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Chapter I

Background to the study

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

Global trends

Global philosophy to working definition

- **Rural development**
- **Sustainability**

South African situation

- **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]

According to Osmundsen, [illegible] dimensions and systems can be grouped as:

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■ 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

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]

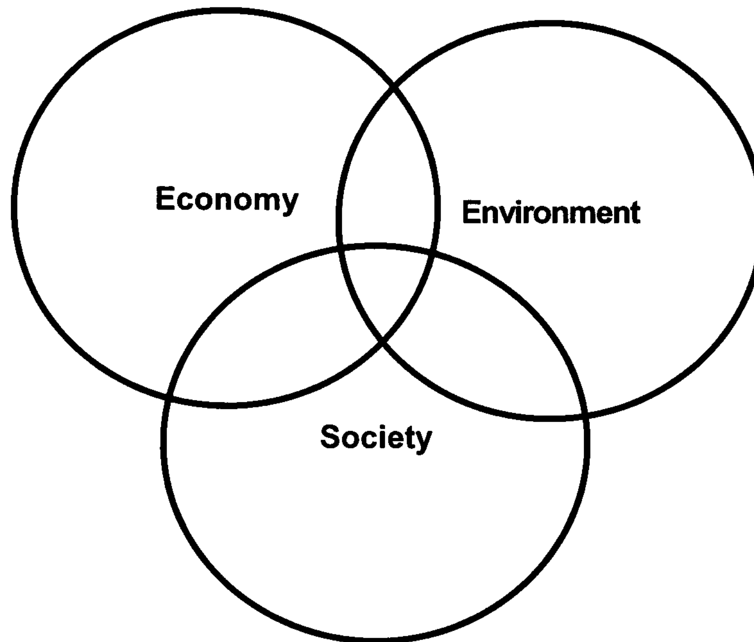

Figure 1.1 Interconnectedness of communal systems

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.

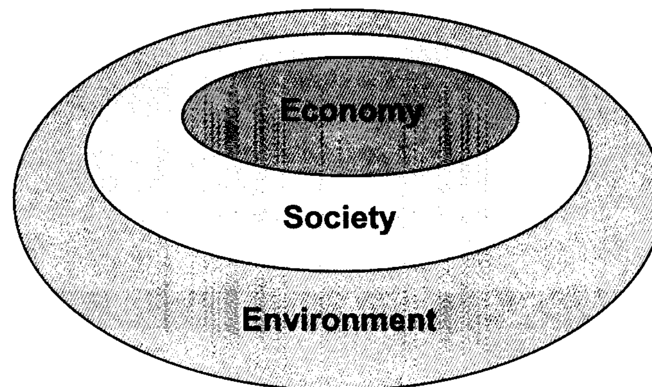

Figure 1.2 Illustration of a sustainable community (Hart Environmental Data)

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.

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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.

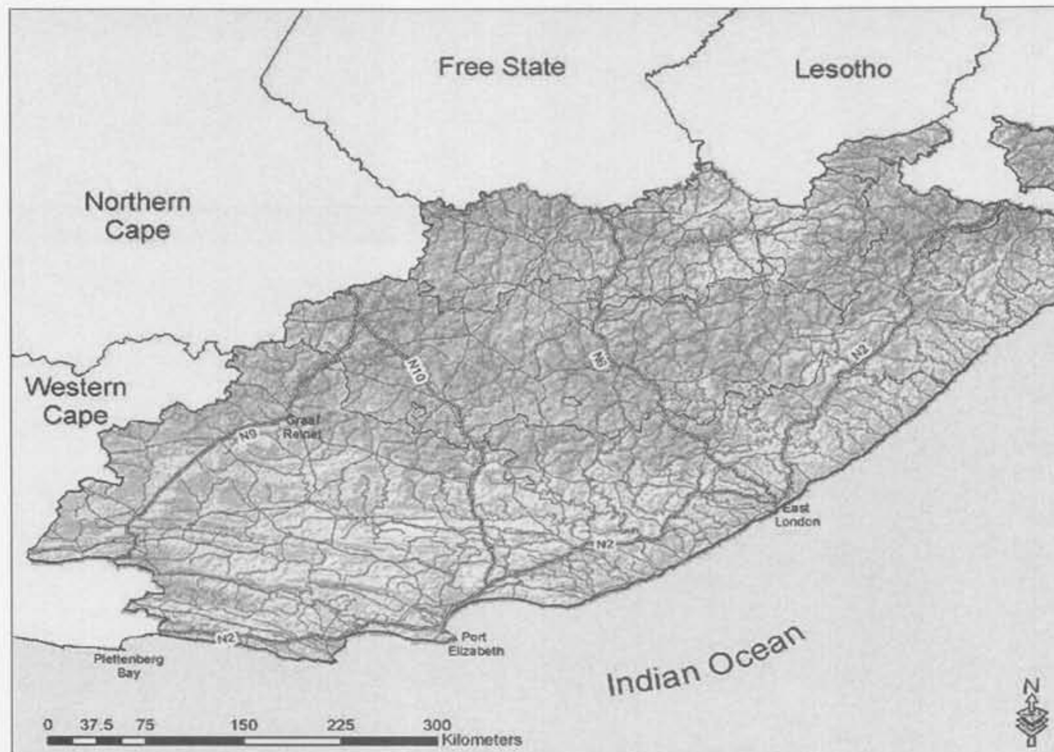

Figure 1.3 Eastern Cape

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.

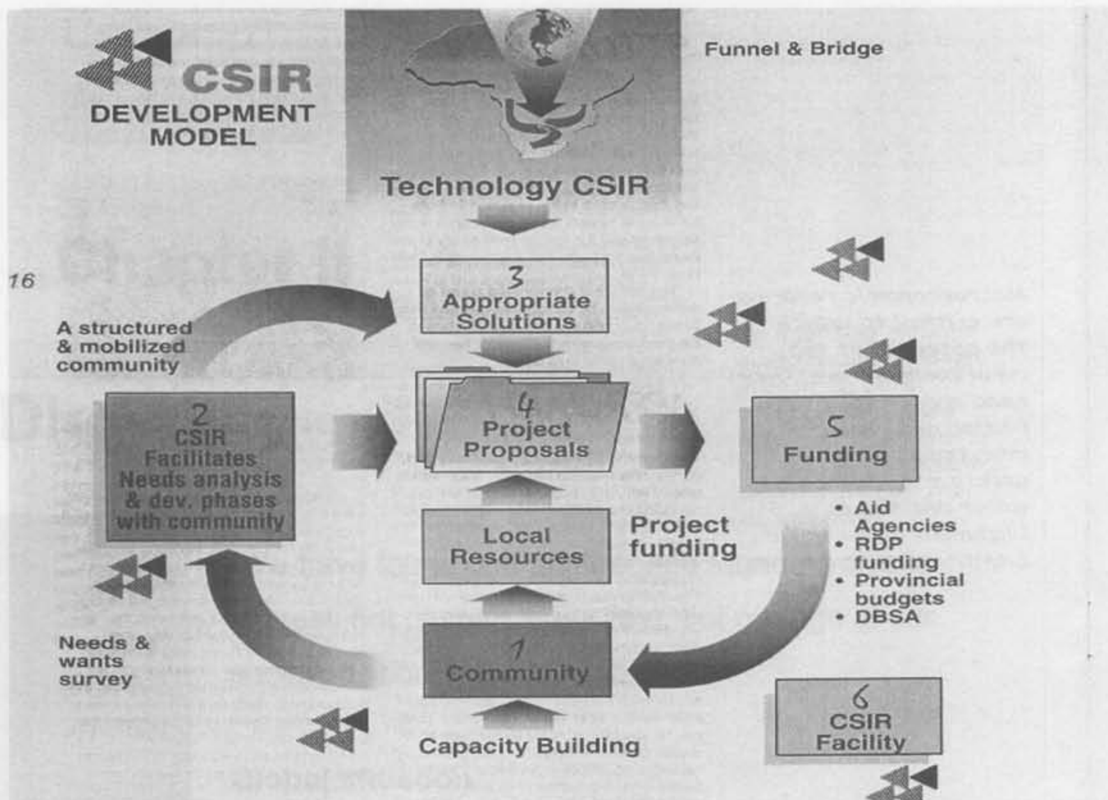

Figure 1.4 Integrated Rural Development Model Development Process

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]:

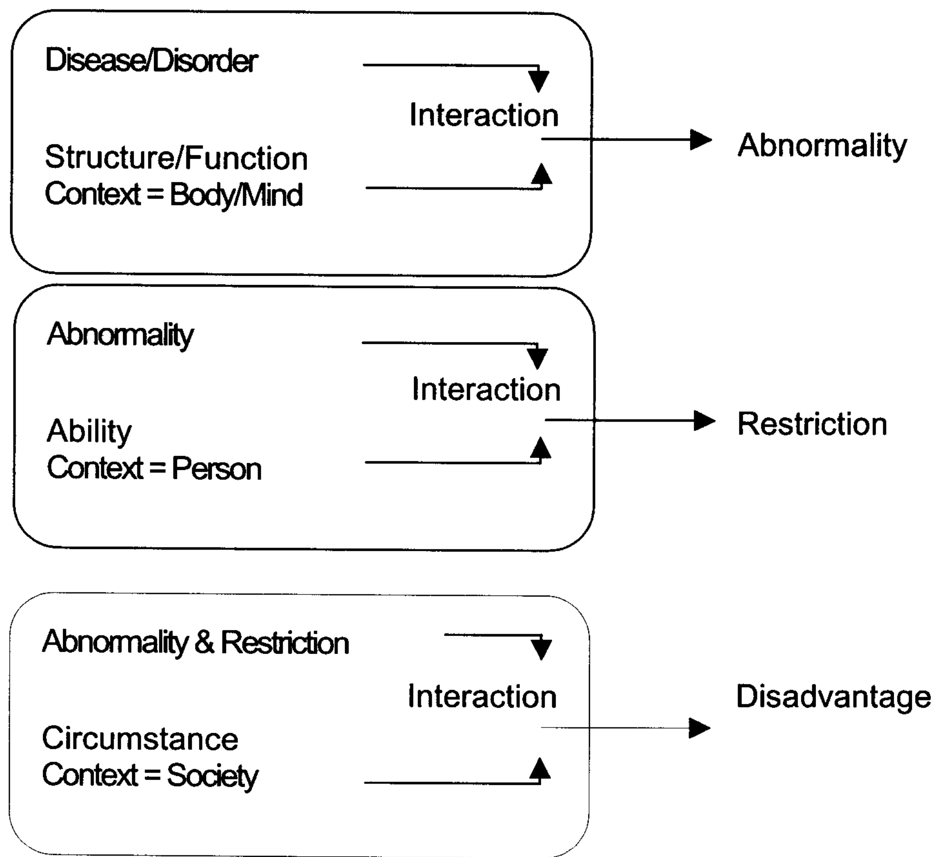

Figure 2.1 Interactional process of disablement

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

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,

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- Receive education, me[illegible]ices 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**).

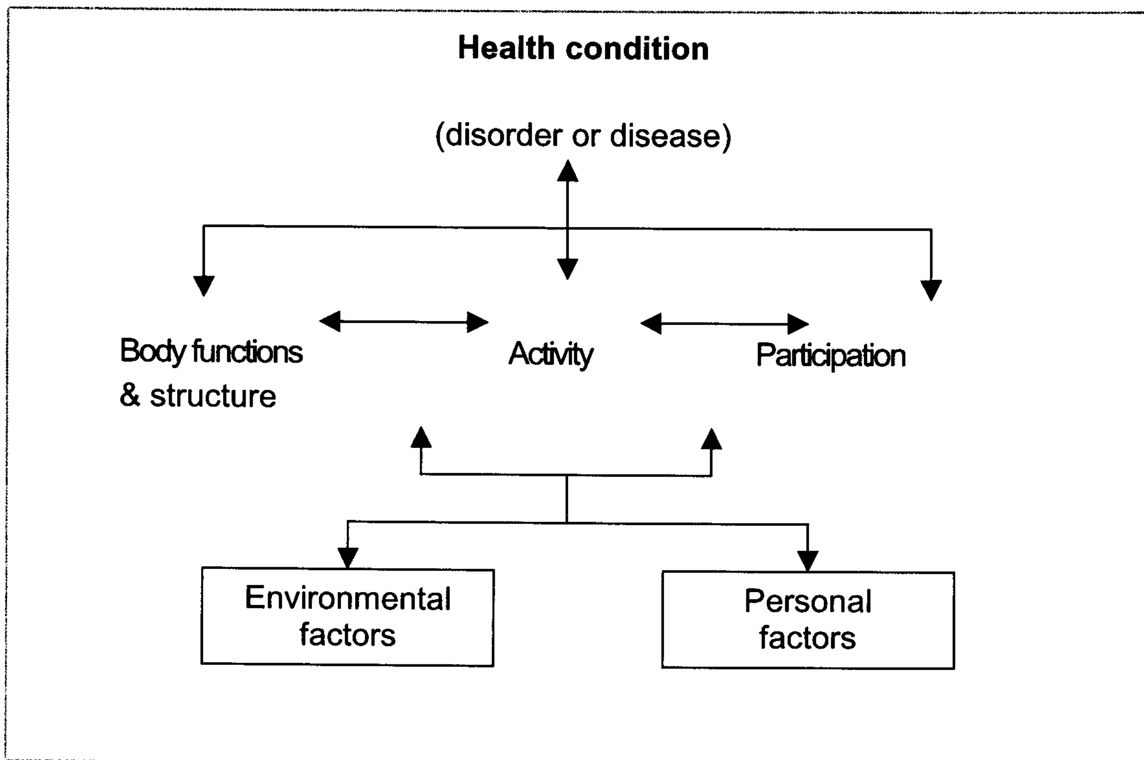

Figure 2.2 Model of functioning and disability

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

[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.

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investigation of economic a[illegible] 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
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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

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.