	4
Child	5
Other	6

Question 4:

None	1
Prim. School	2
Sec. School	3
Tert. Educ.A	4
Tert. Educ. T	5

Question 5 – 11:

Well	1
With difficulty	2
No	3

Question 13:

Psych	1
Cogn	2
Phys	3
None	4

Date: ---------------------------

Name of interviewer: --

1

Village/Zone: ---

2-3

Household No:

4-6

Appendix II   Disability Survey Training
Workshop – March 2000
Disability survey training
Lubisi – Tsilitwa

What is disability

Concepts of wellness – illness – disability/handicap
ICIDH

Differentiate between wellness - illness – disability

Research

Purpose – methodology – this study

Interview

Making contact – interview style/introduction to closure
Content of this survey:
- ■ Background
- ■ Purpose
- ■ Information

Questionnaire

How to fill in form

Head of the household:	Who qualifies as head of the household
Age:	16 – 40 year old adults
Sex:	Code
Position in the family:	Reason/discuss other
Level of education:	Code/discuss possible answers and recording
Vision:	Well – like other people, far and near, ca carry out daily activities without problems
	With difficulty – one eye, central/peripheral vision, hemi-anopia, blurring, double vision, only in very good light, distance problems
	No – none, not functional, only distinguish shapes/light and dark
Hearing:	Well – both ears, functional
	With difficulty – one ear, "hard of hearing", ringing sound
	No – none, not functional
Speech:	Well – fluent, production aspects
	With difficulty – mild aphasias/apraxia, stutter, volume
	No – none, severe aphasia, not functional
Sensation:	Variety, intensity, body parts
	Well – all modalities, discrimination
	With difficulty – lacking one or more modalities, poor discrimination, hypo/hyper sensitive
	No – none

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good breathing?														
13. Does ------- have a problem with his/her body or mind, which we have not discussed yet?	Specify 207-216													

Movement:	Well – all joints/muscle groups, control/co-ordination (quality/speed/accuracy)
	With difficulty – one or more joints/muscles affected, co-ordination problems, low endurance, apraxia
	No – none
Hand function:	Well – all grasps, co-ordination, skill
	With difficulty – problems with one or more grasps, co-ordination
	No – none, not functional
Gait:	Well – normal pattern, balance, co-ordination, different surfaces, steps, distance
	With difficulty – abnormal pattern, poor balance (external support), only smooth surfaces, poor endurance
	No – none (wheelchair), not functional
Cardio-vascular:	Yes – normal activity for age group without becoming out of breath (endurance/fitness level)
	No – easily out of breath (endurance/fitness level), asthma, hart problems
Other:	Psychiatric – mad and synonyms, thought process/mood disturbances, substance abuse
	Cognitive – level of awareness, IQ, attention, memory, higher cognitive functions - not literacy
	Physical – skin problems, intestines
Test run	Problem solving
Planning pilot	1 – normal/1 – disabled
	Method of feedback
Survey planning	

Workshop – March 2000

Disability survey

Screening Questionnaire

1. Interview
Head of the household

Interview:
Establish contact

Background to the survey

Purpose of the survey

Closure

2. Filling in of the questionnaire

Question 1
Age

Question 2
Sex

Question 3
Position in the family

Father	1
Mother	2
Grandfather	3
Grandmother	4
Child	5
Other	6

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Question 4
Level of education

None   1
Prim. School 2
Sec. School 3
Tert. Educ.A 4
Tert. Educ. T 5

Question 5
Can -------------- see?

Well   1
With difficulty2
No   3

Well

With difficulty

No

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Question 6
Can ---------- hear?

Well 1
With difficulty2
No 3

Well

With difficulty

No

Question 7
Can ---------- speak?

Well 1
With difficulty2
No 3

Well

With difficulty

No

Question 8
Can ----------- feel his/her body?

Well   1
With difficulty 2
No   3

Well

With difficulty

No

Question 9
Can ---------- move his/her limbs?

Well   1
With difficulty 2
No   3

Well

With difficulty

No

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Question 10
Can ---------- use his/her hands?

Well   1
With difficulty2
No   3

Well

With difficulty

No

Question 11
Can ---------- walk?

Well   1
With difficulty2
No   3

Well

With difficulty

No

Question 12
Does ------------ have good breathing?

Yes	1
No	2

Well

With difficulty

No

Question 13
Does --------- have a problem with his/her body or mind, which we have not discussed yet?

Psych	1
Cogn	2
Phys	3

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Appendix III   Phase II - Functional Assessment

Pre-job-match assessment

Name: --   Respondent No: ☐☐ 1-2

Date: ----------------------- ☐☐ ☐☐☐ ☐

(Cross-reference: ☐☐   )

Age: ☐ 3-4   Age at onset: ☐☐ 5-6
                                                ☐☐

Disability pension (Yes - 1. No - 2): ☐ 7   Dependants: ☐☐ 8-9

Code	5	4	3	2	1
Description	Unfunctional	Functional with an assistant	Functional with:	Abnormal function ito:	Normal function
			Activity adaptation	Speed	
				Accuracy	
			Assistive device	Pattern	

1. Seeing	10	
2. Hearing	11	
3. Speaking	12	
4. Left arm functioning	13	
5. Right arm functioning	14	
6. Left hand functioning	15	
7. Right hand functioning	16	
8. Bilateral hand functioning	17	
9. Sitting	18	
10. Standing	19	
11. Left leg functioning	20	
12. Right leg functioning	21	
13. Squatting	22	
14. Picking up	23	
15. Walking	24	
16. Carrying	25	
17. Memorising	26	
18. Problem solving	27	
19. Level of motivation	28	

Integrated higher cognitive functioning (Problem solving, memory)
(Set problem: Storm/ roof is leaking over item of furniture. What actions should be taken?)..
....
....
....
....

Level of motivation (Vona du Toit)
(Clinical observation)..
....
....

Work history (Have you ever worked? What work did you do?)
....
....
....
....
....

Work skills (What did you learn to be able to do the work?)
....
....
....
....

Aspirations (What do you want to accomplish, bring about in your life?)
....
....
....
....

Needs (What do you need to achieve this?)
....
....
....
....

Recommendations to family/clinic sister
....
....
....
....
....

Notes

Appendix IV   Facilitator Training Workshop

Tsilitwa - September 2000
Facilitator training workshop

Programme
1. Introduction
- Background to attitude survey
- Purpose
- Definitions
2. Facilitation techniques
3. Role play – practise session
4. Questions

Appendix V

Tsilitwa – September 2000
Community meeting on disability issues

Agenda
1. Introduction
2. Small group discussions
3. Feedback and big group discussion
4. The way forward

Small group discussions on attitude toward disability issues:
What is the role (or place) of a person with disabilities in the family?
What is the role (or place) of a person with disabilities in the community?
Big group discussion:
Should persons with disabilities be given the opportunity to earn money in community work projects?
Who is responsible for making it possible for persons with disabilities to be part of work projects?

Group 1:
Facilitator: _____

What is the role of a person with disabilities in the family?

What is the role of a person with disabilities in the community?

Appendix VI   Planned meeting with PWD and Families

Tsilitwa – September 2000
Meeting for PWD and their families on disability issues

Agenda

1. Introduction
2. Purpose of the survey
3. Feedback from attitude meeting
4. Discussion
5. The way forward

Appendix VII   Fundraising workshop
Tsilitwa September 2000

Workshop on writing proposals for funding

Programme

- **Project planning**
- Purpose: planning, funding, monitoring
- Definition of terms
- Steps: participation analysis, problem analysis, objectives analysis, alternatives analysis, project elements, external factors, indicators.
- **Finding a funder**
- Funding options: inter-governmental agencies, partnerships, other.
- Programme interests/objectives
- Procedures
- Contact persons
- **Writing the proposal**
- Language
- Content
- **Examples**
- Tsilitwa project
- Funders
- **Inter-governmental:**
- European Union
- Embassies (Small/Micro Projects)
- USAID
- Action Aid
- Oxfam
- **Partnerships:**
- Kellogg
- Ford Foundation
- German development Services
- **Other:**
- National Lottery Board
- Doen (Dutch Post Code Lottery)

Appendix VIII   Flowchart for work placement

Functional assessment of PWD referred for work placement

↓

Does PWD participate in any activities? (Motivational level) ⇒ No - Exit programme

↓

Does PWD have any activity limitations? ⇒ No – Exit programme

No assisted placement

No match – Exit programme

Assisted placement

Job match (Motivational level, aspirations, abilities with available work opportunities)

↓

No ⇐ Does PWD need training? ⇒ Yes – Training programme

↓

No ⇐ Does PWD need adaptations, assistance or supervision? ⇒ Yes Refer to professional for consultation

↓

Job Placement (Follow up support locally)

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