Chapter III

The theory of rehabilitation and the workplace

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

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

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

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

3.1 Introduction

Rehabilitation for all

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

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

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

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

3.2 Rehabilitation

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

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

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

The delivery models most commonly described in the literature are:

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

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

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

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

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

3.2.1 The comprehensive rehabilitation programme

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

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

Table 3.1 Professional and their roles in a comprehensive rehabilitation programme

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

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

Table 3.2 The Comprehensive Rehabilitation Programme

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

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

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

3.2.1.1 Types of rehabilitation services

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

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

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

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

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

3.2.1.2 Community-based rehabilitation

Policies

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

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

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

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

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

Approach

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

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

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

Service delivery in the health district

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

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

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

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

Definition and characteristics

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

> *"Community-based rehabilitation is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities.*
>
> *"Community-based rehabilitation is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services."*[116]

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

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

Table 3.3 Features of Community based rehabilitation

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

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

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

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

3.2.1.3 Support networks and referral systems

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

Support networks

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

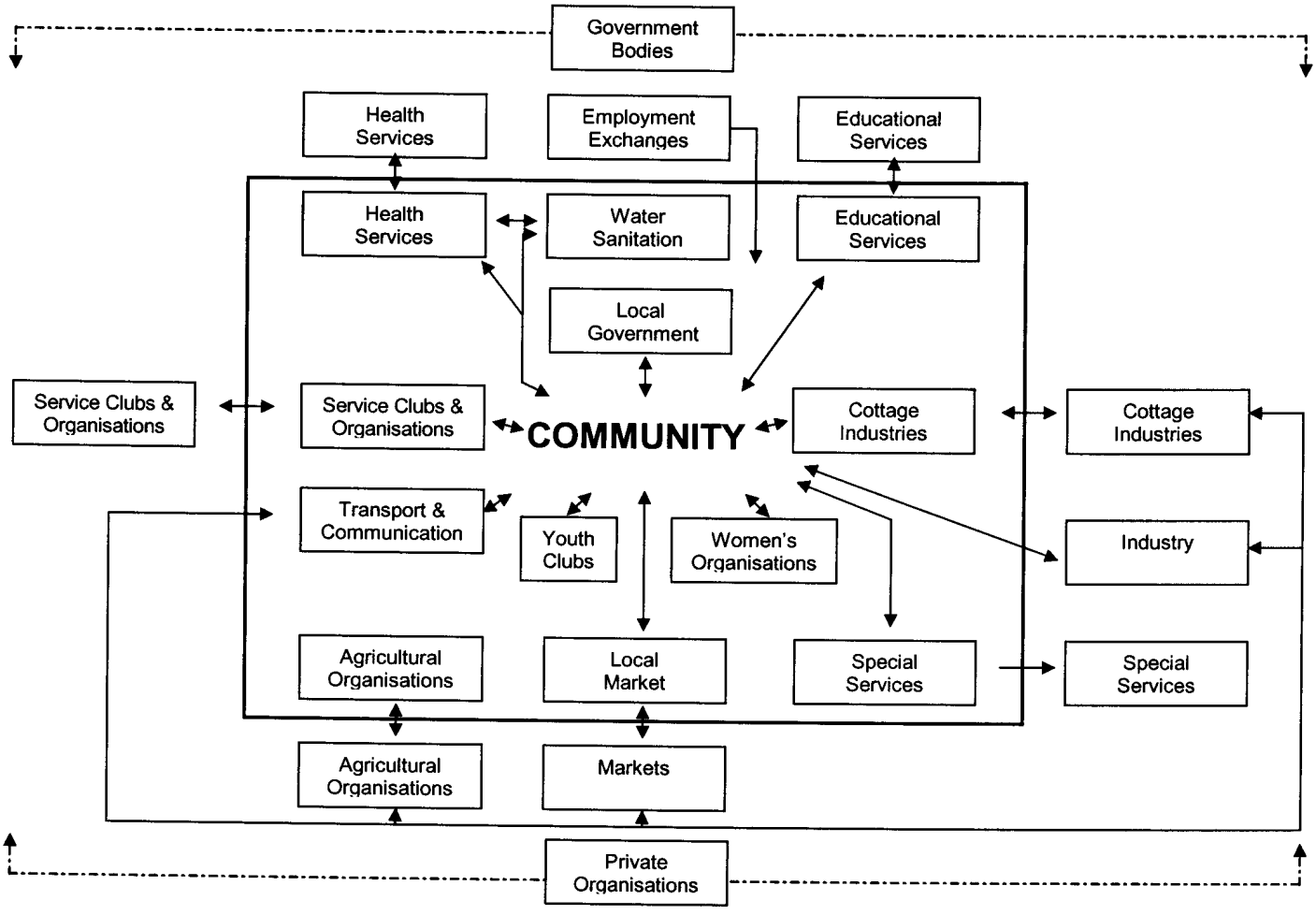


Figure 3.1 Support network (India) for the community

Referral networks

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

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

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

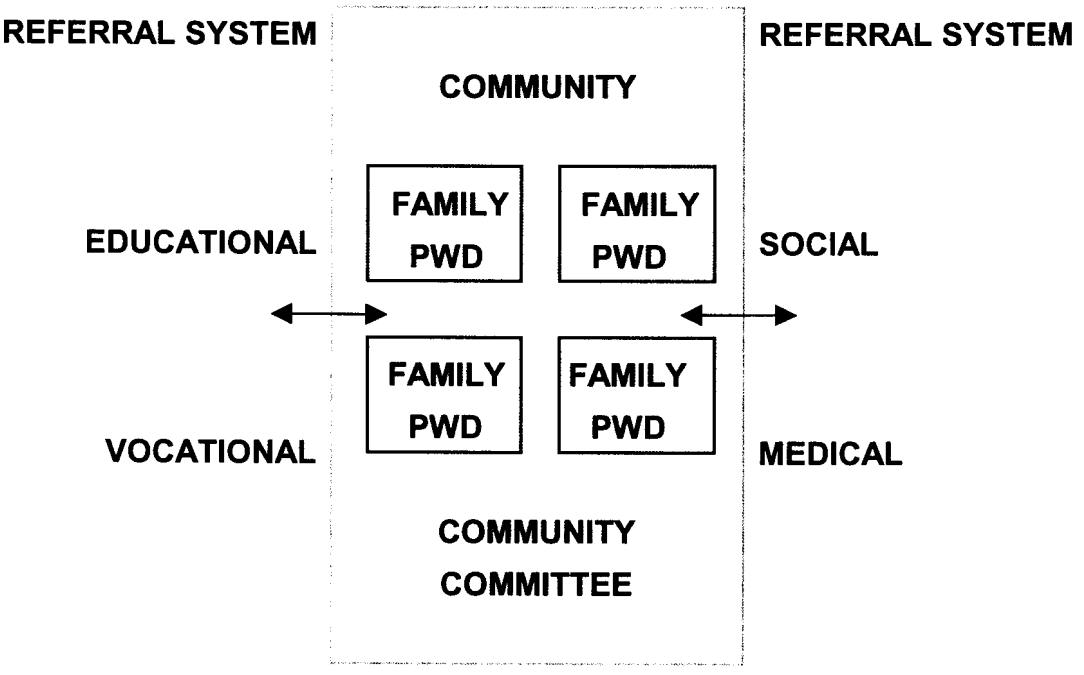


Figure 3.2 World Health Organisation Referral network

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

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

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

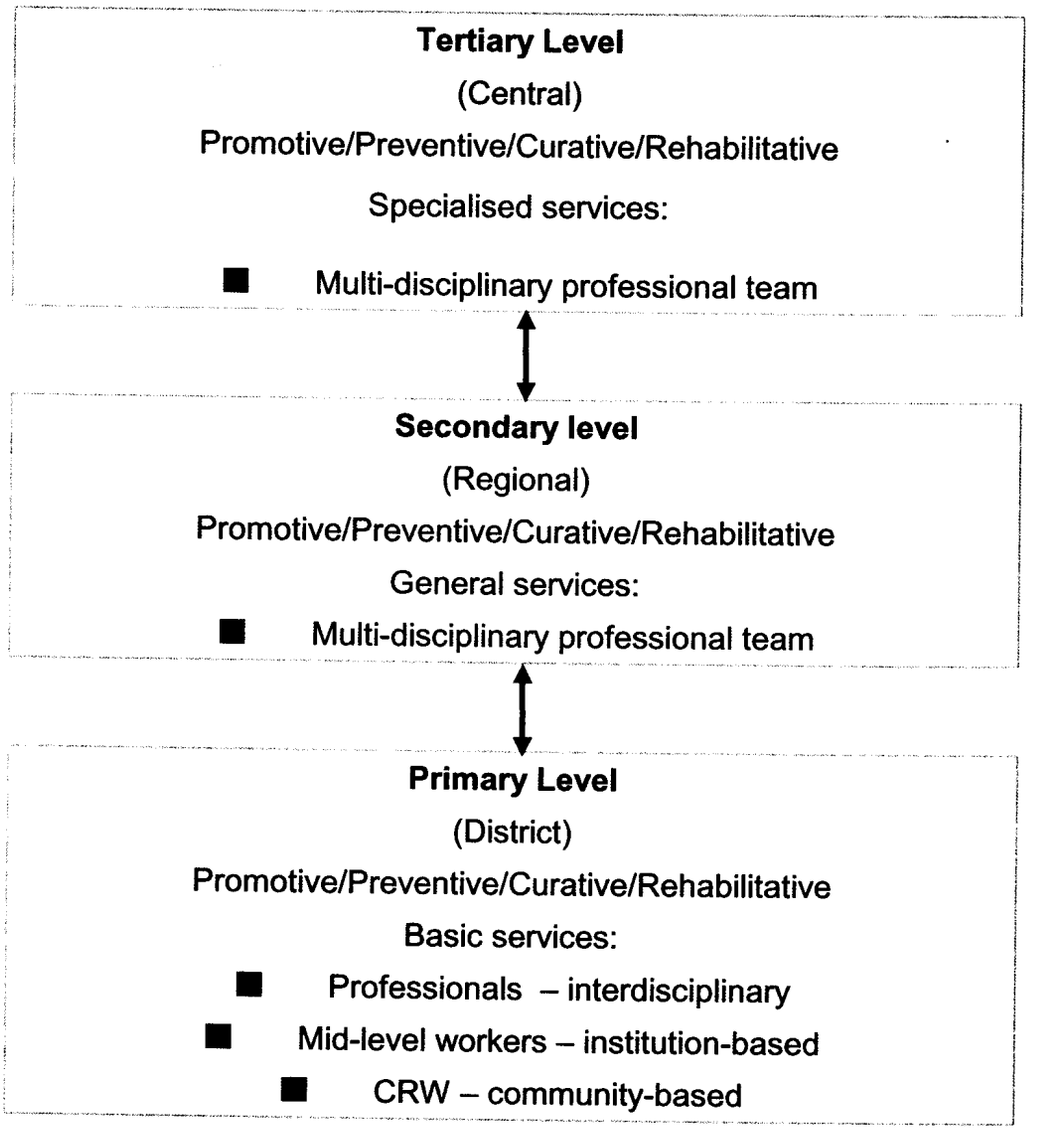


Figure 3.3 Referral network

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

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

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

3.2.2 Occupational therapy

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

3.2.2.1 Definition of occupational therapy

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

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

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

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

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

3.2.2.2 Theoretical basis

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

Models and frameworks

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

Table 3.4 Comparison between holistic and reductionist metamodels

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

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

Table 3.5 Comparison between medicine and occupational therapy

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

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

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

- Engagement in occupation is of value because if affords individuals the opportunity to influence their well-being by gaining fulfilment in living.
- Through the experience of occupation or doing, the individual can achieve mastery and competence in skills and strategies for coping with problems and adapting to limitations.
- With competence the individual gains autonomy and independence.
- Autonomy implies choice and control over the environment, thus opportunities for exerting self-determination are a characteristic of intervention strategies.

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

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

Occupation is defined as:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Vona du Toit – Volition and Action

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

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

The advantages of the approach based on this model are:

- The characteristics of motivation and action at each level of growth or recovery may be analysed.
- The direction and content of treatment aimed at restoring motivation by means of action is defined.
- Demands made on an individual interpersonally and socially are systematised.
- Criteria for selecting, presenting and grading activities on each level of motivational recovery can be extracted. The level attained by the individual can be stabilised and the next level stimulated.
- The work readiness of an individual can be determined.[137]

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

Table 3.6 Levels of motivation and action

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

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

Table 3.7 Levels of volition and work potential

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

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

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

The following sub-section outlines the occupational therapy process.

3.2.2.3 The occupational therapy process

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

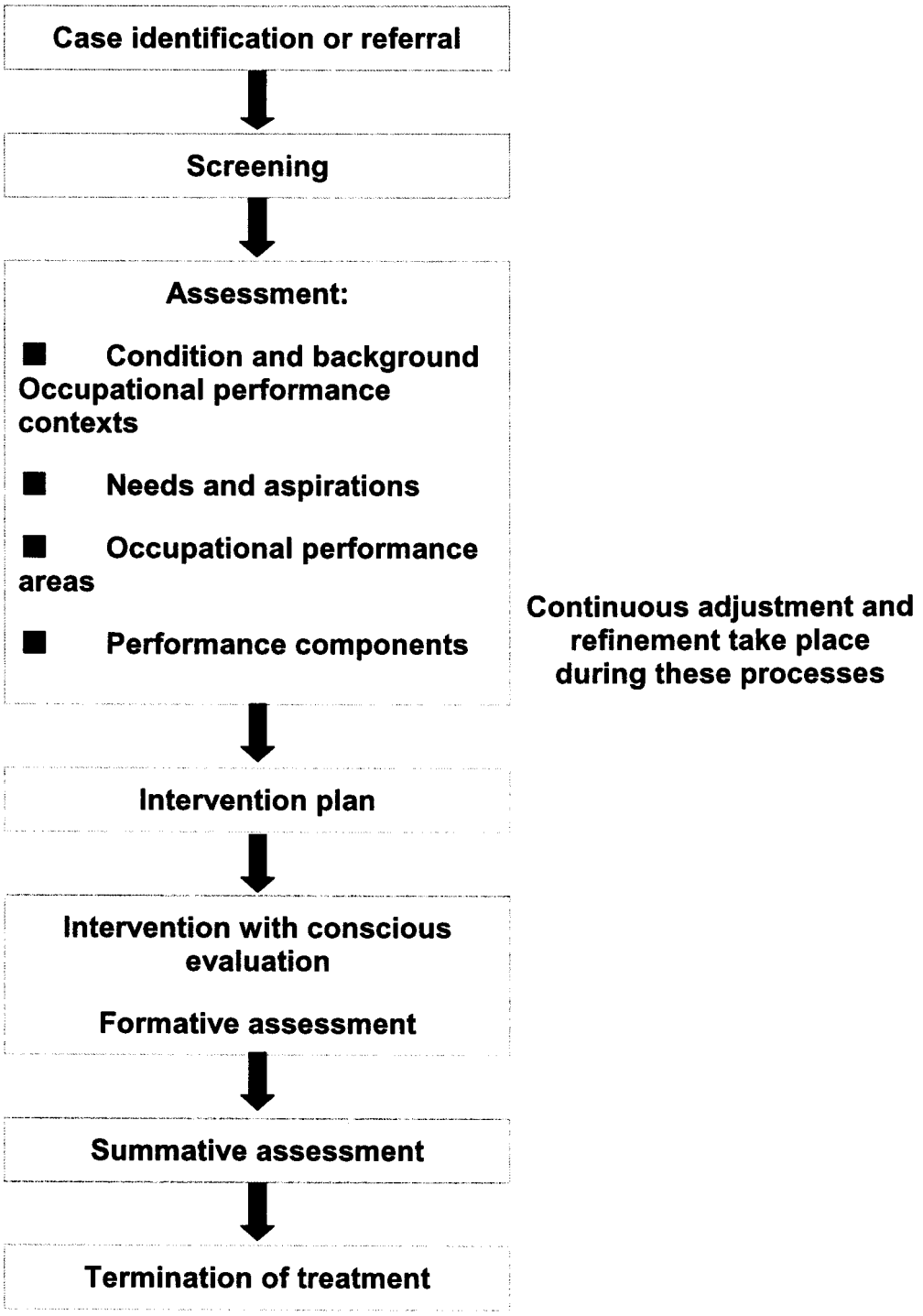


Figure 3.4 Occupational therapy process

Assessment

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

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

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

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

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

- Organisation of daily living routines,
- Life roles,
- Interests, values and goals,
- Perceptions of abilities,
- Environmental influences on the occupational performance.[139,]

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

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

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

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

Treatment

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

The three strategies can briefly be explained as follows:

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

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

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

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

Table 3.8 Treatment strategies in occupational therapy

Major intervention strategies in occupational therapy

Use of occupation as a therapeutic medium

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

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

General principles relevant to occupational therapy are:

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

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

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

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

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

The various fields of specialisation in occupational therapy are:

- Paediatrics
- Psychiatry
- Physical:

- Spinal
- General medicine (burns, cardiology etc.)
- Orthopaedics (hands, amputations etc.)
- Adult neurology (stroke, head-injury etc.)
- Vocational therapy.

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

3.2.3 Vocational therapy

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

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

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

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

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

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

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

- A means for practical survival,
- Improved feelings of self-worth,
- A sense of belonging by contributing to society,
- Structure to their life,
- Social connections.

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

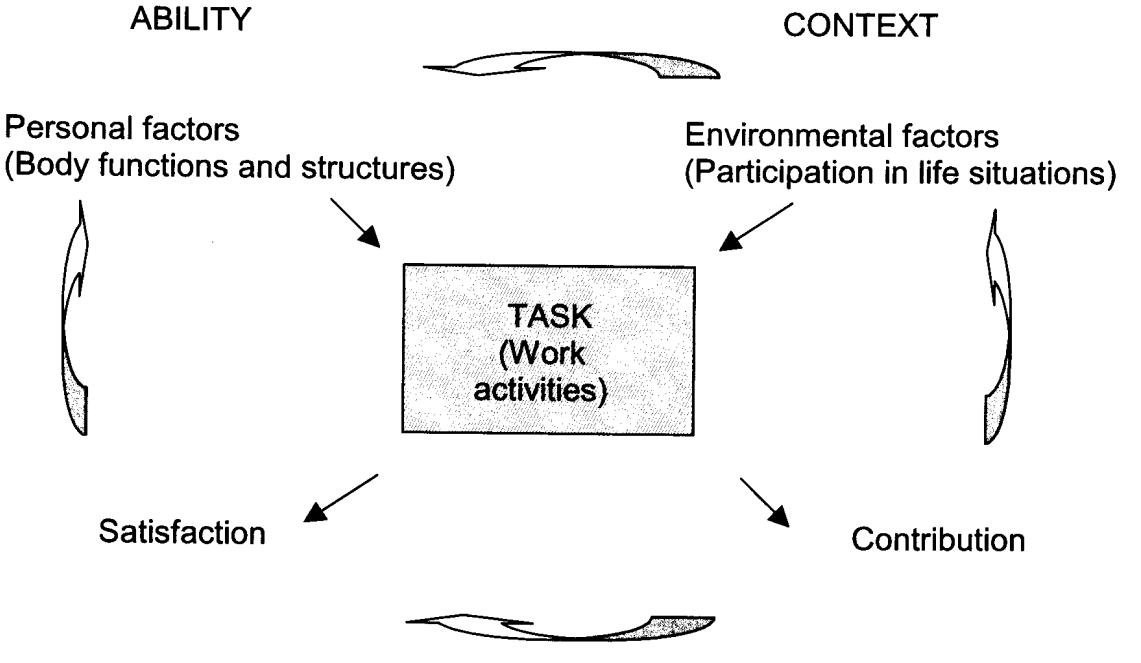


Figure 3.5 Value of work activity performance

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

3.2.3.1 Occupational therapy vocational rehabilitation process

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

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

Assessment

The occupational therapy assessment procedures performed are:

- Review of medical, educational and vocational records,
- Interviews with the client, family, employer (if employed before the incident), teachers (if school leaver) and rehabilitation professionals,
- Observation during simulated activities or work samples that relate to the client's interest field,
- Standardised tests.[150]

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

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

Treatment

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

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

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

- Restore lost confidence,
- Build morale and self-confidence,
- Instil good work habits,
- Increase work tolerance.[154]

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

Training

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

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

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

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

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

Placement

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

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

The placement process involves the following steps:

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

- Job match – including practical adaptations.

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

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

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

Employment options

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

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

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

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

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

3.2.3.2 Inter-sectoral collaboration

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

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

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

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

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

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

3.2.3.3 Community-based approach to vocational rehabilitation

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

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

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

- No community-based services can be imposed on a community; they should be understood and wanted by them.
- Community resources include informal help from within the families and are driven by goodwill and interest.
- As many people as possible, including local government, should be involved to strengthen the support network. Public awareness should be created and maintained by regularly informing the community of objectives and progress.
- The start should be small.
- A relationship of trust and understanding is vital for the sustainability of the programme; this includes relationships with the PWD, their families and the community at large.
- Education in the form of information about disablement issues and training are cornerstones of the programme.

3.2.3.4 Integration of persons with disabilities into employment

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

3.2.3.5 Categorisation of work

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

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

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

MET – Metabolic equivalents

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

3.3 The workplace

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

3.3.1 Physical accessibility

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

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

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

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

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

3.3.2 Access to opportunities

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

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

3.4 Examples of programmes

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

3.4.1 Global

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

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

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

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

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

- Awareness programmes to change negative social attitudes,
- Facilities for education,
- Financial aid to engage in income generating projects,
- Correct assistive devices,
- Better health and recreational facilities,
- Better rehabilitation facilities.[170]

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

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

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

- Suitable land in terms of accessibility for the project;
- Facilities that are suitably adapted to allow access for PWD;
- Transport facilities, good roads and paths that are wheelchair passable and public transport that accepts persons with wheelchairs;
- Accessible workspace with ramps and accessible toilets;

- Appropriate tools and machinery, which may require adaptations or modifications;
- Recreational facilities for socialisation;
- Medical care with special attention for PWD, rehabilitation services that include vocational rehabilitation and promote employment opportunities;
- Educational opportunities for all;
- Welfare and supervision to monitor human rights;
- A running budget until the activity becomes profitable and self-sustainable.

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

Her plan of action provides for:

- Networking with various organisations and sectors (health, welfare, education, employment). Networking would also provide advocacy for disability issues;
- Funding from relevant government institutions, NGOs and development agencies;
- Identification of the organisation that would provide training and skills development for PWD;
- Development of projects that are market and development policy related;
- Adaptation of physical environment.

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

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

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

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

3.4.2 National

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

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

---- ----

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

Chapter IV

Methodology

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

Introduction

Aims of the study

Research design

Population

Research Materials

Procedures
- **Data collection**

4.1 Introduction

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

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

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

4.2 Aim and objectives of the study

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

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

4.2.1 Research question

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

- Work opportunities are scarce in rural villages in the Eastern Cape.
- The projects initiated in the past by various groups in the community did not involve PWD.
- The skills and abilities of the PWD in Tsilitwa have not been assessed.
- The barriers that prevent full integration have not been ascertained.
- PWD have the right to be included in their community projects according to capabilities and not to be separated from the rest of the community.

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

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

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

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

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

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

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

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

4.2.2 Aim of the study

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

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

4.2.3 Objectives of the study

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

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

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

- Number of adults with physical disability,
- Needs and aspirations of the PWD and the community/care-givers for integration into the workplace,
- Level of skills of the PWD in the area,
- Attitudes of the PWD, caregivers and community to equal employment opportunities for PWD.

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

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

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

- Job analyses of planned projects,
- Facilities,
- Resources in terms of the training and adaptations needed by PWD.

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

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

- Job match and
- Establishing the adaptation requirements for the match.

4.3 Research design

4.3.1 Assumptions

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

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

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

4.3.2 Approach and design

4.3.2.1 Research approach

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

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

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

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

Table 4.1 Matrix of approaches and issues

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

CHW-Community health worker

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

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

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

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

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

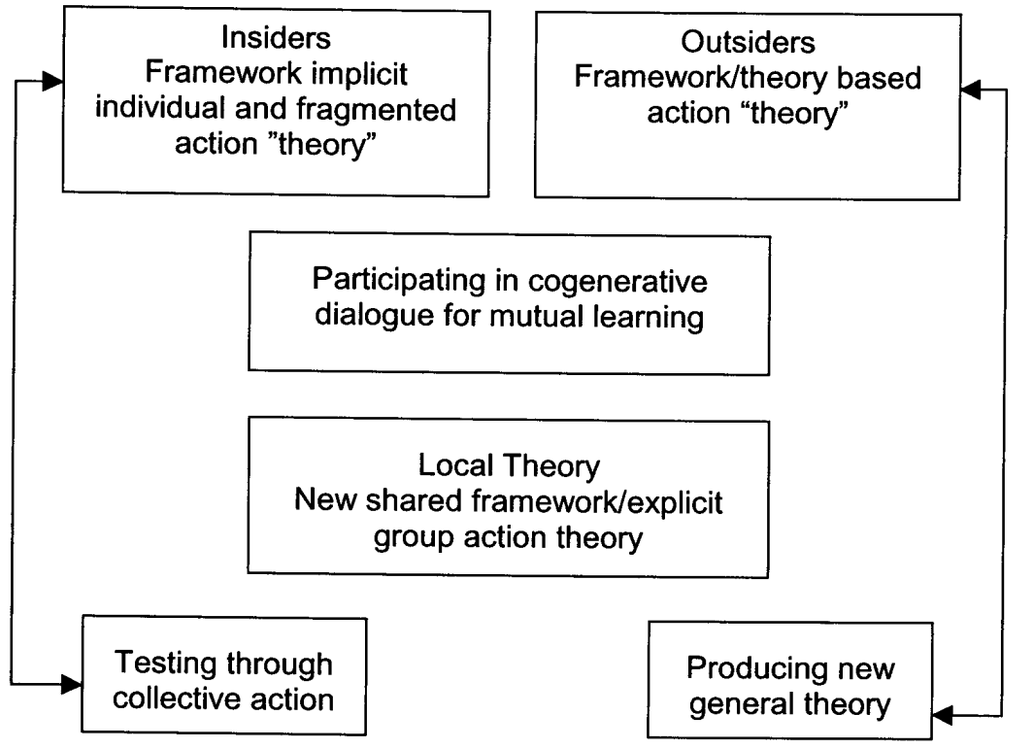


Figure 4.1 Model of participatory action research Scandinavian style: the cogenerative way

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

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

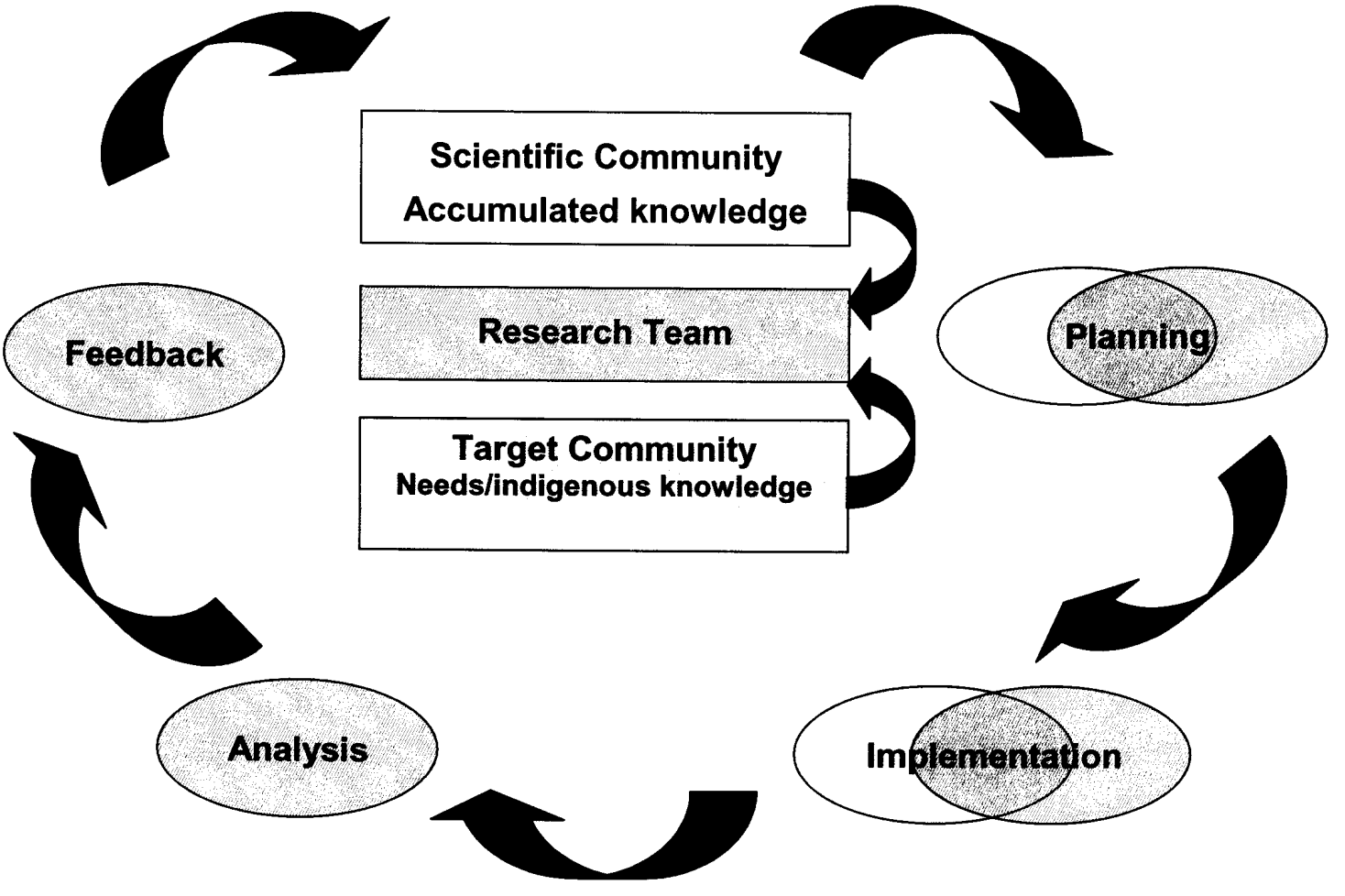


Figure 4.2 Mutual benefit research model (MBR Model)

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

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

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

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

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

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

The MBR model was applied in the following way:

Phase I – Planning

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

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

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

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

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

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

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

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

■ Awareness of the abilities of PWD must be raised.

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

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

1. Deciding on the scope of the negotiations/study

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

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

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

2. Choosing the setting

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

3. Clarifying expectations

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

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

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

4. Prompting participation

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

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

5. Establishing trust

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

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

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

6. Setting priorities

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

Phase II - Implementation

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

Phase III - Analysis

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

Phase IV - Feedback

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

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

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

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

4.3.2.2 Research design

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

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

Table 4.2 Design details of the study

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

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

4.3.3 Population

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

4.3.4 Sample

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

The selection criteria were thus physical disability and age.

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

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

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

4.4 Research materials

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

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

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

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

- Select the item pool,
- Reduce the number of items,
- Choose response options,
- Determine reproducibility,
- Determine validity,
- Determine responsiveness.

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

4.4.1 Questionnaire - Phase I: Screening for impairments

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

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

Step 1 – Selecting the item pool

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

Step 2 - Reduce the number of items

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

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

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

- Mental,
- Intellectual,
- Temperament and personality,
- Sensory,
- Seeing,
- Hearing,
- Voice and speech,
- Speaking,
- Cardio-respiratory,
- Sensations associated with cardio-respiratory functions,
- Neuromusculoskeletal and movement,
- Movement functions.

Step 3 - Choose response options

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

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

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

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

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

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

Step 4 - Determine reproducibility

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

Step 5 - Determine validity

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

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

Step 6 – Determine responsiveness

To achieve maximum responsiveness the following safeguards were incorporated:

- The household survey would ensure a response from every household in the village.
- The format and phrasing as well as the training would make the enquiry comprehensible.
- The use of local research assistants would prevent cultural bias and incorrect interpretation of the responses.
- A cover letter in Xhosa and the background given by the research assistants as introduction to the interview would assist in obtaining consent and eliciting co-operation before continuing with an interview.

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

4.4.2 Questionnaire – Phase II: Assessing activity limitation

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

- Assessment of neuromusculoskeletal functioning,
- Assessment of activity limitation,
- Verification of findings of the screening questionnaire,
- Focus on abilities needed for work,
- Suitable for use by rehabilitation professionals and community based health workers,
- Providing an adequate record of both the assessment and the interview.

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

Step 1 – Selecting the item pool

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

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

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

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

Step 2 – Reduce the number of items

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

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

The ICIDH-2 functional domains included were:

- Global mental functions
  - Energy and drive
- Specific mental functions
  - Memory
  - Higher level cognitive
- Sensory functions
  - Seeing
  - Hearing
  - Vestibular
  - Proprioceptive
  - Touch
  - Voice and speech
- Neuromusculoskeletal and movement related functions

Mobility of joints

Stability of joints

Muscle power

Muscle tone

Muscle endurance

Control of voluntary movement including gait

Step 3 – Choose response options

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

For this very reason it was decided to develop a scale that would be appropriate for this study. The purpose was to develop a scale that might be suitable for community-based health workers to use in future and to test the specific context, i.e. rural communities, in the early stages of development services.

The primary division of the scale, to reflect levels of independence and dependence, is an element borrowed from the Functional Independence Measure (FIM).[195]

The five levels were then formulated for use in both the functional assessment and the job analyses in an attempt to find a unifying classification that would make job matching easier for non-professional workers in the field.

Three levels describe independent functioning and three levels dependence on assistance (see **Table 4.3** below). Level 3 is the turning point, although dependent on intervention, the result is independent action.

The levels reflect the extent of underlying impairment from least at Level 1(identified function) to most at Level 5 (no function). Importantly, they do not

reflect the resulting activity limitation in the same way, because one person might be fully independent with an adaptation or assistive device and function equally well as another person on Level 2.

Table 4.3 Assessment scale

Level	Definition of functioning	Description of level for functional assessment	Description of level for job analysis
Level 1	No function (total assistance)	No performance is carried out without assistance.	Task can be successfully completed without this aspect of functioning
Level 2	Dependent function (with assistant)	Performance is dependent on another person for safety reasons or physical assistance for positioning and/or execution of some of the tasks.	Performance is only required to take up position and/or during occasional complexities that may occur but are not routinely part of task execution.
Level 3	Independent function (with assistive device or activity adaptation)	Performance is/can safely be carried out independently with adaptation to the activity or environment or with an assistive device.	Performance is only required in alternate method or position.
Level 4	Independent function (abnormal)	Performance is/can safely be carried out independently with abnormal pattern, and reduced speed and accuracy.	Normal movement pattern in terms of speed and accuracy is not required for successful and safe completion of task.
Level 5	Independent function (normal)	Normal performance, without modification, carried out safely within a reasonable amount of time.	Normal performance in terms of speed and accuracy is required for safe completion of task.

Step 4 – Determine reproducibility

The principles used to develop the questionnaire as well as the elements and items that make up the measurement tool are recognised and have been

tested in the health professions. They were taken into consideration to ensure reproducibility as far as can be done in the development of a new measurement tool. A pilot study was undertaken in the Bedford Hospital and several occupational therapists were consulted to improve the reproducibility.

One item was added after the consultations. The researcher, for her own purposes of determining the permanency of the activity limitation, also felt the need to add a question on the cause of the underlying impairment.

The final test of reproducibility would be the use of the measurement tool in the field.

Step 5 – Determine validity

The functional assessment as a field observation performed by a professional or trained community health worker has excellent internal validity according to the current literature. This aspect will be discussed in further detail under **4.4.3**.

The researcher would be assisted by the research assistants who would ensure that instructions are clearly understood and provide precise translations of the answers in the interview.

The researcher would execute all the assessments herself to ensure reliable data, and videotape a random sample of assessments for confirmation of her findings by an expert occupational therapist in the field of community-based rehabilitation.

Step 6 – Determine responsiveness

All persons, identified in the screening survey as persons with physical disabilities, were to be visited in their homes for the assessment, thereby ensuring maximum response.

The Phase II questionnaire Functional assessment - is attached as **Appendix III**.

4.4.3 Assessment kit for functional assessment

From the literature studied in **Chapter III** and based on personal professional experience it was decided to use a functional assessment format for the Phase II assessment to confirm activity limitations. The assessment would serve a dual purpose, namely the confirmation of activity limitations, thereby establishing whether the person could be classified as PWD or not, as well as establishing the functional capacity for the planned job matching.

The reasons for the choice were:

- A clinical observation of a person in a functional activity reveals true activity limitation better than deductions from tests of the various performance components.
- It is more difficult to be consistent in faking a disability during functional activity and inconsistent patterns can be observed. The method is therefore effective for discerning true problems in activity participation.
- The use of appropriate, known activities is important for the rural community context.
- Heavy and expensive or computer-based testing equipment is neither practical for transport nor available in the area.
- The test kit would have to be reproducible for community-based health workers in the poorest and most outlying rural communities in the future.
- An appropriate functional assessment can be carried out in any home situation or if necessary under a tree or in the clinic.

To devise an appropriate functional assessment for the situation the theory discussed in **Chapter III** was used as basis.

The assessment had to:

- Result in a full body functioning assessment,.

- Be appropriate for both genders,
- Be appropriate for the social and the cultural contexts,
- Be executed within a limited time,
- Contain nothing that could not be transported on foot over considerable distances.

Another important factor to consider was that the format would be tested for possible future use by community-based health workers and, therefore, had to contain the most important elements at an appropriate level of complexity.

The performance components selected to establish functional abilities for work were:

Sensorimotor -

- Upper limb functioning with focus on hand function,
- Dynamic postures,
- Lower limb functioning.

Cognitive -

- Perception.

The information from the functional assessment would be used to find possible job matches within the income generating programmes planned for Tsilitwa. Therefore the information had to yield a profile of the functional capacities of the PWD.

The key functional capacities included in the assessment were:

- Hand and foot use,
- Full body mobility,
- Walking

- Bending,
- Lifting,
- Carrying,
- Climbing.

The activities chosen to evaluate the above performance components and functional capacities and what could be deduced from them, are given in the following table.

Table 4.4 Functional assessment

Activity	Assessment observation purpose
1. Putting on of long-sleeved shirt and fastening buttons	Range of motion of both upper limbs, muscle tone, balance reactions in sitting, bilateral hand function (individual finger movements, grasps and co-ordination) unilateral hand function, spatial perceptual aspects, praxis
2. Bending (while sitting or standing – highest position that can be maintained) and lifting a brick	Trunk mobility, balance reactions, upper limb muscle strength
3. Standing up from seated position	Whole body mobility, balance reactions, lower limb muscle strength
4. Squatting (clients able to walk)	Balance reactions, lower limb muscle strength.
5. Walking over uneven (outside) surface or negotiating steps	Gait, balance reactions
6. Carrying brick	As 2 and 5
7. Peeling and eating a naartjie	Bilateral hand function, grasps, touch, perception, co-ordination, object handling, cognitive functioning

- Long-sleeved shirt
- Brick,
- Naartje,
- Carry bag.

The findings of the functional assessment would be recorded on the Phase II questionnaire.

4.4.4 Video recordings

Video recordings have the advantage that detailed analyses can be made of actions and procedures at a later stage or by a person not present at the time and place of recording.

Video recordings were therefore useful in this study for:

- Recording a random sample of the Phase II functional assessments for the purpose of consulting an expert to establish the validity of the assessment and the reliability of the assessor,
- Recording authentic income generating programmes in local communities for the purpose of a detailed job analysis, as part of data gathering process.[175]

4.4.5 Form to record community attitudes toward disability issues

The process to establish the Tsilitwa community's attitudes toward disability issues will be discussed in detail under the heading Procedures in sub-section **4.5.1.2, Visit 7-8**. In accordance with the participatory approach a joint decision was made to call for a representative meeting and that the attitudes would be elicited by small group discussions facilitated by trained community members.

Because of time constraints a semi structured group interview method would be used rather than a focus group method. The once-off large group of participants that were expected and the limited experience of the newly trained facilitators would make it difficult to uncover why participants felt the way they did and to investigate the process of how opinions were formed. All groups would take place at the same time in and around the school hall. For practical and financial reasons tape recordings of the various groups would not be possible. It was decided to keep a written record of opinions from the groups.

The questions that would be put to the groups were discussed and formulated with input from all team members to ensure that everybody in the meeting would understand them.

The researcher then constructed a form, for use by the facilitators, to record the attitudes expressed in the small group discussions (See **Appendix V**).

4.5 Procedures

The procedures carried out in this study will be described according to the four phases of the participatory action research model discussed in sub-section **4.3.2.1**. Phases 1 and 2 are discussed under the heading Data collection (sub-section **4.5.1**) and Phase 3 under Data analysis (sub-section **4.5.2**). Phase 4 will be described under its own heading in sub-section **4.5.3**, as this is an aspect not customarily described in scientific or academic reports.

A diagrammatic presentation of the procedures is presented in **Figure 4.3**.

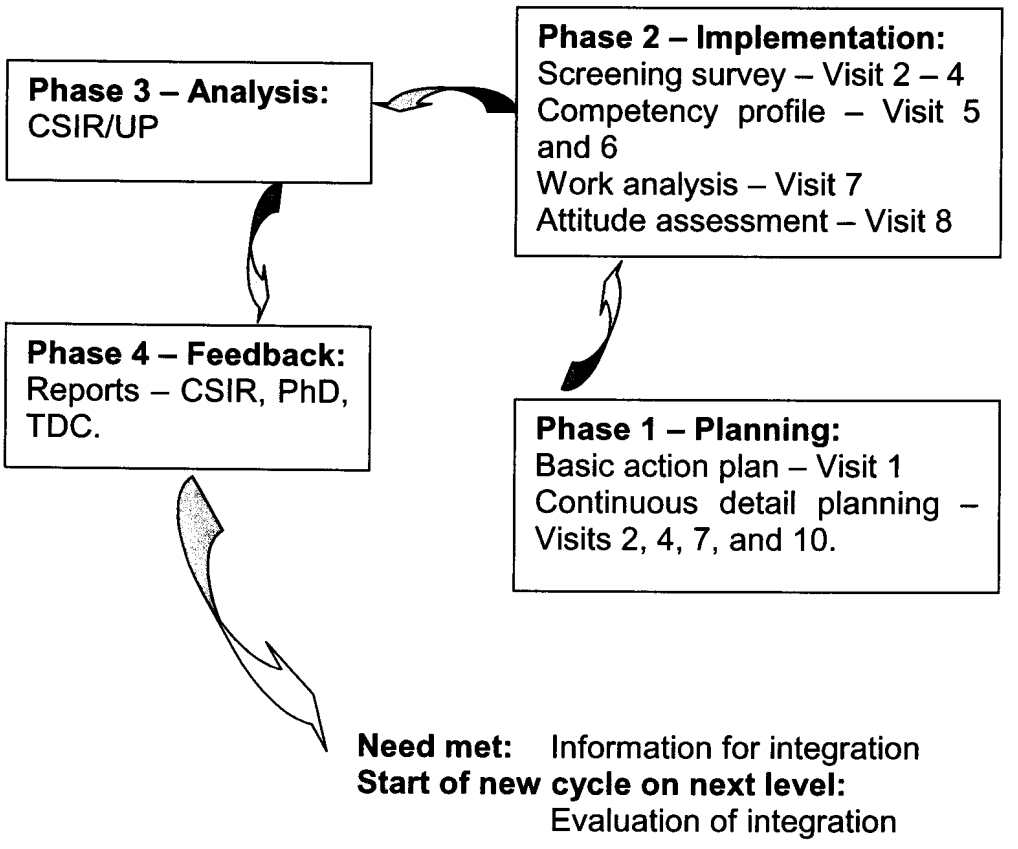


Figure 4.3 Diagram of implementation

4.5.1 Data collection

4.5.1.1 Phase 1: Planning

The request for this investigation was made to other members of the CSIR development team and not to the researcher herself. The first visit to the community was thus used to establish contact, meet the TDC and gather first-hand information on their attitude and commitment to this sub-project of their development programme.

Visit 1

The first day was spent collecting basic information about the village and establishing the precise need of the community that prompted the request for the study.

On day two the researcher met with the representatives of the TDC who would be involved in the sub-project on disability for the purpose of planning the course of action. The following agenda points were addressed:

- Communication channels – direct and regular contact with Mr Jikijela, chairperson of the TDC and Sister Madikane, the clinic sister who would be involved in the implementation of the study.

- Involvement of TDC and community members – committee members were welcome to give inputs at all time to guide the sub-project and ensure that the community's needs were met; three research assistants would be identified by the community to be trained by the researcher and would also act as interpreters; every household in the community would be visited in the survey and would thus be involved in the study.

- Basic plan of action and timeframe – the plan of action and timeframe agreed upon are summarised **Table 4.5**.

- Responsibilities of various participants – the researcher would be responsible for the execution of the plans; Mrs Madikane would represent the sub-project at the TDC and would be available to the researcher for practical implementation issues; Mr Jikijela would act as consultant and be actively involved in the decision making process throughout.

- Desired outcome – a report to the TDC with guidelines on the integration of the PWD in the Tsilitwa development process.

The planning phase in reality does not end after the initial agreement on the scope and the general course of action that has been decided on. Because of the dynamic nature of the process new developments within the community need to be incorporated throughout.

The continuation of the planning process is described as part of the implementation.

Table 4.5 Action plan

Visit/Date	Action	Persons involved
Visit 1 **February 2000**	■ Establish contact, set up participatory team ■ Gather background information ■ Planning	■ TDC ■ Researcher
Visit 2 **March 2000**	■ Train research assistants ■ Plan screening survey	■ Mrs Madikane ■ Research assistants ■ Researcher
Tsilitwa **April 2000**	■ Undertake screening survey	■ Mrs Madikane ■ Research assistants
Visit 3 **May 2000**	■ Establish reliability of screening survey	■ Research assistants ■ Researcher
Visit 4 **June 2000**	■ Hand in screening questionnaires ■ Plan assessment of activity limitation	■ Mrs Madikane ■ Research assistants ■ Researcher
Visit 5 and 6 **July 2000**	■ Undertake assessment of activity limitation	■ Research assistants ■ Researcher
Visit 7 **August 2000**	■ Plan attitude assessment	■ Mr Jikijela ■ Mrs Madikane ■ Researcher
Visit 8 **September 2000**	■ Visits of Umtata rehabilitation team members	■ TDC ■ Community ■ Researcher
CSIR/UP **October 2000**	■ Data analyses	■ Statistician ■ Researcher
Visit 9 **October 2000**	■ Attitude assessment	■ TDC ■ Researcher
Visit 10 **November 2000**	■ Final report to TDC ■ Way forward	■ TDC ■ Researcher

4.5.1.2 Phase 2: Implementation

The implementation followed the action plan, with an additional visit planned during April because of concern whether the assistants were implementing the survey methodology correctly. The visit could not be carried out because of poor road conditions and was compensated for by faxing some of the completed questionnaires and telephonic communication.

The implementation will be described per visit, starting with Visit 2 after the planning phase through to Visit 8 (see **Figure 4.3**). Each visit is divided into two sections, the preparation work done for the visit and the visit itself.

Visit 2

Preparation

- Development of questionnaire: The development of the questionnaire was described under Research materials (sub-section **4.4.1**). The final product was discussed with the data processor to check the format.

- Development of a training programme and handout for research assistant training workshop: - The training programme for the research assistants included the purpose of the sub-project; the objective of the survey, an explanation of the survey methodology and basic interview skills, including how to introduce themselves and explain the purpose of the survey to heads of households In addition, definitions of the concepts of disability and normal functioning, an explanation and examples for each of the questions on the questionnaire and how to score possible responses to them was covered. The handout prepared for the workshop was based on personal experience in grassroots training and basic principles for such training described in the literature.[197,198] It was kept uncluttered, in understandable language, with illustrations and had room for the trainees to write down examples to enhance retention and to refer to, in case of uncertainty, when the trainer was not present (See **Appendix II**).

Visit

■ Training: Two of the three research assistants were trained (See **Appendix II** for programme). The third trainee was unfortunately not available on the day. The two trainees met the criteria decided on during the planning visit, namely: basic English, education to senior certificate level and in dire need of an income. The training programme was completed and comprehension was checked throughout with questions and answer sessions. Mrs Madikane attended the training so that she could later train the third research assistant.

■ Questionnaire: The content of the questionnaire and the cover letter, explaining the purpose of the survey, was discussed with Mrs Madikane and she agreed to translate the cover letter in Xhosa for the final version of the questionnaire.

■ Planning: The discussion on details of the implementation led to the following decisions and actions: Mrs Madikane would train the third research assistant; each assistant would do three interviews for practice and as a pilot run for the questionnaire; Mrs Madikane would supervise the process and fax the pilot questionnaires through; she would also send through comments from the assistants and herself on the content and the format of the questionnaire; payment for the work was agreed upon; each assistant was given a code number; the village was divided into three zones, namely Tsilitwa, Mtondela and Tembeni and given code numbers (see **Table 4.6**); each assistant would visit one third of the village households, they would divide Tsilitwa, the biggest area, accordingly among themselves.

Table 4.6 Research assistant codes

Research assistant code		**Zone code**	
Bukeka Libala	5	Tembeni	05
Esther Rorwana Jikijela	6	Tsilitwa	06
Victoria Nkwindama	7	Mtondela	07

The researcher was concerned about not having met and trained the third research assistant and decided on the said additional visit to ensure the reliability of the data collection.

Visit 3

Preparation

The pilot run of the questionnaire was done in Tsilitwa and also in the Lubisi area. With input from Mrs Madikane and the various research assistants necessary adjustments were made. The Xhosa translation of the cover letter was checked by a lecturer in African languages at the University of Pretoria, attached to the questionnaires and sent through to Tsilitwa for implementation.

Visit

- Screening survey: A workshop follow-up session was used to check on the progress made in the survey and to discuss uncertainties and difficulties in scoring. The survey was progressing well. The third assistant's English was poor and the indirect communication, through translations, was less satisfactory and slowed the session down. The assistants reported full compliance from the households visited and a keen interest in what the outcome of the survey would mean to them. The assistants' answers on these questions were checked and found to be according to the agreement with the TDC and their training. However, it was clear that the community needed to be informed of the purpose of the survey to prevent misconceptions.

- Awareness: A graduation ceremony at the Stophile Makhenkesi Technical High School in the village afforded the researcher an opportunity to explain the purpose of the survey to the gathering when she was asked to give a motivational speech to the graduates.

- Planning: The attitude assessment of the community was discussed and Mrs Madikane was asked to put it on the agenda of the TDC meeting for their input.

- Network: A visit was paid to local rehabilitation services in Umtata (Occupational Therapy, Physiotherapy, Speech Therapy) to establish contact and learn about the services offered and the referral procedures. The purpose of these visits was to establish a support network for Tsilitwa in terms of rehabilitation services, an important factor for the sustainability implementation of the recommendations to the community.[114]

Visit 4

Preparation

In consultation with the statistician a random selection of 15 completed questionnaires was made that would be checked by the researcher to establish the reliability of the data collection. At an average of 20 minutes needed per questionnaire, as reported by the assistants, it was estimated to be a practical quantity for one day's work.

Visit

- Reliability check: Of the 15 selected households 10 were checked by the researcher. At three households nobody was home and the process took longer than anticipated so that the last two could not be checked before the researcher had to leave. A 90% consistency was found, eliminating satisfactorily the possibility of including false negatives in the sample group. At a community function the research assistants were thanked for their work and received their payment.

- Awareness: The opportunity was once again used to explain the purpose of the survey to the gathering.

- Planning: Details for the activity limitation assessment were discussed with Mrs Madikane and Mr Jikijela. It was decided that all persons with physical impairments would be visited in their homes for a detailed

assessment of activity limitations to identify the number of PWD in Tsilitwa, the prevalence of various types of disability and a competency profile of the PWD. The assessment would include a needs survey. The home visits would afford the researcher an opportunity to establish the social and environmental barriers that each of the PWD face. The research assistant who visited the household during the screening survey would accompany the researcher and either Bukeka Libala or Esther Jikijela would act as translator in the households covered by Victoria Nkwindama. An in-depth discussion on the aim and outcome of the study followed with Mr Jikijela.

Visit 5

Preparation

■ Data analysis: The data processing department of the University of Pretoria determined the households in which persons with physical impairments were recorded.

■ Development of questionnaire: The development of the assessment questionnaire is described under Research materials (sub-section **4.4.2**). Professionals in the field of community-based rehabilitation were consulted to ensure that the data collected would be appropriate. The final product was then discussed with the data processor to check the format.

■ Kit: The functional assessment kit described in sub-section **4.4.3** was acquired in Umtata.

■ Pilot run of questionnaire: The questionnaire was tested on a group of patients in the Bedford Hospital in Umtata and an adjustment was made.

Visit

■ Assessment of activity limitations: The assessment kit (see **4.4.3**) was used to establish activity limitations and assess the ability to use performance components needed to execute activities. The findings of the functional assessment were recorded on the Phase II questionnaire (see **4.4.2**) and the additional information for the questionnaire was gathered in

an interview with the PWD and caregiver where applicable. An average of six households was visited each day. A recurring problem was households with nobody at home or the person with the reported problem being absent. The researcher was left with the conviction that the functional assessment was effective in eliminating false positives from the self-reporting screening questionnaire.

- Planning: A suitable time for the completion of the assessment was arranged and the committee's opinions on suitable income generating projects were discussed. The final list was: bread baking, gardening, sewing, poultry, with a special request for leatherwork and shoe repairs from Mrs Madikane, because of the interests of one of the identified PWD.

- Network: The researcher met with the head matron of Sulenkama Hospital under which Tsilitwa clinic is zoned and which is the district hospital through which referrals to the Umtata hospitals have to take place. The purpose of the visit was to inform the matron of the endeavors in integrating PWD into work projects and to draw together the strings of the support network.

- Job analysis: Two income generating projects were visited in the Umtata area with the purpose of investigating appropriate projects to develop in Tsilitwa and acquiring permission for video recording of the projects for the job analyses. The types of work provided in the projects were: sewing, beadwork, bread baking, poultry and communal gardening.

Visit 6

Preparation

Files were compiled for the three research assistants containing official letters about the training they had received, work they had done and photos of them at work.

Visit

■ Assessment of activity limitations: After the still recurring problems of absence hampered progress on the first day, it was decided to ask persons with reported impairments who had been visited at their homes three times without success to report to the clinic for assessment there. The argument was that persons roaming around don't have serious mobility problems and their home environment probably does not present them with any barriers. By the end of the visit all persons, with reported physical impairments in Tsilitwa at the time, had been assessed and it was decided to end the assessment.

■ Planning: The results of the screening survey were reported back to the representatives of the TDC. Because analysis showed a high number of hearing impairments, it was decided to approach the speech and hearing therapists at Umtata General Hospital for a day's screening in the village. Similarly Mrs Madikane and the researcher believed that some of the identified PWD would benefit from home visits by the occupational therapists at Bedford Hospital. It was decided that the visits should take place during the researcher's next visit so that she could provide the necessary transport and make the introductions. Mr Jikijela and Mrs Madikane felt strongly that the whole community should be invited to a meeting to establish their attitudes toward disability issues because the TDC wanted to be transparent and allow all inhabitants to participate in the process of their development. It was decided that details would be planned at a meeting during the next visit.

■ Network: The researcher suggested the above-mentioned visits and made the arrangements in order to introduce the various professionals within the network to each other and to create awareness of the available services among the clinic staff and in the community.

Visit 7

Planning

The data was analysed by the data processor. In consultation with the statistician a random selection of three identified PWD and three persons with no activity limitations from their impairment was made. It was decided that six home visits would be feasible, because of the average number of visits achieved in the assessment. Video recordings were to be made of these six persons for the purpose of consulting an expert in community-based rehabilitation to check the reliability of the researcher's findings.

Visit

- Assessment of activity limitations: The three PWD were video taped but only one of the three non-disabled persons was home. According to memory, the closest-living person previously assessed was then used as a substitute for the randomly selected person.

- Network: The visit of the occupational therapist and the occupational therapy assistant from Bedford Hospital in Umtata established a renewed commitment to community work because of the successful home visits. The contact with the clinic staff was effective in creating an awareness among them of the services available and the role of rehabilitation in general. There was an overwhelming turnout for the hearing clinic and all reported the contact between the two community speech therapists and the clinic staff to have been a success.

- Planning: A prolonged meeting took place between the researcher, Mr Jikijela and Mrs Madikane. The purpose was to plan the assessment of the community's attitude toward disability issues. As the study was nearing its completion, however, the concerns of the TDC representatives enjoyed priority. Although both representatives agreed that it was understood that the research aim was to supply guidelines for integrating the PWD in Tsilitwa into the projects that the TDC was to develop, they felt that the researcher should find funding to initiate such projects. As the rest of the

CSIR team, because of funding problems, was still waiting to become involved they felt that the community would blame them if the recommendations could not be implemented soon. After lengthy negotiations it was decided to continue with the sub-project with the compromise that the researcher would present a workshop to the TDC on writing proposals for development funding. The final planning concerning the format of the attitude assessment was done. It was decided that a plenary session should set the objectives for the day and clarify the concepts, followed by small group discussions and ending in a feedback session; in the afternoon the PWD of Tsilitwa and their families would be invited to obtain their views on the subject and to clarify the outcome of the sub-project; Mr Jikijela would meet with the sub-headmen of the various zones, explain the purpose of the meeting and ask them to identify suitable representatives from their zones to attend the meeting; Mr Jikijela would organise a youth component from the school to represent the next generation; a maximum of 100 participants could be accommodated; Mr Jikijela would ask four teachers to assist the clinic staff and the research assistants in facilitating discussions in the small groups, bringing the total number of facilitators to 10 and allowing for 10 community members per group; the workshop on the writing of proposals as well as a workshop to train the facilitators for the small group discussions would take place a day before the community meeting; the questions to initiate the discussions in the small groups were discussed and Mr Jikijela agreed to finalise the wording to ensure that they would be well understood.

■ Job analysis: The two income generating projects were visited and video recordings were made of beadwork, machine sewing, bread baking and gardening for the job analyses. No leatherwork projects could be found.

Visit 8

Visit 8 was not spent collecting data for the study as such, but was the culmination of various meetings during previous visits with the rehabilitation team members stationed at Umtata hospitals. These meetings were used for

the investigation of the local resources in terms of vocational rehabilitation and possible adaptations that might be needed for successful work placement.

In preparation for the implementation of the recommendations following the study it was necessary to introduce the community to the services available and to establish direct contact with them.

During visit 8 the researcher brought the speech and hearing therapists from Umtata General Hospital on one day and the occupational therapists from Bedford Hospital on the following day to meet the clinic staff and explain their services and the referral lines that would bring them in contact with the clients from the area.

On both days the professionals provided services in the community for clients arranged by Mrs Madikane. The speech and hearing therapists did hearing tests and home visits were done by the occupational therapists to the homes of PWD.

Visit 9

Preparation

The content for the various workshops was researched and compiled. Handouts for the participants of the workshops were prepared as well as a resource file for the community with information on various types of funding agencies and their funding application protocols.

Visit

- Attitude survey: Nine facilitators were trained instead of 10, it was decided that the research assistant with the language problem might have difficulties during the training and she was asked just to attend the meeting (see **Appendix V** for programme). Because of unavoidable delays, the meeting started late and many people had left already. The youth component did not materialise, possibly because of the school holidays. Four of the PWD, who were to attend the meeting arranged for PWD and their families that was to follow the attitude survey, had already arrived and

joined the meeting. In total there were 39 participants. After the introduction, in which a common understanding of the term physical disability was achieved and the objectives for the small group discussions were set, the participants were divided into four groups. One facilitator was assigned per group and each facilitator was given one trained facilitator as a scribe. This solved the possible problem of accurately recording the attitudes expressed in the meeting whilst facilitating the discussion at the same time. The ninth facilitator joined the researcher in making rounds and assisting the discussion in the groups. Lively discussions took place in all four groups, results were recorded (see **Appendix V** for forms) and reported back to the meeting. It was decided to combine the agendas for the two planned meetings of the morning (see **Appendix VI** for agenda of PWD and families' meeting). In the general discussion the PWD were given opportunities to express their individual views. From the discussion on the way forward the following decision was reached: two TDC members would call a meeting of all PWD in Tsilitwa with the purpose of establishing a committee that would address disability issues. A representative of this PWD committee would join the TDC. The PWD committee would include non-disabled persons from the community.

■ Job analysis: As no leatherwork/shoe repair project could be found in the area, the researcher videotaped the occupational therapy assistant at Bedford Hospital, himself a paraplegic, during leatherwork and shoe repair activities for the purpose of a job analysis.

■ Fundraising workshop: The workshop on how to approach fundraising and write funding proposals was attended by 12 persons involved in development projects in Tsilitwa (see **Appendix VII** for programme).

■ Planning: In an in-depth discussion on the process and the results of the sub-project with Ms Madikane it became clear that the TDC, in spite of their request for integration of the PWD in the village and all the awareness drives about the rights of PWD, still considered a separate workshop for PWD. In planning the following visit it was thus agreed that the format of the feedback to the TDC would include various scenarios for

implementation. Once again the researcher was asked to provide the necessary assistance to obtain funding for the implementation. A provisional date for the last visit was set.

4.5.2 Phase 3: Data analysis

■ Statistical analysis: The respective departments of the University of Pretoria did the data capturing and analysis. The SAS statistical package was used to identify persons with physical impairments from the screening survey for the assessment of activity limitations. All persons who had scored a 2 (see **Table 4. 3**) were included in Phase II of the survey. The same programme was used to establish frequencies from the data obtained in the functional assessment. The intention of the statistical data analysis was to obtain descriptive statistics in terms of frequencies, e.g. number PWD identified, percentage population PWD with physical impairments in Tsilitwa, number of lower limb functional problems, and averages of the degree of limitations. Some of these data were useful to describe the findings. However, because of the small number of PWD identified by the process it was decided in consultation with the statistician to use a single case study methodology to process and present the results.

■ Competency profiles: The scale developed for the assessment of the PWD identified in Phase I of the survey was used to draw up a competency profile for each of PWD identified in Phase II of the survey as having a physical disability (see **Table 4. 3**).

A recording design was developed for future use by community based health workers. In the design the relevant aspects of a human figure are represented on a chart to ensure that all aspects were considered in drawing up the profile. See example below.

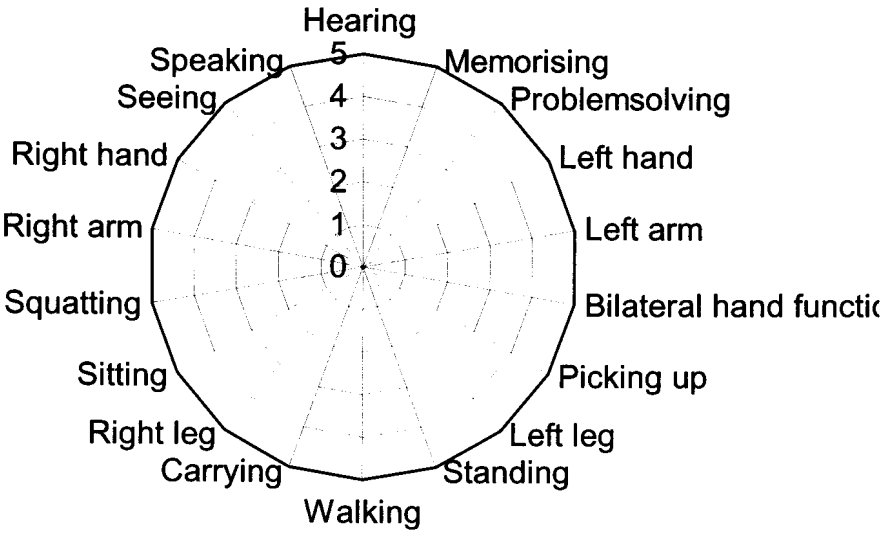


Figure 4.4 Example of profile

The design was used to provide graphic illustrations of the case studies.

■ Job analyses: The five types of income generating projects, requested by the community, bread baking, gardening, sewing, poultry and shoe repairs (see under Data collection **4.5.1.2 Visits 5** and **9**), were analysed from the video recordings to identify the following:

- Key tasks of the activity,
- Groups of tasks that would have to be carried out to make a meaningful contribution to the project,
- Requirements in terms of the aspects assessed for the competency profile to perform the tasks.

The assessment scale described in **4.4.2** was then used to quantify the requirements for successful completion of the tasks (see **Table 4.3**).

A matching design was used to record the data. The data of the functional analysis and the job requirements were then plotted on one web, the work ability web (WAW) to illustrate compatibility. The additional information from the Phase II questionnaire on aspirations and level of motivation as well as the WAW were used to arrive at a conclusion whether a job match could be made. The charts were used to illustrate the job analyses in the chapters on results and the job match.

■ Job match: The occupational therapy process of making the job match has not been analysed. It is described as a result of clinical reasoning with more emphasis on the models used to organise the information than on the process used to make the match.[148] The researcher presented the data to two experts in the field of vocational rehabilitation to make job matches. The process was then analysed and the following steps identified:

1. Investigate:

- Level of motivation – e.g. awareness of norms, ability to comply with norms, level of supervision if needed,
- Aspirations and work skills – e.g. interests expressed or already acted upon, previous work skills and experience, availability for training,
- Abilities – e.g. performance components, availability of adaptations, possibilities for reasonable access,
- Employment alternatives.

2. Select closest match according to aspirations and physical abilities to perform work tasks.

■ Needs and attitude analyses: the qualitative data from the investigations in terms of the needs and aspirations of the PWD as well as the attitude survey of the caregivers and the community was categorised, themes identified and quantified where possible.

The process used for this analysis followed Schön's reasoning that reflection in action can clarify tacit understandings that develop from repetitive experiences of a specialised practice. Reflection in action therefore can construct new theory from established practice.[199]

4.5.3 Phase 4: Feedback

A formal feedback meeting was scheduled for the last visit. A report on the completed research was handed over to representatives of the TCD at a meeting that included community members and PWD from the area.

Visit 10

Preparation

- Report: A report containing relevant statistics from the statistical data analysis and three scenarios that the community could use in their deliberations on the use of the data. The three scenarios were full integration of PWD into the new projects, home industries for PWD or a separate workshop for PWD. Full job analyses were not yet available and were therefore not included in the report.

- Funding proposal: Information on format, content and contact persons was collected to assist Mrs Madikane with a proposal to the Mbeki Development Trust for the implementation creating work opportunities for the PWD of the area.

- Tsilitwa Committee of PWD: Mrs Madikane had called a meeting with the TDC, headmen of the community and PWD of the area and established a committee of three members that would look after the interests of the PWD in the area and be represented at development meetings.

Visit

- Feedback to the TDC and the community: Mr Jikijela, TDC chairperson, had to officiate at a function at a neighboring school, but the rest of the

committee, several community members, the newly formed Tsilitwa Committee of PWD and the research team were present at the meeting. The report was presented with advantages and disadvantages for the three scenarios. The researcher used the opportunity to educate the audience on current policies and national and international trends on disability issues.

- Closure meeting with research team: A final discussion of the feasibility of implementing the three scenarios took place with Mrs Madikane and the research assistants in which it appeared that the TDC would favor the establishment of a separate workshop for PWD.

- Planning: The researcher agreed to assist the TDC with their application for funds and made the necessary arrangements for this with Mrs Madikane. It was agreed that both the TDC and the researcher would keep in contact on future developments concerning the study.

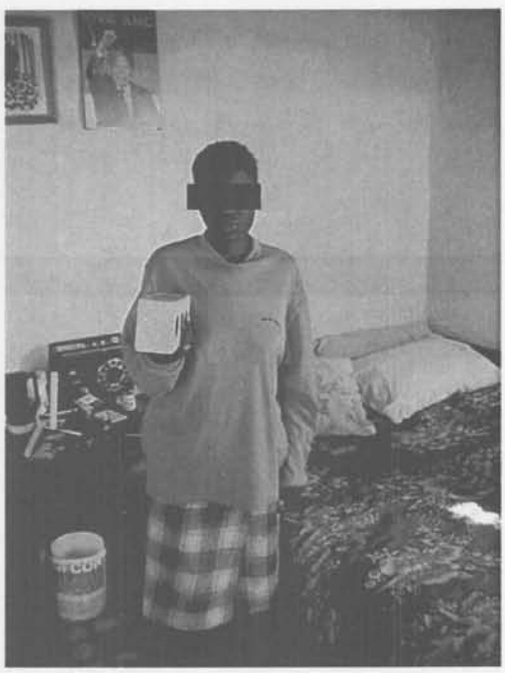
---- ----

The four phases of the MBR model described in **4.3.2.1** were applied. The final analyses will be reported back to the community on completion of the thesis.

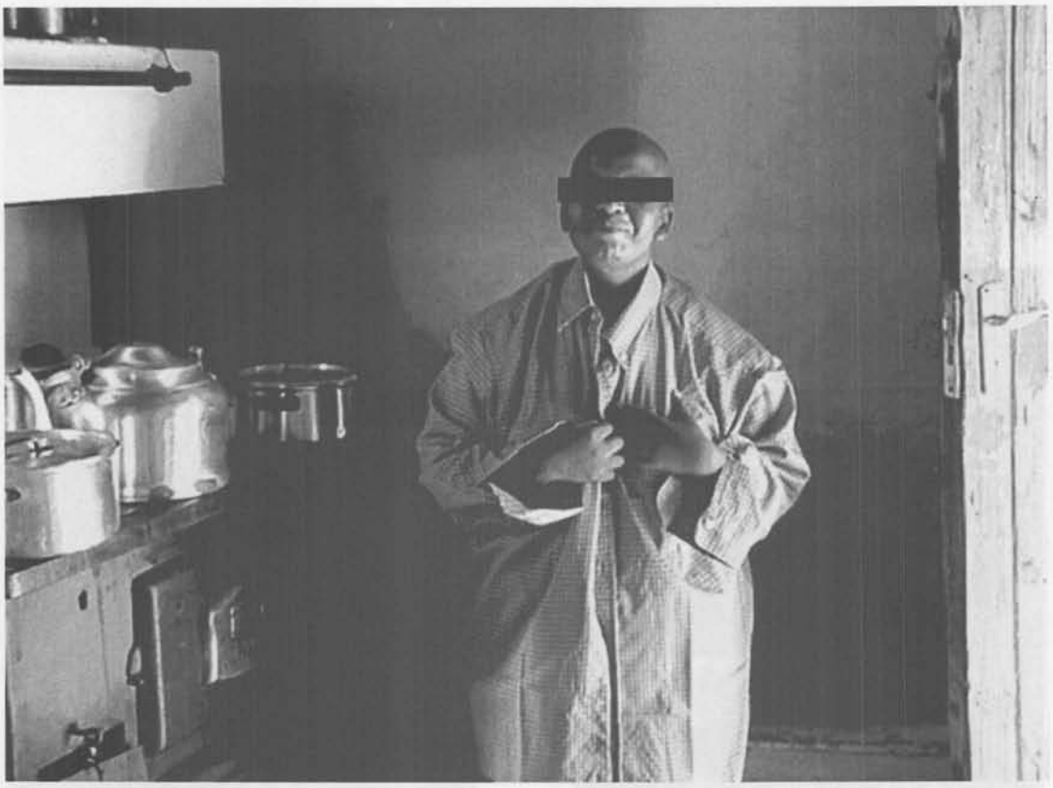
The ownership created by the participation was felt throughout and contributed to the completion of the fieldwork. The results described in the next chapter are the result of this collaboration and provide new information that could guide professionals and communities to development that will benefit all.

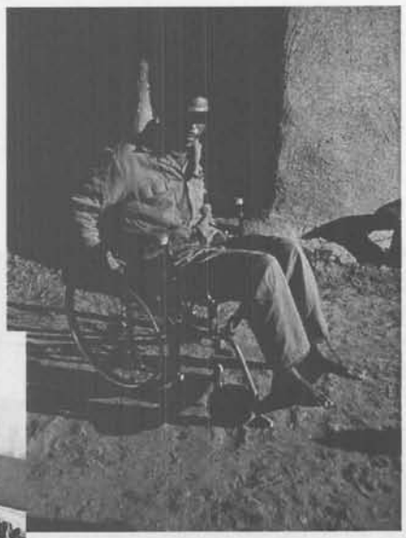
Representatives of the Tsilitwa Community development committee with research assistants after training

Phase I of disability survey

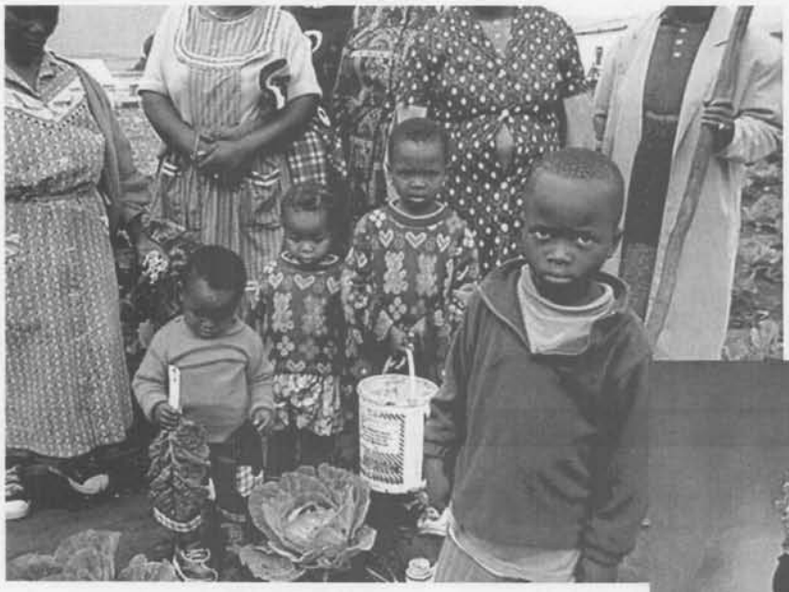


Phase II Functional assessment



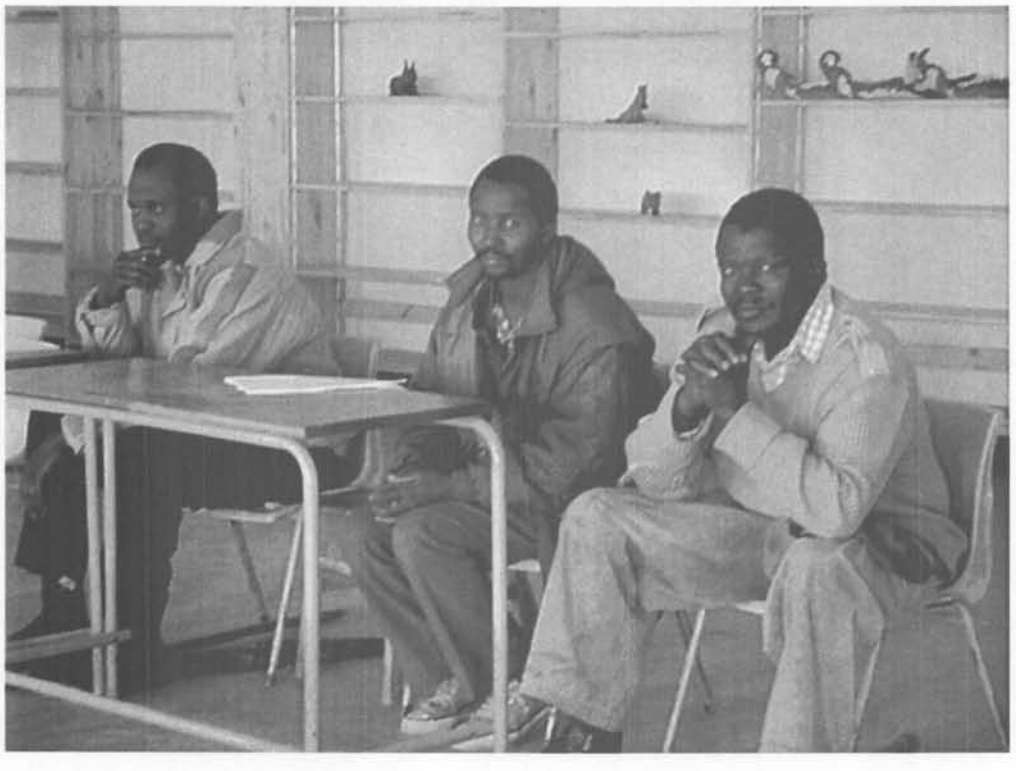


Community meeting for attitude survey



Community projects
In the Umtata region

The road leading into Tsilitwa



The Tsilitwa Committee of Persons with Disabilities