THE FEASIBILITY OF IMPLEMENTING COMMUNITY BASED CARE FOR MODERATELY MENTALLY-RETARDED PERSONS IN A SPECIFIC CENTRE IN PORT ELIZABETH

By

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I declare that: *The Feasibility of Implementing Community based Care for Moderately Mentally Retarded Persons in a specific centre in Port Elizabeth,* is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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SUMMARY

The purpose of this study was to investigate the possibility of implementing community based care for moderately mentally retarded persons in a specific centre in the Port Elizabeth area.

The objectives of the study were to identify

- the needs of the moderately mentally retarded children.
- the physical, psychosocial and vocational rehabilitation means of meeting these needs.
- how involved the communities, parents and government were in the care of moderately mentally retarded children.

A quantitative, exploratory and descriptive design was used.
A sample of 50 moderately mentally retarded children was utilised.
Data were collected by means of questionnaires and semi-structured interviews.

The major research findings indicate that community care for MMRPs could only be feasible with sufficient resources, expertise and community involvement. All these aspects appeared to be lacking in the centre where this research was conducted raising questions as to benefits which the mentally retarded children and their parents and the community could derive from these services. However recommendations were made on identified shortcomings, problems and needs.

KEYWORDS:

care of mentally retarded persons

community based mental health care

mental health

mental retardation

moderately mentally retarded persons

reconstruction and development programme

LIST OF ABBREVIATIONS USED IN THIS DISSERTATION:

ANC - African National Congress
APA - American Psychiatric Association
DSM - Diagnostic and Statistical Manual of Mental Disorder
EDO - Education Development Officer
HOD - Head of Department
IQ - Intelligence Quotient
MMR - Moderate Mental Retardation
MMRP Moderately Mentally Retarded Person
MR - Mental Retardation
MRP - Mentally Retarded Person
NHS - National Health System
PE - Port Elizabeth
PHC - Primary Health Care
RDP - Reconstruction and Development Programme
RSA - Republic of South Africa
UK - United Kingdom
USA - United States of America
WHO - World Health Organisation

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CHAPTER 1

OVERVIEW OF RESEARCH STUDY

1.1 INTRODUCTION

"Moderate mental retardation" refers to that category of persons who acquired communication skills during early childhood years, and gain from being trained in social and occupational skills, but are unlikely to progress beyond the second grade level in academic subjects. These people benefit from vocational training and, with supervision can attend to their personal care, American Psychiatric Association (APA) 1994:41.

According to the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders' (APA 1994:40) classification, four degrees of severity are specified, which reflect the level of intellectual impairment: mild, moderate, severe and profound.

Bower (1999:324) in his research study of the chromosome ends in 284 children with moderate to severe mental retardation; found that these youngsters had Intelligence Quotient (IQ) scores lower than 50. (Intelligence Quotient can be defined as "a score which can be derived for each child, and which makes it possible to compare the

intellectual ability of children of the same and different ages". The formula for calculating the IQ is referred to the
ratio between mental age (MA) and chronological age (CA) multiplied by 100 (Louw, Edwards, Forster, Gilbert, Louw, Norton, Plug, Shuttleworth-Jordan & Spangenberg 1997:335).

The total number of mentally retarded children at the centre where the research study was undertaken amounted to 240, with a waiting list of 699 (See Annexure B).

The research attempted to study the needs of these children, as well as the availability of resources and facilities to meet these needs in the specific centre in the Port Elizabeth area. This research endeavoured to make these needs known to the school, local, district and provincial authorities, as well as to the Department of Health and the Department of Education.

The feasibility of implementing community-based care for moderately mentally retarded persons in the Port Elizabeth area was explored. If such community-based care could be provided to increased numbers of moderately mentally retarded persons who could not be admitted to care centres, the quality of these persons' lives would be considerably enhanced, as well as those of their families.

Possible enhanced community involvement in the care of moderately mentally retarded persons was also investigated

1.2 LIST OF ABBREVIATIONS USED IN THIS DISSERTATION

ANC	-	African National Congress
APA	-	American Psychiatric Asociation
DSM	-	Diagnostic and Statistical Manual of mental disorders
EDO	-	Education Development Officer
HOD	-	Head of Department
IQ	-	Intelligence Quotient
MMR	-	Moderate Mental Retardation
MMRP	-	Moderately Mentally Retarded Person
MR	-	Mental Retardation
MRP	-	Mentally Retarded Person
NHS	-	National Health System
PE	-	Port Elizabeth
PHC	-	Primary Health Care

RDP	-	Reconstruction and Development Programme
RSA	-	Republic of South Africa
UK	-	United Kingdom
USA	-	United States of America
WHO	-	World Health Organisation

1.3 PROBLEM STATEMENT

The research study was prompted by a growing concern about the high number of moderately mentally retarded persons at the identified centre in the Port Elizabeth area, as well as the long waiting list for enrolment.

The unique contribution of nursing to rendering effective care to such persons should be clarified. Nurses should collaborate with other health-care professionals including psychiatrists, psychologists, occupational therapists, physiotherapists, speech therapists and social workers, as well as maintaining close links with day-care centres, hospitals and general practitioners. (Taylor 1995:461).

There is a growing need for different professionals to be enlightened about mental retardation, so as to improve their understanding of the diverse needs of mentally retarded persons (Tierney 1983:142).

It is essential to develop comprehensive networks of resources and facilities within neighbourhoods to meet the range of needs presented by people with mental retardation (Sines 1990:28).

According to Taylor (1995:461):"The moves towards community care may place a greater responsibility on the local authority to provide

services, however there will be a continuing necessity for a multi-disciplinary approach in the assessment and management of clinical problems among this group of people who have extremely complex biological, psychological and social needs,"

The multi-disciplinary team approach is a necessity in the process of providing quality care to moderately mentally retarded persons. However, questions arise, including whether such a team can indeed provide effective care, what the availability of the team is, and how best the necessary care can be provided.

There seems to be some confusion as to where mental retardation belongs. One may find a number of mentally retarded persons being kept in psychiatric hospitals (Department of Health) and others attending special day schools (Department of Education). Thus the question may be raised whether mentally retarded persons fall under

the jurisdiction of the Department of Health or that of the Department of Education in the Republic of South Africa (RSA).

1.4 RESEARCH QUESTIONS

Parents, though not members of the team, are expected to care for their mentally retarded children in the community and in their homes. Research needs to determine whether these parents:

- can cope;
- possess the required skills to perform these tasks;
- receive financial support;
- involve other community members in rendering care to their children.

The proper management of mental retardation requires a carefully planned system of interlocking services. To implement such a system, an accurate assessment of needs is essential (Grover & Cooke 1987:85). This research attempted to determine whether there were enough resources such as material, manpower and finances, to care for moderately mentally retarded persons at this centre.

Problems presented by mental retardation should be handled by a team of professionals working in close co-operation (Joubert 1987:17). This study investigated the availability of multi-disciplinary team members in the centre being studied, and also investigated how best they could provide the necessary quality care needed by the children.

For many years the focus has been mainly on the retarded persons themselves, analysing and treating their problems through medical, educational and vocational facilities, and establishing different forms of institutional care.

Globally, greater emphasis is being placed on mentally retarded persons in their family systems, communities and social environments (Joubert 1987:17).

This investigation attempted to determine whether moderately mentally retarded children were hospitalised in psychiatric hospitals in the Port Elizabeth area, and to establish the reasons for such hospitalisation should this be the case.

1.5 PURPOSE/AIMS OF THE STUDY

The aim of the study were to investigate:

1.5.1 The possibility of retaining the mentally retarded persons in their communities, under the care of their parents.

1.5.2 The availability of resources to meet the needs of mentally retarded persons in the Port Elizabeth area, including

1.5.2.1 manpower (staff and multi-disciplinary team)

1.5.2.2 material - training equipment and transport facilities

1.5.2.3. finances e.g. school / hospital budget, parent support

1.5.2 Whether moderately mentally retarded children were indeed hospitalised in the Port Elizabeth area.

1.5.4 Reasons for hospitalisations

1.5.5. Ways of making the authorities aware

1.5.6 Findings / problems and needs of the mentally retarded in this area.

1.5.6. Ways to involve the Port Elizabeth community in the care of moderately mentally retarded children.

1.6 RESEARCH OBJECTIVES

To identify

1.6.1 the needs of the mentally retarded children

1.6.2 physical, psychosocial and vocational rehabilitation means of meeting the needs of these children in the Port Elizabeth area

1.6.3 how involved the communities/parents were in rendering care to these children

1.6.4 the reasons for the long admission waiting list at the centre

1.7 DEFINITION OF KEY CONCEPTS

1.7.1 The Diagnostic and Statistical Manual of Mental Disorders

The Diagnostic and Statistical Manual of Mental Disorders refers to the fourth edition of the manual that specifies and addresses criteria that guide the clinician in formulating a diagnosis. It uses a descriptive approach in classifying psychological, behavioural and physical phenomena. It is a multi-axial format that observes the many variables that impinge on each designated condition (APA 1994:1).

1.7.2 Mental Retardation (MR)

Mental retardation is described as " a significantly sub-average general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two (2) of the following skill-areas: communication, self-care, home-living social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety. The onset must occur before the age of 18 years" (APA 1994: 39).

The WHO defined mental retardation as "an incomplete or insufficient development of mental capacities" (Brett 1997:407).

1.7.3 Classification of mental retardation

Severity of mental retardation	**Intelligence Quotient**
Mild	50-55 to approximately 70
Moderate	35-40 to 50-55
Severe	20-25 to 35-40
Profound	below 20 or 25

(APA 1994: 40).

1.7.4 Mentally Retarded Persons (MRPs)

This concept refers to persons whose functioning is as described in section 1.7.2 (APA 1994:39).

1.7.5 Moderate Mental Retardation (MMR)

This level of retardation refers to that category of persons who acquired communication skills during early childhood years, and gain from being trained in social and occupational skills, but are unlikely to progress beyond the second grade level in academic subjects. These people benefit from vocational training and, with supervision, can attend to their personal care (APA 1994:41).

1.7.6 Moderately Mentally Retarded Persons (MMRPs)

This refers to persons who are moderately mentally retarded, with an IQ level of 35-40 to 50-55 (APA 1994:40).

1.7.7 Mental Health

Mental health is an evolving process in which the individual's internal demands and needs are brought into a harmonious relationship with the reality of the environment in which they live (Kreigh & Perko 1988:24). Mental health problems are common to people, but youngsters are especially vulnerable (McMillan 1996:21).

1.7.8 Mental Illness

According to the Mental Health Act (No19 of 1992 as amended) mental illness is any disorder or disability of the mind, any arrested or incomplete development of the mind. Umphred (1995:723) described a person with mental retardation as one who has had some degree of intellectual impairment all her/his life.

1.7.9 Community-based care

This concept refers to the care rendered to mentally retarded persons within their own family homes and within a network

of community services. The care requires consideration and sharing of ideas among professionals (Taylor 1995:461).

1.7.10 Primary Health Care (PHC)

The term "primary health care" can be used interchangeably with "community-based care". It is health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals through their full participation, and at a cost that the community and country can afford. Primary health care should be maintained at every stage of development, in the spirit of self-reliance and self-determination. It is the first level contact between individuals, the family and community, with the National Health System, bringing health care as close as possible to where people live and work (Vlok 1996:27).

1.7.11 Reconstruction and Development Programme (RDP)

The RDP is an integrated, coherent, socio-economic policy framework. It seeks to mobilise people and the RSA's

resources towards the final eradication of apartheid and the building of a democratic, non-racial and non-sexist future (ANC 1994b:1) It emphasises five key programmes:

- meeting basic needs
- developing human resources
- building the economy
- democratising the state and society
- implementing the RDP (ANC 1994b:7)

1.8 STRUCTURE OF CHAPTERS

Chapter 1: Overview of Research Study

This chapter introduces the research topic. It discusses what the research attempts to establish, the reasons for the study, and the significance of the study.

Chapter 2: Literature Review

Various aspects of the research are substantiated by research published by other researchers.

Chapter 3: Research Methodology

The research methods used, such as the subjects, methods of sample selection, and reasons for the selection of the design, are discussed. An overview is also provided of the construction of the questionnaire/interview schedules, data gathering techniques, and data analysis.

Chapter 4: Data Analysis

The analysis of the information is presented in tables, diagrams and graphs, and discussed.

Chapter 5: Conclusion, Limitations and Recommendations

This chapter addresses conclusions about the research results, and the implications thereof, as well as limitations of the research. Finally, recommendations for further research are provided.

In this chapter an overview of the entire research study was done. To follow is chapter 2 which presents a detailed literature study.

CHAPTER 2

LITERATURE STUDY

2.1 INTRODUCTION

This chapter discusses the literature reviewed in relation to mental retardation as viewed by different authors, with special emphasis on community-based care for moderately mentally retarded persons.

In the RSA, about 2-4 percent of the population are mentally retarded persons. Of these, most are mildly retarded, approximately 20 percent are moderately retarded, and 5 percent are severely or profoundly retarded (Uys & Middleton 1997:492).

Mental retardation is regarded as one of the three chronic neurological handicaps that are common to childhood, the others being cerebral palsy and epilepsy (Brett 1997:407).

South Africans are faced with the challenges of having to design a comprehensive programme to redress social and economic injustices, increase efficiency, and promote greater control by communities and individuals over all aspects of their lives.

All legislation, organisations and institutions related to health should:

- recognise that the most important component of a health system is the community.
- ensure that mechanisms are created for effective community participation, involvement and control (ANC 1994a: 7).

Community-based services which are committed to improving the care rendered to persons suffering from mental retardation face the challenges of identifying, addressing and redirecting a host of issues (Crosby & Barry 1995:257). This study investigated the availability of resources to meet this "host of issues" and the needs of mentally retarded persons in the Port Elizabeth area.

2.2 EXTRACTS FROM ACTS; WITH MANY DIRECT QUOTATIONS

2.2.1 The Health Act No 63 of 1977

Through this Act a comprehensive approach to health care was introduced. The aim was to improve the health status of communities (Vlok 1996:15).

Functions of the:

- **first-tier government** - Department of National health and Population

- Development at the national level, affecting all nine provinces.

  (a) The co-ordination of health services and the provision of additional services towards the establishment of a comprehensive health service.

- **second-tier government**

  1. The provision of:
     - hospital facilities and services
     - facilities for the treatment of patients suffering from acute mental illness
     - personal health services, either on their own or at the implementation of a decision by the Minister, or in co-operation with any local authority.
  2. The co-ordination of the services with a view to the establishment of a comprehensive health service.

- **third-tier government** - Local Authorities
- The co-ordination of services with due regard to similar services rendered by the Department of National Health and Population

- Development, and the Provincial Administration, regarding the institution and maintenance of comprehensive health care.

According to Clark (1999:29), a health care system is a structured, organised setting to provide specified promotive, preventive, curative and rehabilitative services of designated persons, the MMRPs in this case, using resources allocated for that purpose.

2.2.2 The Mental Health Amendment Act No 19 of 1992

In this Act (19 of 1992 as amended)unless otherwise indicated by the context:

- A "child" means any person under the age of 18 years.
- Provided that any person detained in an institution who is over the age of 16 years may, with the approval of the Minister, be treated therein as a child up to an age recommended by the hospital board concerned.

Although the Act does not clearly provide for the definition of mental retardation *per se,* it does define mental illness as any disorder or disability of the mind including

- any mental disease
- any arrested or incomplete development of the mind.

According to the APA (1994:39) the onset of mental retardation must occur before the age of 18 years (Criteria C).

The Aim of the mental health policy according to the National Health Plan for South Africa (ANC 1994a:46) is to

- ensure the psychological well-being of all South Africans
- eliminate fragmentation of services and ensure comprehensive and integrated mental health care.

2.2.3 The Child Care Amendment Act No 96 of 1996

Section 14.4 of the above Act (96 of 1996 as amended) refers to a "child in need of care" as children in especially difficult circumstances which deny them their basic human needs.

Mental retardation is described as a sub-average general intellectual functioning (Criteria A) which is accompanied by significant limitations in adaptive functions in any two skill-areas, such as:

- social/interpersonal skills
- use of community resources
- self-direction, functional academic skills
- work, leisure, health and safety (Criteria B).

The onset must occur before the age of 18 years (Criteria C) (APA 1994:39).

In terms of section 31 of the Child Care Act, 1996 (Act No. 96 0f 1996 as amended) a social worker, a nurse or any commissioner may (and shall if so directed by the Minister) enter any children's home or place of care (other than a children's home or place of care maintained and controlled by the State, and) shelter or place of safety in order to

(a) inspect that children's home or place of care, shelter or place of safety and the books and documents appertaining thereto and

(b) observe and interview any child therein, or cause such child to be examined by a medical officer, psychologist or psychiatrist.

Section 42:14 of the Act states that:

(a) Every dentist, medical practitioner, nurse, social worker, teacher or any person employed by or managing a

- children's home, place of care, or shelter
- who examines or deals with any child
- in circumstances giving rise to the suspicion
- that the child has been ill-treated or

- suffers from any injury, single or multiple, the cause of which might have been deliberate
- or suffers from a nutritional deficiency disease, shall immediately notify the Director General or any officer designated by him or her.

Clark (1999:950) USA, described the National Health objectives related to women as reducing the prevalence of mental disorders among children and adolescents, and increasing the proportion of people aged 18 and older who use community support groups. In the present study an exploration of the related phenomena was carried out with MMR children between the ages of 6-12 years.

2.3 THE NATIONAL HEALTH PLAN FOR SA (1994)

The African National Congress (ANC) emphasised that the National Health System (NHS) should be organised on four levels.

1. Community Level

This is the most important level of the delivery of comprehensive primary health care (ANC 1994a: 61).

2. District Level

The district boundaries will, as far as possible, be common with those of the administrative and political boundaries in order to facilitate effective, integrated and comprehensive service delivery (ANC 1994a: 65).

3. Provincial Level

The main task of this body is to

- identify development needs in the province
- mobilise and allocate resources to the best advantage of the people of that province, particularly the poorest (ANC 1994a:65).

4. National Level

Responsible for the development of the multi-sectoral collaboration necessary for the implementation of health programmes and healthy lifestyles, as well as for the co-ordination of training systems for the health personnel (ANC 1994a:69).

2.4 RECONSTRUCTION AND DEVELOPMENT PROGRAMME (RDP)

The RDP is said to be people-oriented. The aim of the Government of National Unity's (GNU) five-year plan was to uplift the standard of living of the millions of very poor people in SA. This required the RDP team to form close links with the communities.

Stimulation and learning programmes in the RSA are hindered by many factors, including the poor environment in which the MMRPs live (Uys & Middleton 1997:491).

2.5 COMMUNITY-BASED CARE APPROACH

One of the aims of this study was to investigate the possibility of retaining the MMRPs in the community in the Port Elizabeth area of the RSA.

2.5.1 Attitudes

Throughout the years there has been a variation in the attitudes of the community towards mentally retarded people,

from total disregard and rejection to positive involvement (Uys & Middleton 1997:491).

McConkey (1991:3) in Scotland, emphasises the need for communities to be educated about mental retardation, and the need for attitudes to change. He states that a week does not go by without some new horror story in the press, either about abuse or discrimination against MMRPs.

Neighbours might reject a moderately mentally retarded person's home in their street, or parents might be requested to leave a holiday centre because of what their sons/daughters "might do" (See Annexure C).

2.5.2 **A shift from institutionalisation to community based care.**

There has been a good deal of discussion about institutionalisation in the big psychiatric hospitals. However, it is not clear whether community care will improve. The move away from the big psychiatric hospitals is a move away from institutionalisation towards community-based care.

A shift from a hospital-based to a community-based setting provided a critical situation for the mentally retarded persons

and their parents which result in the neglect of their health care needs (Thornton 1996:1169).

Nurses should be prepared to function individually and collaboratively in communities, focusing on prevention and promotion of health care. This necessitates an emphasis on the location of clinical experiences and on population-focused practice, involving families, groups and communities (Eshleman & Davidhizar 1997:24).

2.5.3 **Rehabilitation programmes.**

Community health care places emphasis on designing health care programmes that meet the needs of the population groups (Clark 1999:31).

There is a need for housing, vocational options and educational rehabilitation programmes need to be developed in the RSA. These aspects are essential for enabling MMRPs to function optimally in their communities (Uys 1999:31). Actions excluding the community, which fail to empower others to render care, may be considered to be mere technical expertise, but not to constitute community health nursing (Benner 1991:59).

2.5.4 **Community service systems**

Community services for psychiatric patients are severely limited. (Uys 1999:31). The mentally retarded population has the same wide variety of characteristics as people with normal Intelligence Quotients, and they change their preferences just as normal people do. It therefore becomes imperative that they be treated likewise (Uys & Middleton 1994:459).

Service users have to find voices and proclaim their views with the same validity as other people. This could be the starting point for establishing and maintaining truly consumer-oriented services (Crosby & Barry 1995:257).

Stainton (1994:149) states that long-term service goals include establishing a comprehensive community service system in which all developmentally handicapped people receive the support required in their homes and communities. In this way the institutional placement of people with development handicaps can be phased out.

People with long-term mental illnesses living in the community often lack effective safety nets. The blame is sometimes put on the clients and their responses to care provision, linking the breakdown to inadequate or badly coordinated services. It becomes evident that someone has to be aware of the needs of the clients, the extent to which these needs are met, and by whom. (Lear, Morris, Parnell and Wharne 1991:25).

The emphasis on the closure of long-term hospitals and the provision of small, domestic-style accommodation integrated into the local communities, helps to ensure that people with a learning disability become part of the community. This carries with it the challenge of change for both service users and professionals (Parrish & Birchenall 1997:92). Community nursing services are responsible for the provision of comprehensive, coordinated and accessible care to all people (Stanwick 1994:38).

2.5.5 **A mentally retarded child in need of care**

In the case of a child who is capable of being taught to manage himself and his affairs to some extent, but appears by reason of

mental illness to be permanently incapable of receiving benefit from the education and training in an ordinary school

- (at which special classes have been instituted for the education and training of children who for various reasons are unable to benefit sufficiently from the training given in ordinary classes) shall be received only at an institution in which separate accommodation is provided for such children and in which reasonable provision is made for their care and instruction (Mental Health Act, No.19 of 1992 as amended).

The Port Elizabeth daily newspapers, the *Evening Post* (1997) and the *Eastern Province Herald* (1998) indicated that mentally handicapped children were victims of child abuse and rape. Police reportedly investigated four cases of rape and one of indecent assault at a special school. It was alleged that some children were so desperately unhappy in the school that they preferred living on the streets. During 1999, an eight-year-old retarded child was raped by a 50-year-old man in Port Elizabeth (See Annexure C).

A shift from institutionalised care to community-based care is not necessarily beneficial to the MMRPs, their families, or their

communities. The transition to community living could induce stress for both clients and carers (Read 1996:40).

2.6 AVAILABILITY OF RESOURCES

According to the ANC, health services will be planned and regulated to ensure that resources are rationally and effectively used, to make basic health available to all South Africans (ANC 1994a:20).

One of the aims of this study was to investigate the availability of resources (manpower, material and finance) to meet the needs of the MMRPs in the community in the Port Elizabeth area.

2.6.1 Manpower

The primary health care (PHC) approach forms the basis for the restructuring of the health system (ANC 1994b:19).

The shortage of psychiatric nurses in primary health services in the RSA impedes the early detection of mental retardation. Primary school teachers and clinical psychologists are also too

few in number to remedy the situation for MMRPs in most communities in the RSA (Uys & Middleton 1997:491). In order to develop client-centred programmes of care, flexible responses are required for clients whose behaviour might present challenges to direct caregivers.

Nurses should consider the fact that primary health care based on comprehensive practices is becoming the major focus for care delivery outside hospitals. They should work collaboratively and effectively in, and on behalf of the primary health care team. This will enable them to achieve professional goals of caring, as well as ensuring that community nursing survives (Fatchett 1996:42).

The research results of Crosby & Barry in England (1995:82) reveal that 83% of Scheme 11 staff felt that further training and qualifications were necessary to provide effective care, and that there was a need for staff training, mainly related to providing greater insight into the management of challenging behaviours.

2.6.2 Material-Training equipment, services

To improve the quality of life for MMRPs requires:

- allocating resources to those programmes which achieve the greatest benefits at the least cost for given benefits
- "at the least cost" implies the most efficient programmes to be selected (Freeman, Henderson & O'Donnel 1991:174).
- services available for the full development of all identified mentally retarded people throughout their lifetime in the RSA (Uys & Middleton 1997:491).

An ideal that has not yet been realised is that of having adequate goal-directed programmes in the RSA. For teachers to be able to modify the children's behaviours, they should utilise continuous teacher-managed techniques that are generally effective for skill acquisition (Tabor , Seltzer, Heflin & Alberto 1999:159).

Mental disability is regarded as one of the most difficult disabilities to rehabilitate with regard to vocational, social and educational life roles. More attention should be given to the

rehabilitation of these people in the community. It has to be accepted that they are mostly poorly rehabilitated, with many secondary handicaps manifesting, such as speech and hearing defects (Uys 1999:30).

The introduction of psychosocial rehabilitation and psycho-educational and supervised employment methods and programmes, is a vital aspect to optimise community care for MMRPs. Many governmental systems have treated these as separate programmes added to community services. The result is that these programmes have been under-utilised, or not utilised at all, for delivering quality outpatient mental health services. Poor delivery of integrated services has resulted in serious deficits in addressing the physical, mental, social and maintenance needs of MMRPs (Fox 1992:220).

Community services for MMRPs are severely limited in the RSA. Housing, vocational options and educational rehabilitation programmes need to be developed (Uys 1999:31).

2.6.3 Finances

Vlok (1996:19) quoted the 1990 Regulation under the Health Act 63 of 1977, in which, on 16 May, the then Minister of National Health and Population Development stressed the importance of PHC and more equitable distribution of funds for PHC.

The PHC approach placed emphasis on care that was made accessible to individuals and families in the community through their full participation, and at a cost that the community and country could afford (ANC 1994a: 20).

Service providers need to establish and improve many services in order to establish comprehensive community care services. Radical improvements in health, education and social work funding are needed to supply these enhanced community services for MMRPs in the community in the RSA (McConkey 1991:6).

Although the emphasis is on providing care in the community, few increases occurred in the expenditure on the MMRPs outside institutions in the USA (Goodwin 1993:163).

The same situation apparently continues to prevail in the RSA. As stated by Uys (1999:30) "Community support services are severely limited in South Africa."

The involvement of nurses in local commissioning gives them great opportunities such as those of controlling the budget. This makes them mindful of future service needs and enables them to work with other nurses and get them involved in making decisions about how resources are shared (Antrobus 1998:50).

2.6.4 Environment

Stimulation and learning programmes in the RSA are hindered by many factors including the poor environments in which the MMRPs live (Uys & Middleton 1997:491).

People with chronic mental disabilities, given the right environment and adequate resources, have the capacity to enhance their quality of life. Care-provision for MMRPs during the 1970s was fragmented, services were inaccessible, and organisational and professional boundaries prevented continuity of care in the USA (Brown & Wistow 1990:1).

The same problem seems to prevail in the Port Elizabeth area in the RSA. This research attempted to find out whether this was indeed the case. Based on the research results, recommendations would be made which could help to improve the situation for MMRPs in this area.

According to Matson, Johnny, LeBlanc and Linda (1999:649) social skills have become vital aspects of the evolving definition of MR. These skills enable the MMRPs to adjust and respond to environmental complexities.

It is vital that the environment, in which care is delivered, is such that it meets the training needs of the MMRPs it serves. Also, the attitudes of those delivering the service should be as health enhancing as possible (Armstrong 1995:103).

2.7 THE MULTI-DISCIPLINARY TEAM

2.7.1 **Role of health workers in the health system**

The South African government emphasises that all health workers have an equally important role to play in the health system, and should ensure that team work is a central component of the health system (ANC 1994a:7).

2.7.2 **Assessment and management of clinical problems among MMRPs.**

Taylor (1995:41) writes: "the moves towards community care may place a greater responsibility on the local authority to provide services. However, there will be a continuing necessity for a multi disciplinary approach in the assessment and management of clinical problems among MMRPs who have extremely complex biological, psychological and social needs."

A more effective service for people with learning disabilities can be provided if there is effective multi-disciplinary collaboration in the community services provided for MRPs (Parrish & Birchenall 1997:91). This research investigated whether multi-disciplinary collaboration was present in the services provided to the MMRPs in the Port Elizabeth area.

2.7.3 **Importance of sharing responsibilities**

"Partnership requires a willingness by the partners to share responsibilities as well as the risks and gains. It is a relationship - a social contract based on mutual trust and respect in order to achieve stated goals. It requires agreement between the health sector and the community in decision-making and priority setting. The sharing of common goals - how to promote health, prevent illness and alleviate pain and suffering and enhance well-being by participants from different professions and sectors can lead to a more efficient attainment of objectives than if each were working in isolation (Herbst 1998:39).

Owing to their many complex causes, health problems demand an inter-sectoral approach to be solved (ANC 1994a:9). In order for psychiatric-mental health nurses to obtain the best care for the MMR disenfranchised persons, they will need to build partnerships and alliances with health-care colleagues, clients, families and advocacy groups (Krupnick & Wade 1999:6).

2.7.4 **Highlights of a multidisciplinary team**

McGrath (1991:1450) quoting from previous authors, explains the implications of a multidisciplinary team approach as following:

(i) The multidisciplinary team might vary in detail, but that it requires three common elements.

- team members having shared aims
- distinct roles for team members
- a structure to facilitate joint work and communication.

The present research endeavoured to find out whether these three essential components did indeed exist in the Port Elizabeth area.

(ii) Teams as being "comprised of persons of varying levels of knowledge and who assume different roles and task responsibilities necessary for the achievement of team as well as organisational goals and objectives."

(iii) A team as a group of people each of whom possesses particular expertise; each of whom is responsible for making individual decisions; who together hold a common purpose;

who meet together to communicate, collaborate and consolidate knowledge from which plans are made; actions determined and future decisions influenced.

(iv) Aims of the multi-disciplinary team include efforts to

- reduce duplication and overlap
- identify service gaps
- seek out families who do not receive services
- attempt to overcome scepticism from carers
- identify social groups
- develop services for MMRPs in the community
- offer support for parents/carers to improve the retarded person's quality of life.
- maintain these people in the community and prevent or delay movements into institutions (McGrath 1991:1450).

Much has to be done to establish social links for MMRPs living in the community (McGrath 1991:145). The idea of the multi-disciplinary team functioning in the community and drawing on a range of resources
and skills, is viewed as the most outstanding vehicle for achieving the goal of the health and social care agencies, namely collaboration care planning and care delivery.

2.7.5 **Problems to fulfil expectations and manage a team.**

However, the roles and tasks of the team remain questionable. The team is not always able to fulfil the expectations of a new form of co-ordinated services for MMRPs and their families. The various disciplines represented in community care teams do not always manage to co-operate effectively. The problem of managing staff from different professions and organisations remains difficult in many communities. Whether or not such problems continued to exist in the Port Elizabeth area was investigated in this research.

If community teams are to become effective in rendering services to the different community sectors, difficulties must be identified and addressed (Brown & Wistow 1990:x). This research investigated how the multi-disciplinary team operated in the community where the study was undertaken.

Community MR teams in the USA were perceived to take on diverse forms. The teams ranged in size from two to eleven.

- 18% had no social services representation
- 20% had no mental retardation nurse

- about half did not have a consultant in mental retardation
- 80% had no therapists such as physio, speech, and occupational therapists
- 89% had no education representative
- half of the teams were based in hospitals, which implied that MRPs in the community might not have received adequate care (Brown & Wistow 1990:1).

The question arose of why there should be such diversity. How was the studied centre's team structured? Could it provide community services to the MMRPs in the Port Elizabeth area of the RSA?

Huxley (1990:23) claims that, if disciplines are poorly co-ordinated owing to geographical organisational and accessibility problems, the best solution would be to place them all under one roof, with common service goals and referral systems. It would also be wise to involve community representatives as they would have useful knowledge about the needs of their own areas. Thus they could be of great help in the planning of comprehensive community services (Huxley 1990:34).

Information about the effectiveness of treatment for children's mental health problems is described as limited, but there are suggestions that a primary health care setting is preferable for treatment (Tyrer, Higgs & Strathdee 1993:31).

2.8 DEPARTMENT OF HEALTH VERSUS EDUCATION

Because of the shortage of psychiatric nurses in primary health services throughout the RSA, it is difficult to launch learning and stimulation programmes for MMRPs (Uys & Middleton 1997:491).

Since psychiatric nurses are mentioned in primary health services, as well as alternative staff such as primary school teachers, the question

arises where mental retardation belongs. Does it belong to the Department of Health or the Department of Education?

Brown & Wistow (1990:5) state that in the USA, a significant point was the acceptance by the Department of Health and Social Security that the process of de-institutionalisation be facilitated. This implies that the authorities needed to find

people to plan and develop alternatives to hospital care. Huxley (1990:126) states that successful services rely less upon hospital care, and more upon the provision of adequate and co-ordinated community care.

This latter type of care is more cost-effective than institutional care. However, merely leaving MMRPs in the community to cope on their own does not constitute "care". The present study attempted to establish whether, and which types of care might be available to MMRPs in the studied community in the Port Elizabeth area.

People with mental retardation are part of communities. In the process of educating and training them, programmes for community care should be developed (McConkey 1991:33). Whether such programmes existed in the studied communities would be investigated.

2.9 PARENTAL ROLE

2.9.1 Parents' reactions to the birth of a mentally retarded child

The birth of a mentally retarded child causes disillusionment to parents. Their hopes and expectations are shattered and they are forced to make vast changes. The most common effects include denial, apathy, shock and tension. These are often followed by anger, bitterness, rejection, bargaining, and going from service to service for help. The parents may lapse into depression, sadness, grieving, despair and guilt. They undergo a period of acceptance and are then faced with the task of having to plan their own, their
families' and their children's lives according to their retarded child (ren)'s needs and capabilities (Uys & Middleton 1997:501)

Parents may react to the knowledge of having a developmentally disabled child in fairly predictable ways (Stanhope & Lancaster 1992:567). These predictable parental reactions include:

(i) **Awareness** - if the problem is of a mental nature, at times awareness may come as late as the beginning of

school. Emotional reactions like denial and anger dominate this stage.

(ii) **Recognition** - by parents of the prevailing problem, in which they gain insight that there is something just not right with the child.

(iii) This makes them **search for the cause**. This stage becomes most difficult in coping with the parent's reactions, especially when mothers begin to blame themselves. The inability to cope with an unknown cause leads to poor adjustment. Emotional reactions like hostility, anger and self-pity may appear. Many parents **may lose a lot of money** trying to find a reason for the child's problem.

(iv) The parents then begin to search for **a cure to the problem**. This stage often leads to family destruction caused by neglect of other family members. There are hopes that each new drug, therapy, place, doctor, or

(v) school, will bring help only to find little or no real help. The despair and grief may overwhelm many parents.

(vi) The parents get to the final stage, namely **acceptance of the problem.** This requires much time. Only after they have really accepted their child's condition can they seek and participate in therapeutic plans of care for their

children. Only parents who have reached the acceptance stage can make meaningful contributions towards caring for their own child(ren) in the community. Such parents offer guidance and support to other parents in the community. Ideally, any community programme for MMRPs should provide counselling and support services to the parents of MMRPs. The ultimate success of such a programme depends on the participation of the parents and other community members. However, this study focused on MMRPs only.

2.9.2 Parental involvement in the care of mentally retarded persons

"A large proportion of the RSA's population is illiterate and very poor ..." (Uys & Middleton 1997:491). These factors may hinder the parents from becoming fully involved in the care of their mentally retarded children.

The problems presented by a MR child demand close teamwork within and among professions, and between professional and lay persons.

- The most important lay persons involved are the parents and immediate family of the child.

- Owing to lack of knowledge and experience, and being emotionally involved, parents of MR children are seldom prepared or equipped for the role of looking after their children (Joubert 1987:17).

In one service planning session, one member felt that parents had to be listened to. As the nitty-gritty of caring falls onto them, their views need to be heard (McGrath 1991:90). In another operational system for family-based respite care in Sydney, Australia, where parents were included, but where social workers played a major role, parent representatives felt that they were there only in a token fashion. They perceived themselves not to be contributing to team decisions affecting their children's care. They were undervalued. Subsequent to this realisation, the parents became essential partners helping to support other parents of MMRPs (McGrath 1991:149).

Professionals who work with the parents of mentally retarded children should be knowledgeable about issues such as social, educational, medical and behavioural aspects of mental retardation. They should also know the available resources, agencies and services (Uys & Middleton 1997:501).

This research investigated whether parents are involved in the care of their MMRPs in the centre being studied.

2.10 INVOLVEMENT OF GOVERNMENT

The research aimed to identify the needs and problems of the MMRPs in the Port Elizabeth area. These research findings would be communicated to the relevant authorities so that improvements might be made.

A Port Elizabeth press report (*Evening Post* June 18, 1997:1) indicated that the number of mentally retarded pupils who were being sexually molested on their way to and from school was increasing. As a result of this, the school nurse, pupils and parents planned a march against rape, child abuse and

violence. Their objectives in staging the march were to highlight their plight and to show that children were victimised by adults with nothing being done about it by the authorities (See Annexure C).

According to the Mental Health Act (19 0f 1992 as amended), it is the duty of a police official to act in circumstances where he believes that

- any person is not under safe and proper supervision
- is being neglected or ill-treated, or
- is wandering at large and is unable to take care of him/herself.

Educational efforts need to be directed at the community - people who are in the best situation to help and support the MMRPs and their families. Influential groups such as counsellors and social workers, key figures in the community such as police officials, sport/leisure officials, nurses and teachers who come into contact with MMRPs, need to be identified, so that their efforts, skills and capabilities can be co-ordinated. By the nature of their work they can make life easier for the MMRPs in their communities, if they have the required knowledge and skills to do so (McConkey 1991:17).

The questions arise:

(i) How involved is the RSA government in the policy and programme design that looks after the needs of the MMRPs in the community?

South Africa has a lot to learn from other countries in the region, especially the implementation of PHC policies and programmes. The apartheid legacy has left large disparities between racial groups in terms of socio-economic status, education, and health. These policies have caused a fragmented health system with resultant inequitable access to health care (ANC 1994a:27).

The mental health policy will aim to:

- eliminate fragmentation of services and ensure comprehensive mental health care (ANC 1994a:48).
- support the development of non-governmental community-based mental health care services
- improve the provision of community care rehabilitation and education of mentally retarded people
- enforce respect for the right of people with mental retardation (ANC 1994a:40).

McConkey (1991:7) in Scotland, states that "politicians have more pressing concerns on which to spend money", in other words, much to say and little to spend on the mentally retarded person.

(ii) How available are resources like manpower, services, material, finance and transport, to cater for the needs of the mentally retarded? Persons with mental disabilities and their families in the community setting need much more assistance than they are currently receiving in the RSA (Uys 1999:30).

The needs of persons with disabilities should be accommodated in a manner respecting their dignity, considering their human rights, privacy, confidentiality, comfort, autonomy and esteem. This will maximise their integration and promote their full participation in the society; Canada (Stainton 1994:138).

2.11 SUMMARY

Literature about community-based care for moderately mentally retarded persons was reviewed. However, it is evident that there are few authors from the RSA, compared to those from other countries. Thus this research would seem to address a need for investigating the needs of MMRPs in the RSA.

To follow is Chapter 3, which presents a detailed description of the research methodology such as: study design, sampling, subjects, instruments, data collection, and ethical issues.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION AND STUDY DESIGN

This chapter describes the research methodology adopted to conduct this research. It includes the study design, research population and sample, the instrument used, the pre-test, how data was collected, and a description of the instrument's reliability and validity in relation to the pre-test.

This was a descriptive, exploratory, quantitative type of study, using semi-structured interviews and questionnaires. Since the research was descriptive in nature and not necessarily concerned with relationships among variables, it was guided by the research questions and objectives rather than hypotheses (Polit & Hungler 1993:14).

Several authors like Polit & Hungler (1987:38) and Treece & Treece (1986:166) have indicated that descriptive research can proceed without a hypothesis *per se.*

The moderately mentally retarded children, who were represented by their parents, the principal and staff at a specific centre in the Port Elizabeth area, were included in the research study.

3.2 THE RESEARCH POPULATION AND SAMPLE

The purposive sample was drawn from the centre's population of 240 pupils. It comprised 50 black children, of both sexes, between the ages of 6-12 years.

With the help of the Head of Department (HOD) and two class teachers, a list of 50 names (20.8%) was obtained from the school records of the three different classrooms where moderately mentally retarded children were accommodated.

The centre's classification of children is based on criteria of age:

Years

6-9 - junior

10-14 - intermediate

15 - 17 - pre-vocational

18 - 21 - vocational

These are different criteria to those of the APA(1994:40) which are as follows:

Table 1: Example of classification criteria of mental retardation.

Code	Severity of Mental Retardation	Intelligence Quotient
318	moderate	35-40 to 50-55

Due to the centre's classification criteria, some difficulties were encountered with the selection of the required sample.

3.3 PERMISSION TO CONDUCT STUDY

Permission to conduct the study was obtained from the school authorities, the staff, and the parents involved with the study. Anonymity and confidentiality were guaranteed as no names were requested and the researcher conducted all interviews. The study subjects (parents were assured that only the researcher and school teachers had an access to the school records concerning the sample used (Kyriacos 1995:38). Deception and exploitation of subjects were avoided, no bribery was used, and no-one was forced to participate in

the interviews or the completion of the questionnaires. The task was done willingly and voluntarily.

3.4 THE RESEARCH INSTRUMENT

A 50-item questionnaire was used to collect data. The questionnaire was divided into three sections:

Section A: The demographic data about the centre where the research study was undertaken. This section consisted of 21 questions.

Section B: 17 questions to the parents of MMRPs.

Section C: The hospital/health institutions that serve the Port Elizabeth metropole, consisting of 12 questions.

All these sections were designed by the researcher. They were based on the format used by other recognised researchers. Most of the item responses relied upon the information given by respondents. The questionnaires were self-delivered by the researcher.

3.4.1 Contributory factors to the final selection of the questionnaire as the most suitable instrument for this research:

- It provided information which could be processed relatively quickly and easily.
- It was easy and cheap to dispatch and collect, as there was no postage involved
- It allowed respondents to remain anonymous
- It offered respondents time to consider a response to each item

3.4.2 Development of Questionnaire

No previous research conducted on the possibility of implementing community-based care for moderately mentally retarded persons (MMRPs) in the Port Elizabeth area could be traced, therefore the researcher designed this instrument.

The researcher sought the help of the UNISA library personnel to find information from the internet:

- CD ROM SEARCH of RSA material
- CD ROM SEARCH of periodical articles and books

- OPAC SEARCH of UNISA books
- SABINET SEARCH of references in RSA libraries' material
- References from USA, UK and American Nurses' Association
- Also the P E Health Resource Centre's personnel, who offered assistance in the literature search.

All these efforts proved successful, and subsequent to this in-depth literature study, the researcher developed the questionnaire.

3.4.3 Question construction

The nature of the desired information necessitated the use of various types of questions. The expected answers could be divided into relatively fixed categories.

Dichotomous questions:

- yes / no
- male / female

Multiple-response questions

- 0 - 6 months
- 7 - 11 months
- 1 year - 2 years 11 months

- 3 years - 4 years 11 months

Tick the appropriate member (usually providing three or more response)

- psychiatrist
- psychologist
- physiotherapist
- occupational therapist
- speech therapist
- psychiatric nurse
- social worker
- medical practitioner

3.4.3.1 Open-and Closed-ended questions

In an attempt to ascertain the respondents' knowledge, feelings and attitudes, open-ended questions were included. However, these were limited, in anticipation of difficulties in coding. Certain closed-ended questions required elaboration on a specific answer by means of open-ended questions. This was done in an attempt to explore a specific response in greater depth.

3.5 PRE-TESTING THE QUESTIONNAIRE

A pre-test may be defined as the process of measuring the effectiveness of an instrument (Polit & Hungler 1993:443). The purpose of a pre-test should be to reveal problems related to understanding, answering and completing the questionnaire.
A pre-test was conducted for one day, using a group (14%) of teachers representing the three classes from which the sample was drawn, one HOD and five (10%) of the parents (See Annexure D).

Teachers were requested to comment on the format, style, and possible ambiguities and irrelevancies of the questions.

3.5.1 Reliability and Validity

"Reliability", according to Polit & Hungler (1987:316) is the degree of consistency with which an instrument measures what it is supposed to measure.

"Validity" refers to the degree to which an instrument tests what it is supposed to be testing. (Polit & Hungler 1987:323)

Determining the validity of most psychologically oriented measures is difficult. For instance, it would be difficult to know the validity of measurement of nurses' attitudes toward the mentally retarded (Polit & Hungler 1987:323). Treece & Treece (1986:256) point out that it is much easier to determine the reliability and validity of measurements of a piece of material than of human behaviour.

According to Leedy (1993:25) "content validity is the accuracy with which an instrument measures the factors or situations under study; the 'content' being studied". This is sometimes equated with "face validity"

The content validity of this instrument could be debated, as it was based on a comprehensive health care plan of nursing, focusing on a community-based approach to care, and the vocational training of the MMRPs. This followed on from the literature studied.

The face validity of the instrument seemed acceptable. All the questions asked were related to the MMRPs. The respondents appeared to have understood the questions, and could reply to

them. The questions that were unclear were explained by the researcher.

3.5.2 Criteria included in the questionnaire to enhance its reliability

- Questions were formulated as simply as possible to reduce possible ambiguities.
- Sufficient time was allowed for completing the questionnaire
- Objectivity was enhanced by an in-depth literature study, and by requesting critical evaluation of questions by colleagues with expertise and experience in psychiatric nursing and primary health care.

Reliability of the instrument might be influenced by the ability of the respondents to remember present and past events about their children, as well as the honesty with which they answered questions.

- Some parents were too untrained to relate events logically.

- People might become dishonest when financial issues were discussed, for example, to the question of whether the child
- received a state grant, the answer might be a definite but untrue "No". Others might claim to be the sole supporters of their children, which might also be untrue.

3.5.3 Final Preparation of the questionnaire

To prevent confounding the research findings, no participants in the pre-test were included in the research study. However, the minor changes suggested by pre-testing the questionnaire, as well as by the content validity test, were implemented. These led to modification of some sections of the questionnaire. The questionnaire and permission letter were checked for grammatical errors and sentence construction.

The pre-test confirmed the possibility of the instrument being used on a larger scale over a period of time.

3.6 DATA COLLECTION

3.6.1 Permission to collect the data

A telephonic appointment was made to see the school's principal about the intended research study. This was followed by a letter requesting permission to utilise the centre, and to have the principal, staff and the parents of the MMRPs as subjects. The requested permission was granted. The researcher was also assured that the educational development officer (EDO) and the school governing council would be notified (See Annexure A).

3.6.2 Distribution of questionnaires

Data was obtained through completion of the questionnaire and the use of semi-structured interviews. The questionnaires were distributed by the researcher.

The school principal, staff, and those parents who could complete the questionnaires without assistance, were issued with the instruments to complete on their own.

The completion of the questionnaire took 20 to 45 minutes depending on the individual's level of understanding. These were collected immediately thereafter.

3.6.3 Interviews

Semi-structured interviews, which were based on the questionnaire, were conducted with those parents who needed assistance.

The parents were included to obtain information about their children which might not be available in the centre's records. The interviews consisted of closed and open-ended questions. The questionnaires were written in English but the interviews were carried out in Xhosa to facilitate good communication for those parents who did not understand the English language (See Annexure E).

Each interview took about 20-45 minutes to complete, depending on the respondents' ability to remember their experiences and those of their children. This did not create a big problem in terms of time as a week (21-25 June 1999) was kept open for the data collection.

The staff indicated that this was not a very busy period as the school was about to close for the June-July holidays.

Those parents who could not come to the centre because of work constraints and other commitments, phoned the centre and requested that they be visited at home over the weekend. This was done, and 4 (8.5%) respondents were interviewed. The interviews took about 20-30 minutes to complete. The researcher collected the questionnaires after completion.

3.6.4 Visits to Psychiatric hospitals/institutions

To provide answers to the research question whether mentally retarded children were still being hospitalised in psychiatric hospitals and, if so, to establish the reasons for this, a two-day visit was paid to the following hospitals:

- 4 August 1999 - Kirkwood
- 5 August 1999 - Fort England and Tower

(See Annexure F).

Interviews which were based on the questionnaire were conducted with the relevant persons in charge of the units

where MMRPs were accommodated. The questionnaires were collected by the researcher immediately after completion on the same day on which they were distributed.

3.7 DATA ANALYSIS

A word-processing program (Word 98) and an Excel print-graph computer were used in the analysis of the data. The help of a statistician was obtained.

On completion of the data gathering, the following procedures were followed:

- numerical figures were added
- relevant items were compared
- conclusions were drawn from these comparisons (Polit & Hungler 1993:444).

The precise analysis of the data will be discussed in Chapter 4 of this dissertation.

CHAPTER 4

DATA ANALYSIS AND INTERPRETATION

4.1 INTRODUCTION

In this chapter a numerical comparison of items, statistical references as well as sorting of data and a computer analysis were utilised. The recording, discussion and interpretation of the analysed data will be presented. Graphs will be used to illustrate certain trends.

From an intended sample of 50 moderately mentally retarded children (represented by their parents), a total of 47 (94%) responded positively and were successfully utilised as subjects.

The questionnaire was divided into three:

Section A: School data

Section B: Parents of MMRPs

Section C: Psychiatric hospitals/institutions that serve the Port Elizabeth metropole.

Data capturing was done by transferring the questionnaires onto the computer. The information was analysed on a Word Processing program (98), and the printing of graphs on the MS Excel.

4.2 SECTION A

DEMOGRAPHIC DATA – THE SCHOOL

According to the unveiled stone situated in the foyer of the school, the centre was officially opened in 1984 by Mr B J du Plessis of the then Department of Education and Training (DET). It was partially government subsidised. It had a total of 240 pupils (140 boys and 100 girls), all Blacks, ages ranging from 6-21 years. They were all day scholars who contributed R7 per month for school fees. Also

- 21 teachers - 1 acting principal,
  - 3 HODs and 17 teachers
- 23 non-educators – a clerk, drivers and general assistants.

4.2.1 Classification

Figure 1: Histogram showing the percentage of pupils according to the centre's classification of mental retardation.

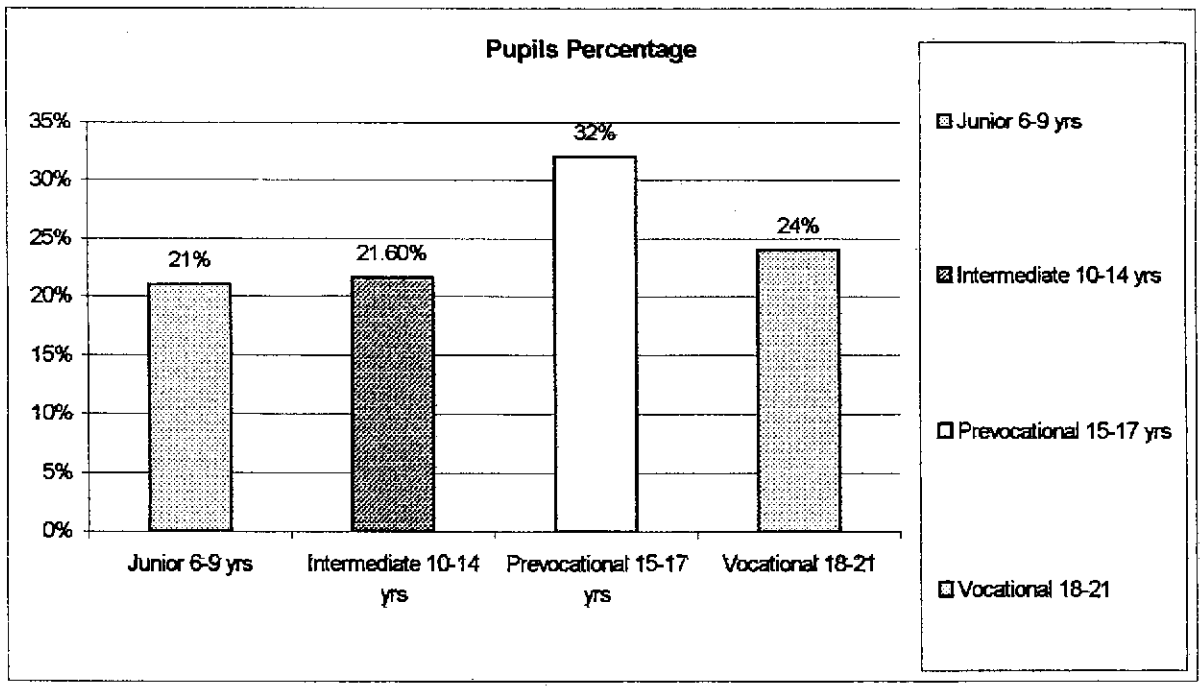
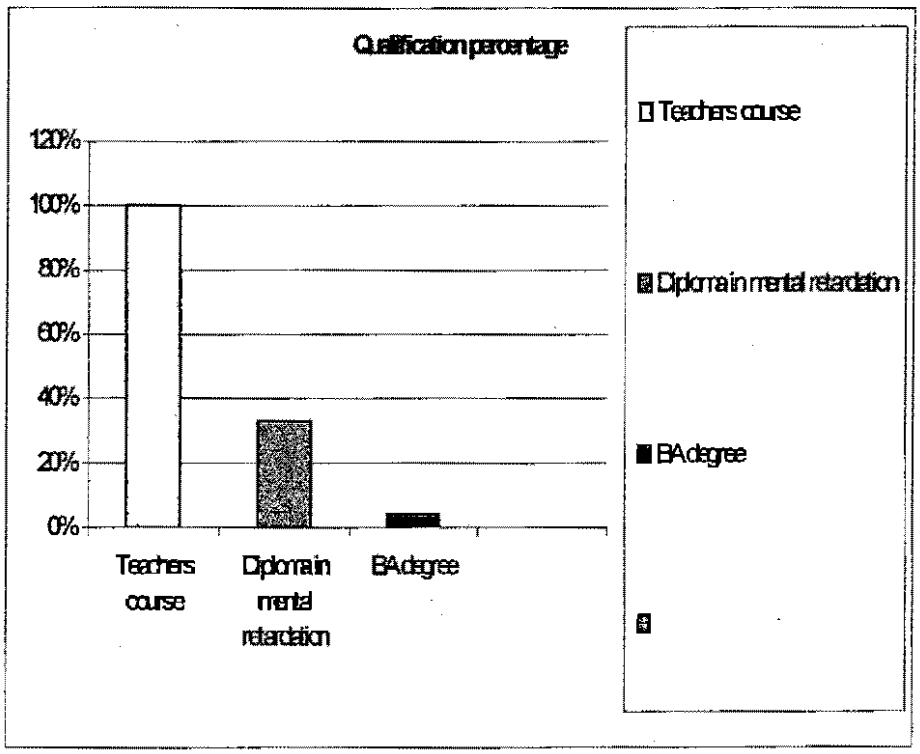


Table 2: Classification according to age.

Type	Age	Total	Percentage
Junior	6-9yrs	51	21.3
Intermediate	10-14	52	21.6
Pre-vocational	15-17	79	32.9
Vocational	18-21	58	24.2
Total		**240**	**100%**

4.2.2 Qualifications

Figure 2: Different teachers' qualifications



All the respondents were qualified teachers either in primary or senior courses. Only 33% possessed a diploma in mental retardation and 4% a BA degree.

Table 3: Subjects taken by those teachers who posses a Diploma in mental retardation.

Subjects taken	**Diploma in MR**	**%**
Orthodidactics I & II History of Education Physiological medical aspect Psychological aspects	7	33

Subjects seemed not to be directly related to the care of mentally retarded persons. The curriculum did not appear to allow for vocational training, and also was not community-based.

Moderately mentally retarded persons gain from being trained in social, vocational and occupational skills but are unlikely to progress beyond the second grade level in academic subjects (APA 1994:41).

4.2.3 Experience as a teacher

Figure 3: Histogram showing the length of time (in percentages) as a teacher.

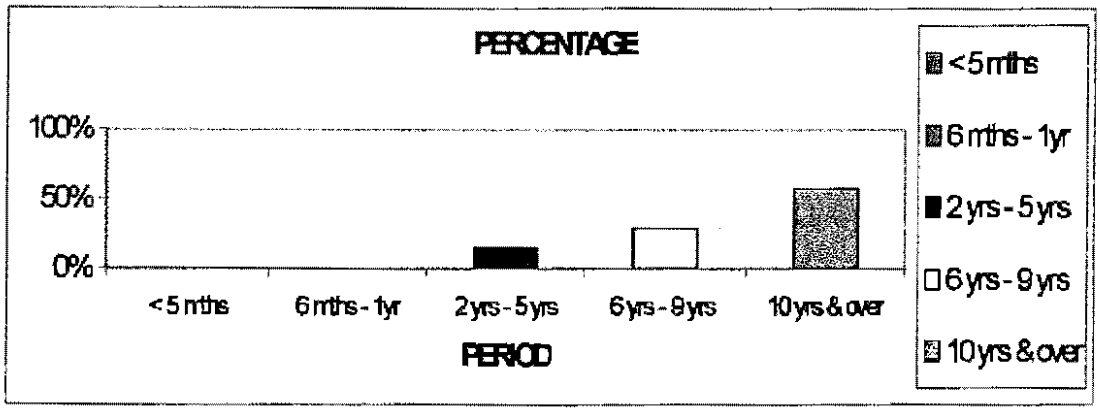


Table4: Total number of teachers and percentages according to their experiences.

Period	**Total**	**%**
Less than 5 months	0	0
6 months - 1 year	0	0
2 years - 5 years	3	14.28
6 years - 9 years	6	28.57
10 years and over	12	57.15
TOTAL	**21**	**100%**

The majority (57%) of respondents had more than 10 years' experience. However the training programmes remained unchanged, not beneficial to the MMRPs. Vocational options and educational rehabilitation programmes need to be developed in the RSA (Uys 1999:31).

4.3 THE MULTI-DISCIPLINARY TEAM MEMBERS

The following disciplines are required in the centre. Except for a professional nurse, none were available in the centre:

- Social worker
- Medical practitioner
- Professional nurse
- Psychologist
- Occupational therapist
- Psychiatrist
- Physiotherapist
- Speech therapist

The results from the respondents revealed a gross lack of team members except for the presence of a professional nurse. The

professional nurse was not trained in psychiatric nursing or mental retardation but possessed a diploma in paediatric nursing.

4.4 THE AVAILABILITY OF THE SCHOOL'S GOVERNING BODY

The results revealed a shortage of members of this body. The original membership number was reported to be seven but during 1999 there were only five members left. Two members have since resigned and had not yet been replaced. This resulted in insufficient members serving on the governing body. This could lead to overlooking of a lot of problems such as the lack of the multidisciplinary team problem, which was not attended to. Even the original number of seven seemed too little.

4.5 SKILLS /TRAINING OF TEACHERS - TOTAL NUMBER OF TEACHERS 21(100%)

Out of the skills listed below, the result revealed the position of the current teachers as follows:

Table 5: Skills/training possessed by teachers.

Skills /Training	Total	(%)
• Basic nursing/first aid	2	9.5
• Home economics	2	9.5
• Computer literacy	1	4.8
• Art	1	4.8
• Designing	0	0
• Hair Salon	0	0
• Woodwork	1	4.8
• Any other	0	0
TOTAL	**7**	**33.3%**

The above results showed a gross lack of skilled teachers. This could affect the MMRPs who should benefit from vocational training skills.

4.6 RECREATIONAL FACILITIES

The respondents revealed that there were no facilities, and no equipment for the following activities:

- Rugby
- Netball
- Table tennis
- Soccer
- Cricket

Despite the absence of facilities and equipment, the pupils were compelled to play these on the open, unlined grounds. This could make the children lack knowledge, skills and an understanding of the rules, regulations and technicalities pertaining to that particular sport.

4.7 TEACHING SKILLS / TRAINING EQUIPMENT / FACILITIES

There should be equipment to teach some of the following:

- Woodwork
- Panelbeating
- Motor mechanics
- Metal work
- Basket weaving

All the respondents indicated that these were unavailable.

4.8 TRANSPORT

The school had 5 combis which were used to transport pupils to school and back home, also a small sedan car which was used for administrative purposes. From this response it appeared that there were no problems is this area.

4.9 ACADEMIC CLASSES

The centre was run like an ordinary academic school. The following subjects were taught:

- English
- Afrikaans
- Xhosa
- Environmental studies
- Basics in Mathematics
- Religious education

4.10 HIGHEST EXIT-LEVEL

According to some (65%) respondents the highest exit-level was indicated as "the highest possible potential" and others (35%) as "vocational group". This was meaningless as no reliable deductions could be made from such responses.

4.10.1 The specific skill achieved by pupil at exit-level

The responses varied from "vocational skills which were not specified though", to "depend on the child". These responses could not be used effectively because they were too vague about the actual skills and void of proper guidelines to achieve any goal.

4.10.2 Where is the child placed after exit-level?

According to all respondents the child was placed at a workshop if there was a vacancy, or would stay at home. The reasons for staying at home were the limited number of sheltered employment workshops. Another contributory factor could be that the centre classified children in terms of age, not disability, so that when classified as "vocational 18-21 years" a child had to leave without having learned any skills.

4.10.3 Reasons for placement

All respondents stated that the child was placed at a workshop to further vocational skills and/or joined a sheltered employment.

4.10.4 *Reasons for non-placement*

According to all respondents there were too few workshops so it was impossible to admit all the children in the Port Elizabeth area.

4.10.5 What happens to the children?

Should the children not be placed anywhere, all responses indicated that they either,

- stayed at home
- roamed about the streets depending on the type of care they received from their parents.

4.11 How many children are on the waiting list?

The numbers indicated by respondents varied from 300 – 600 (See annexure B).

4.11.1 For how long have these children been on the waiting list?

Table 6: Teachers' responses regarding the waiting list.

Length of time on waiting list	**Total**	**%**
6 months - 1 year	0	0
2 year - 5 years	0	0
6 years and more	21	100

All the respondents (100%) indicated that the children had been on the waiting list for more than 5 years.

4.11.2 Reasons for waiting so long

There were few schools for these children in Port Elizabeth. Some (88%) respondents quoted three as the maximum number of schools that were available.

4.11.3 Other options given to parents of children who were not placed anywhere

The unanimous response was – none

4.12 PROBLEMS ENCOUNTERED BY PRINCIPAL AND STAFF WHILE CARING FOR THESE MMRPs:

School
- not enough facilities
- no support services
- burglary and theft of school property
- surrounded by shacks a major contributory factor to burglary and theft.
- lack of "specialists"

Pupils
- poverty – children come to school dirty, clothes torn and very hungry
- physical and sexual abuse by their families and the community. Most cases were not reported, as family members were involved.
- poor attendance
- alcohol and drug abuse

Parents - unconcerned

- reluctant to involve themselves in school activities
- did not attend school meetings
- did not pay school fees
- some were co-operative, others not
- negligent and very lazy
- no follow-up

Facilities: - There was a gross lack of sports grounds.

- no gymnasium, no swimming pools
- no recreational hall
- no proper kitchen
- virtually no workshops

Finance: - severe budgetary cuts by the Department

- these financial constraints had resulted in delays in carrying out many projects.

Any other problems?

Hijacking of school combis whilst transporting children to school and back home.

4.13 COMMUNITY INVOLVEMENT

According to the respondents the community was not interested/ involved at all in the activities of the centre.

It would be wiser to involve community representatives as they have useful knowledge about the needs of their own areas (Huxley 1990:34). The problems presented by a MR child demand close teamwork between professionals and lay persons (Joubert 1987:17).

4.14 SECTION B

PARENTS OF MODERATELY MENTALLY RETARDED PERSONS

Table 7: Children sample according to age and gender

Age in years	Male	%	Female	%	Total	%
6-9	10	21	7	14.8	17	36
10-12	15	31.9	11	23	26	55
13-15	1	2	1	2	2	14
16-18	2	4	0	0	2	4
TOTAL	**28**	**59.5**	**19**	**40.5**	**47**	**100**

All the children in the centre were Black. A mixed group of males and females were used. They ranged between the ages 6 to 9 (36%) and 10 to 12 (55%). The males were mostly affected (59.5%). Also there were a few (8.5%) between the ages 13 to 18.

Table 8: Ordinal position of the child

Ordinal position of child	**Male**	**Female**	**Total**	**%**
First born and only child	8	5	13	27
Middle child	11	9	20	43
Last born	9	5	14	30
TOTAL	**28**	**19**	**47**	**100%**

The number of children in the different families ranged from one to seven , the child being either the first, middle or last-born. The results revealed middle children as mostly affected. This could have caused a heavy burden to the parents who had other children to take care of. The percentages of the first as well as the last-born were also high, a factor which could be emotionally disturbing to parents,

especially because usually the relationships between the parents and their first and last-born children are very close.

In the majority (86%) of cases the mother was the sole supporter. She was responsible for all the child's basic needs, including food, clothing, shelter, education and medical expenses. They were required to pay R7 school fees per month and buy school uniform. The amounts quoted ranged from R105 to R450 (See annexure G).

These mothers were unemployed, but a few (6.5%) did odd jobs, like selling fish, vegetables, "afval" and sewing (2%).

The majority (90%) of the children had been diagnosed as mentally retarded when they entered school. Few psychiatric nurses were employed in primary health care services throughout the RSA who could establish programmes for early detection, stimulation and learning among moderately mentally retarded children (Uys & Middleton 1997:491).

The reaction of respondents when they heard about their children being mentally retarded varied from worry, shock, hurt, shame, disbelief and anger to later acceptance. Emotional reactions like denial and anger dominated the awareness stage, also in their search

for the cause, they felt hostility, self-pity, despair, grief and finally acceptance (Stanhope & Lancaster 1992:567)

None of the children were getting any state grant as it was said that they benefited from school activities and only when they reached the age of 18 years would they qualify for a grant.

None of the respondents belonged to any support-group. They did not even know what that meant.

There seemed to be no problem with transport, as the children were fetched from home to school and taken back home. Only seven percent walked to school.

Almost all the respondents had not noticed any skill achievement/ development since the child attended this school.

The respondents wished that their children could be taught handwork such as carpentry, sewing and knitting so as to be skilled and able to fend for themselves during adulthood.
They all preferred to help their children at home while they attended the day school, for them to be taught how to write and read and to do handwork to keep them away from the streets.

4.15 SECTION C

HOSPITAL / HEALTH INSTITUTIONS

A visit was paid to three psychiatric hospitals that serve the Port Elizabeth metropole, namely Kirkwood, Fort England and Tower Hospitals.

4.15.1 Objective

To investigate whether moderately mentally retarded children were still hospitalised in psychiatric hospitals, and also to establish the reasons for such practices.

Table 9: Total number of mentally retarded patients in the ward/hospital.

TOWER

Race	**Total**	**Age**	**Total**	**Gender**	**Total**
Black	24	6-9	11	Male	15
White	2	10-12	6	Female	11
Coloured	0	13-15	7		
Asiatic	0	16-18	2		
TOTAL	**26**	**26**	**26**		

KIRKWOOD

Males and females aged 5 to 60 years all racial groups.

Not specified as done by Tower.

Total no: 350

FORT ENGLAND

There were no mentally retarded children that were admitted to Fort England. If any did come, they were immediately transferred to Tower Hospital. All other adult mentally retarded persons were kept with other chronic patients in long-term wards.

The results revealed a large number of mentally retarded patients still hospitalised in psychiatric institutions. A total of 26 were counted at Tower and 350 at Kirkwood.

4.16 TYPES OF MENTALLY RETARDED PATIENTS IN THE INSTITUTION

Table 10: Total number of patients in the institutions according to classification criteria.

CLASSIFICATION	TOWER **Total**	**%**	KIRKWOOD **Total**	**%**
Mild	0	0	150	42.8
Moderate	5	19.2	55	15.7
Severe	14	53.8	120	34.2
Profound	7	26.9	25	7.1
TOTAL	**26**	**100%**	**350**	**100%**

This revealed that there were moderately mentally retarded children who were still kept in the psychiatric hospitals, despite de-institutionalisation being promoted. This was revealed by the 19% patients at Tower and 15% at Kirkwood.

4.17 LENGTH OF STAY OF THE PATIENTS IN HOSPITAL

Table 11: Period in hospital

PERIOD	TOWER Total	%	KIRKWOOD Total	%
6 months - 11 months	7	26.9	0	0
1 years - 2 years 11 months	4	15.3	0	0
3 years - 4 years 11 months	6	23	0	0
5 years and longer	9	34.6	All 350patients	
TOTAL	**26**	**100%**		**100%**

The respondents stated that for the past many years Kirkwood had been having a full quota of in-patients, hence all 350 patients had been in the hospital for five years and longer.

4.18 QUALIFICATIONS/CATEGORIES OF STAFF WORKING IN THE WARD

Table 12: Different categories of ward staff.

	TOWER	%	KIRKWOOD
General Nurse	3	18.75	Yes
Midwife	3	18.75	Yes
Community health nurse	Nil	0	Yes
Speciality in Mental Retardation	Nil	0	Nil
Assistant nurse	8	50	Yes
Any other : SASO (Specialised auxiliary service officers)	2	12.5	Nil
TOTAL	**16**	**100%**	

Unfortunately Kirkwood did not give actual numbers for the "YES" responses. Though Tower complained of shortage of staff, looking at their total number of patients versus the staff numbers reflected above, there appeared to be no staff shortage.

4.19 MAIN FUNCTIONS OF STAFF CARING FOR MMRPs

Table 13: ***Activities done by staff in the different institutions.***

TOWER	**KIRKWOOD**
• Provision of basic needs. • Stimulation - active and passive exercises. • Positioning	• Therapeutic programmes • Behaviour modification • Basic nursing care • Vocational skills training • Activities of daily living • Spiritual activities

4.20 THE MULTIDISCIPLINARY TEAM MEMBERS AVAILABLE IN THE HOSPITAL / INSTITUTION

Table 14: Indication of the team members available in each institution.

MEMBER	TOWER		KIRKWOOD	
Psychologist		No		No
Social worker	Yes		Yes	
Medical Practitioner	Yes		Yes	
Psychiatrist		No	Yes	
Speech therapist		No		No
Psychiatric nurse	Yes		Yes	
Physiotherapist		No	Yes	
Occupational therapist		No	Yes	
Pharmacist	Yes		Yes	
Minister of religion	Yes		Yes	

The results revealed an incomplete team. Members that were vitally important to be part of the team were absent, such as:

- Tower - psychologist, psychiatrist, speech-therapist, physiotherapist and the occupational therapist.
- Kirkwood - psychologist, and the speech-therapist.

4.21 AVAILABILITY OF FACILITIES

Table 15: Confirmed facilities available in the different institutions.

	TOWER	KIRKWOOD
Manpower	Shortage	*Enough*
Material / Equipment for vocational skills	None	*Provided in different areas,such as Occupational therapy department - craft room* *Industrial subcontract work.* *Stimulation activities* *Wards – bedmaking*

	TOWER	**KIRKWOOD**
Stimulation programme	- Puzzles - Music - Dancing	*Sensory stimulation programmes, perceptual stimulation for children developmental play activities including ball, swings.*
Recreational	Short walks Match watching	*Indoor and outdoor games soccer, netball, cards drafts, ludo, snakes & ladders, finger board, music, video viewing, Watching TV*
Finance	Controlled by the Dept. of Health	*Private company*
Under which sector does the institution belong?	State	*Private*

	TOWER	**KIRKWOOD**
In your opinion by which Department should MMRPs be cared for? Health vs. Education	Both Dept of Health and Education	*Under the Dept of Education*
Motivation	They need both, as intersectoral collaboration is encouraged. However the profoundly mentally retarded need to be nursed in the community	*They can be well trained especially skills and activities of daily living. As they are not really sick, they can benefit more under the Dept. of Education. In a hospital setting they are deprived of certain aspects in their development especially children.*

	TOWER	**KIRKWOOD**
If you were to choose, where would you prefer mentally retarded persons cared for? • **Hospital** • **Day care centre** • **Special day school** • **Home**	Yes	*Yes* *Yes*
Motivation	They should be under the care of their parents and professional staff so as to get parental love with professional	*Special day school will concentrate on their developmental skills according to their grades of retardation. Their families will also be involved and will understand how to deal*

	assistance and be with their siblings. Unlike in hospital situation where they are isolated from their families and end up institutionalised.	*with retarded persons if they stay at home and attend day school. Institutionalisation is avoided as the person goes from home to school then back home. Community aware-ness improves as the people who are retarded are within the community.*

The analysed data revealed a lack of knowledge by the various respondents about aspects of community-based care with regard to MMRPs. It became evident that there was a need for further consideration of the identified aspects. This will be discussed in detail in Chapter 5 of this study.

CHAPTER 5

DISCUSSION OF FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS

This chapter involves the discussion of findings, limitations, implications, conclusion and recommendations.

5.1 DISCUSSION OF FINDINGS

In this centre the children were classified according to their ages

- junior 6-9 years
- Intermediate 10 - 14
- pre-vocational 15 - 17
- vocational 18 -21

This was contrary to the APA (1994:40) classification which described four degrees of severity of mental retardation that reflected the level of intellectual impairment degree - moderate. IQ level - 35-40 to 50-55. This type of classification could create a problem for the MMRPs In being identified, cared for according to their needs and trained in proper skills in relation to the severity of their mental retardation.

The centre was run like an ordinary academic school. The APA (1994:41) specified that the MMRPs should be trained in vocational, social and occupational skills. They were unlikely to progress beyond the second grade level in academic subjects. Whereas the centre's classification emphasised "prevocational" as "children from 15 - 17" and "vocational, age 18 - 21 years". There should be a link between the special training centres and protective workshops so that the children in training are prepared for effective functioning in the sheltered workshop to which many are referred when they reach the age of 16 (Vlok 1996:718).

TEACHERS' QUALIFICATIONS

The majority (93%) possessed only a teacher's course which qualified them to teach in an academic school. A few (7%) had a diploma in mental retardation, plus the teacher's course. However, it was doubtful whether the Subjects taken by those teachers who possessed a diploma in mental retardation made them fully skilled and equipped to care for the MMRPs as expected. The Subjects taken were as follows;

Orthodidactics I & II

History of Education

Physiological-medical aspects

Practical teaching - psychological aspects.

Crosby & Barry (1995:82) emphasised a need for further training and qualifications for staff to provide effective care and greater insight into mental retardation and into the management of related challenging behaviour.

A big number (69%) of respondents fell into the category of "10 years experience being in the centre", and yet programmes and the classification criteria remained unchanged. The MMRPs were not catered for in the programmes. An idea that has not yet been realised is that of having adequate goal-directed programmes (Freeman Henderson & O' Donnel 1991:174).

The centre had virtually no multidisciplinary team. There was only a professional nurse who was not qualified in mental retardation but only in paediatrics.

The idea of the multidisciplinary team functioning in the community and drawing on a range of resources and skills, is viewed as the most outstanding vehicle for achieving the goal of the health and social care agencies, including collaboration care

planning and care delivery. However, the problems of managing staff from different professions and organisations remain problematic in many communities (McGrath 1991:145).

"The highest possible exit" as indicated by respondents seems to be confusing. Teachers saw it as "the highest possible potential reached by the child", or as the "vocational group". Until the classification criteria are revised such discrepancies will exist.

The centre was surrounded by a lot of shacks, a contributory factor to the reported high rate of theft and burglary.

The respondents reported a problem of children coming from poor homes, where they came to school hungry, dirty and torn. The researcher also observed this. However, the children did not get any grant, they had to wait until they turned 18. There was poor school attendance, and some children abused alcohol and drugs. Others were highly destructive; they were reported to be tearing their books and breaking their pencils. Aggression might be caused by pressure being applied on the child to achieve; lack of insight and the need to experiment. A loving, understanding teacher and parent will encourage conformity (Vlok 1996:719).

It might be difficult to transfer vocational skills from teacher to MMRPs because there were few teachers in the school who specialised in any other field than teaching. Skills possessed by these few teachers, included training in:

Table 16: Discussion and reflecting on analysed data (as on Table 5)

	Number of skilled teachers	%
First Aid	2	9.5
Home economics	2	9.5
Computer Science	1	4.8
Art	1	4.8
Woodwork	1	4.8
TOTAL	**7**	**33.3%**
Total number of teachers: 21 - 100%		

The other factor which made the situation even worse was the absence of workshops and equipment where the one teacher's woodwork knowledge could be utilised.

There was enough transport to take the children to school and back home. Despite this safe measure, there was a high incidence

of child abuse. The possibility might be that children found nobody at home after being dropped by their transport. They stayed outside and become prey to child abusers. Hijacking was also reported.

Huge budgetary cuts and government financial constraints were reported by school respondents with resultant delays in carrying out planned programmes / projects.

The teachers responded that it was difficult to organise any inter-schools sports owing to their poor financial status, because they did not have the equipment and facilities. Also there were no workshops, because of budgetary cuts. The teachers were pessimistic as to whether they would ever have any workshops built for the MMRPs

The parents have confirmed that they did not belong to any support-group. They did not know the meaning of support groups. This made it evident that the professionals were failing in the task of educating the parents and community about health care matters. Health educators are not good role models for the people whom they educate. They have no time for health

education, they often lack appropriate attitudes, and they are inconsistent (McKenzie, Ngobeni & Bonongo 1992:26).

"Actions that exclude the community and which fail to empower others to render care, may be considered to be more technical expertise, but not constitute community nursing"
(Benner 1991:59).

The fact that a large proportion of the parents were poor and illiterate might prevent them from becoming involved in the care of their mentally retarded children.

The parents were happy with their children staying at home and attending day-school, as they maintained that the children would have no chance of roaming about the streets. The parents wished that their children would be taught handwork in the centre to be able to make a living at a later stage. They wished them to acquire skills like sewing, carpentry and knitting, something that the children were not presently getting from the centre.

The community members were totally uninvolved in the welfare of the MMRPs in the community. The centre functioned with only five members of the school governing body and yet the school had a total number of 240 pupils. Parents were not involved in school activities, probably they were not well informed as to what a governing body meant. At exit-level the child had nowhere to go. There were no vocational training facilities at the centre, the possibility was great that the child reached the age 21 years being unskilled, and had to leave school. He could not fit in any sheltered employment thereafter.

Table 17: Institutionalisation is still promoted in the psychiatric institutions visited.

Institution	Severity of mental retardation	Number of patients	Number of years in hospital
Tower	Moderate	5	3-5 years
Kirkwood	Mild Moderate	150 55	5 years and over

The closure of long-term hospitals has helped to ensure that people with a learning disability become part of the community.

It was interesting to find that even the hospital respondents agreed that the Department which would be suitable for the training of the mentally retarded person was that of Education. However one institution mentioned that both Departments should see to the needs of MMRPs. These people were not really sick, but they needed intersectoral collaboration.

If special day-schools were created, they could concentrate on their development according to their grades of retardation, while the families would also be involved in the care of their children. If the child stayed at home and attended a day school, institutionalisation would be avoided. Community awareness about the mentally retarded persons would improve as these people would be within the community.

At the centre, the waiting list was long. 300-600 pupils were still awaiting admission. The problem was that the children were growing in the meantime. It was also difficult to have them admitted to another centre as there were a few centres that served the PE metropole.

5.2 LIMITATIONS

The research in this study was exploratory and descriptive in nature. It was restricted to a centre in the Port Elizabeth area. The small sample therefore did not permit generalisation about the findings. However the data collected in the institution revealed some problems.

Shortcomings in knowledge were acknowledged in some instances, and these produced a variety of reactions including eagerness to learn, resentment and anger. Due to classification and age grouping irregularities, there were a few (8,5%) children whose ages were above the cut-off age (6 to 12).

However, the use of the centre was successful in providing the researcher with a wide view of the topic under study. It also provided an opportunity for the subjects (teachers and parents of MMRPs) to become aware of many sensitive issues and to be able to address these without fear or intimidation.

5.3 IMPLICATIONS

Because primary health care is rendered by nurses working in the community health services, more professional nurses should be trained in primary health care and mental health trends. This would

benefit the RSA in improving primary health care for all its citizens, and also contribute to early diagnosis of mental retardation, instead of it being detected as late as when the child enters school.

There is a need for professional nurses and teachers to follow clinical specialisation, such as advanced psychiatric nursing and mental-retardation courses. This could improve the quality of care rendered to the MMRPs.

The entire research study was an eye-opener to the researcher about the many shortcomings and irregularities that MMRPs are experiencing. They are disadvantaged and discriminated against in many ways, such as being placed in institutions where there are no facilities and equipment to train them, and being kept in hospitals despite the shift to community-based care. There is still a lot to be done to improve the care of mentally retarded persons in the RSA.

5.4. CONCLUSION

The institutional placement of people with mental retardation can be phased out, provided comprehensive community service systems are established, and resources made available. This will ensure that all

developmentally retarded people receive the support required, in their homes and communities.

This study addressed the research question of the feasibility of implementing community-based care for the moderately mentally retarded persons in a specific centre.

The major role of a health authority is to provide services needed to ensure effective action in the maintenance of good health, prevent and treat ill-health, and to rehabilitate people to good health as well as to provide support and care for those people who are retarded (Thornton 1996:1175).

5.5 RECOMMENDATIONS

It is recommended that;

- more nurses be trained in community health nursing, mental retardation and primary health care, and be placed in the various community settings where their services are required.

- a proper multidisciplinary team be instituted in the centre with immediate effect.

- parents take interest in school activities, be involved in rehabilitation programmes of their children and form partnerships with teachers. By doing this maybe the expectations of seeing their children mastering marketable manual skills such as knitting, sewing, cooking, brick making, building and carpentry might one day be fulfilled.

- the classification criteria of mental-retardation be reviewed to follow that of APA (1994) and children be properly placed according to the severity of their mental retardation, strengths and needs.

- teachers be updated regarding what mental retardation is all about.

- consideration of employing teachers with vocational skills and a qualification in mental retardation.

- services and facilities be made available immediately to ensure effective rendering of care to the MMRPs, under government initiative.

- health talks be given to the community about mental retardation and related topics such as child abuse, to create an awareness of the problem.

- an attempt be made to effect a change in the negative attitudes of the community, parents and service providers towards mentally retarded persons.

- an immediate parental and community involvement in the care of MMRPs be made.

- the problem of the shacks surrounding the school with resultant burglaries, theft and child abuse be addressed by the community, local authority and the community police forums and school governing body.

- those guilty of child abuse whether physically, sexually, emotionally, socially, or psychologically be brought to book and prosecuted.

- parents be involved in self-help schemes and support groups and be taught basic skills especially seeing that the majority of them

are unemployed, they will surely benefit themselves and their families in taking lessons such as sewing and building.

- that the government provide the mentally retarded children with state grants. The parents who are not working and mothers who are sole supporters of their children should be considered.

- funding negotiations be made to be available for MMRPs. Proper accountability should be arranged for resources to individual by provider and by individual to funder.

- the plight of the mentally retarded coming to school hungry, torn and dirty be looked into by the school parents' association and proper referrals be made if necessary to government, local authorities and social workers.

- a proper and fair distribution of resources be made so as not to deprive children because of their condition.

- institutionalisation be done away with by proper placement of MMRPs e.g mild and moderate do not belong in a psychiatric institution but special schools. The mild group can even attend an ordinary academic school.

- the parents of MMR children be taught basic skills such as mothercraft, stimulation programmes, washing, feeding and grooming and looking after the children in their homes.

- proper placement be sought for the children on reaching exit level.

- The MMR children should not be left alone at home to fend for themselves.

  Further investigations should be done to establish whether children could be kept at the centre for longer periods of time, and perhaps practise manual skills, or even perform unskilled labour such as assembling plastic flowers or making wire clothes hangers during these times.

  If this could be implemented the MMR children's mothers might be more willing to accept jobs, knowing that their children are being cared for at the school even outside school hours. The children would have better chances of developing manual skills. The community and producers of products which the MMR children could assemble should assist by providing these opportunities.

Further research is needed to evaluate whether recommendations have been carried out, and what improvements have been made. Also in the near future a research study should be done to give answers to the question whether mental retardation belongs with the Department of Health or that of Education.

The future research should focus on the needs of, and services available for, parents of MMRPs.

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ANNEXURE A.

20 Surrey Street
Kabega Park
PORT ELIZABETH
6025

08 April 1999

The Principal
Luthando Luvuyo Training School
Kwazakhele

Dear Mrs. Nkomombini

RE: **OUR TELEPHONIC CONVERSATION:**
- **THE FEASIBILITY OF IMPLEMENTING COMMUNITY BASED CARE FOR THE MODERATELY MENTALLY RETARDED PERSONS IN A SPECIFIC CENTRE IN PORT ELIZABETH.**
- **ST/NO. 4279131 REGISTERED MACUR STUDENT AT UNISA.**

Permission is hereby requested that the principal, staff and parents (of the moderately mentally retarded children) of your institution complete the questionnaire used for the above quoted research study.

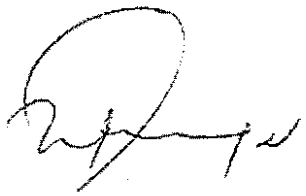
I also request you to allow me to conduct a pretest session with the staff as well as parents (10% will be used). The pretest session will be done on 22 April 1999.

This will be followed by an actual research study which will take place in the week 21 - 25 June 1999.

I hope that my request will receive your favourable attention.

I thank you.

Yours faithfully



NGCANGA N.M. (MS)

Luthando - Luvuyo

SPECIAL SCHOOL

All correspondence to be addressed to : -
The Principal

(041) 466-2738
(041) 466-2931
Fax : (041) 466-4809

11042
Algoa Park
Port Elizabeth 6005

14 APRIL 1999

Dear Ms Ngcanga

This Letter refers :-

1.Permission for you to do a pretest/ research in our school is granted

2.The staff and parents will be informed re - the research quoted dates.

3. Also the Educational development officer and the school Governing Council will be notified.

We wish you success in your studies.

Thanking You

C.T. NKOMOMBINI
Shake
p/ **ACTING PRINCIPAL**

Luthando - Luvuyo

SPECIAL SCHOOL

All correspondence to be addressed to : -
The Principal

(041) 466-2738
(041) 466-2931
Fax : (041) 466-4809

11042
Algoa Park
Port Elizabeth 6005

15 JUNE 1999

Mzali Obekekileyo

Mzali uyacelwa ukuba nakanjani uzaine ufike apha e Sikolweni nangaluphina usuku Olukula veki iqala ngomhla ka 21 June ukuya ku 25 June 1999 ngo 9am kusasa . kuza kufika I nurse eze malunga nomntwana wakho

Nceda usazise ngoluphi na usuku onokuphumelela ngalo kule veki Ikhankanywe ngentla . nikela impendulo nge-Transport okanye ngomntwana wakho.

Enkosi

C.T. NKOMOMBINI
ACTING PRINCIPAL

ANNEXURE B

1997 INFO

SITUATIONAL ANALYSIS: LSEN-EASTERN CAPE

NAME OF SCHOOL ..LUTHANDO – LUVUYO SPECIAL SCHOOL
POSTAL ADDRESS ..P.O. BOX 11042 ALGOA PARK
RESIDENTIAL ADDRESS ..MAKUBALO STREET
DAY/RESIDENTIAL ..DAY SCHOOL
CAPACITY ...228.....(POSSIBLE NO. OF STUDENTS)
PRESENT ENROLMENT ..240
NUMBER OF CLASSROOMS USED:..18
NUMBER OF CLASSROOMS UNUSED:../
REASONS WHY SOME CLASSROOMS ARE NOT USED:-

THIS CLASSROOM IS FOR HOME ECONOMICS , WE DO NOT HAVE A HOME ECONOMICS TEACHER AT THE MOMENT

TOTAL NUMBER OFCLASSROOMS:..19
KIND OF LSEN ..S.M.H.....(e.g BLIND/DEAF/SMH. ect..)
NUMBER OF BOYS ..132
NUMBER OF GIRLS ..108
CLASSES FROM JUNIORS.... TO SENIORS..(lowest to highest)
DATE ESTABLISHED ....OCTOBER 1982
STATE/STATE-AIDED/PRIVATE ....STATE - AIDED
PRINCIPAL:../
SENIOR DEPUTY PRINCIPAL:..NONE
DEPUTY PRINCIPAL:..NONE
HEADS OF DEPARTMENTS (HOD'S):..4
TEACHING STAFF NUMBER:..17
TEACHER AIDS NUMBER..3
REMEDIAL TEACHER:..NONE
SENIOR ADMIN CLERKS :..2
SENIOR ACCOUNTS CLERK:..NONE
SOCIAL WORKERS NONE
SENIOR TYPIST /

ADMIN CLERK: 1
ACCOUNTS CLERK: NONE
STOCK CLERK: NONE
PHYSIOTHERAPISTS NUMBER: NONE
OCCUPATIONAL " " NONE
SCHOOL PSYCHOLOGIST NO NONE
GUIDANCE & COUNSELLING TEACHER NONE
NURSES 1
GENERAL ASSISTANTS 9 (labourers)
DRIVERS: 2
FACTOTUM 2
SEMI-SKILLED
SPEECH THERAPISTS NONE
SPEECH & HEARING COMMUNITY WORKER NONE
AUDIOLOGISTS : NONE
SENIOR HOUSEMOTHERS 7
HOUSEMOTHERS 2
SENIOR COOKS: NONE
COOKS NONE
WAITING LIST BOYS 453 GIRLS 246 TOTAL 699
WATER TREATMENT ATTENDANTS: NONE
TECHNICIANS: NONE
SIGN LANGUAGE SPECIALIST: NONE
BRAILLE SPECIALIST: NONE
PHOTOCOPIER ATTENDANTS: NONE
PREVOCATIONAL TRG CLASSES (tick applicable ones with an X)
WOODWORK X
WELDING
BUILDING
NEEDLEWORK & CLOTHING
HOME ECONOMICS
WAITING LIST BOYS 453 GIRLS 246 TOTAL 699

TEACHER PUPIL RATIO

CLASS	NO.OF PUPILS	BOYS	GIRLS	NO.OF TEACHERS
JUNIORS	51	33	18	3
MIDDLE GR.	84	49	35	7
SENIORS	105	50	55	7

ANNEXURE C.

cap 2

G.P.-S. 81/143299

ANNEX C.

E. METROPOLE:

By JIMMY MATYU, Chief Reporter

MENTALLY handicapped children are the latest victims of alleged child abuse and rape in Uitenhage.

Uitenhage residents are outraged at allegations of the abuse of children at the Mzam'omhle Special School at Ponana Tini Street in KwaNobuhle.

One 14-year-old was so badly injured after allegedly being raped by three men that she had to be admitted to the Uitenhage Provincial Hospital.

Police are investigating four cases of rape and one of indecent assault at the school. It is alleged that some children were so desperately unhappy there, they preferred to live on the streets.

The incidents have enraged the Uitenhage community and community-based organisations have called for action.

Workshops and educational programmes are being planned.

Uitenhage Mayor Rascus Kopo, the Uitenhage Child Protection Unit, the ANC Women's League and Cosatu have con-

● Turn to Page 2

● From Page 1

demned the increasing sexual molestation of young children, violence against women and crime in general in Uitenhage.

Mzam'omhle's senior professional nurse in charge, Zinzi Hopa, said the 14-year-old girl was on her way to the school on June 1, to join those going to the International Children's Day rally at the Feather Market Centre in PE.

She took a short cut and was accosted by three men, who allegedly raped her.

The girl was admitted to hospital, treated for a few days and discharged, but has not yet been able to return to school.

"The number of our pupils being sexually molested is increasing at an alarming rate without the perpetrators being brought to book," she said.

Miss Zinzi said the staff, pupils and parents planned a march against rape, child abuse and violence next Wednesday.

Principal Marjorie Davids said the number of raped children at her school was increasing. She knew of five.

"Our objective in staging the march is to highlight this problem and to show our dissatisfaction that children are victimised by adults with nothing being done about it by the authorities," she said.

Jenny Rose - June 18 1997

Child raped in PE

Post Reporter

A 50-YEAR-OLD man from Soweto on Sea has been arrested for raping an eight-year-old retarded child.

Police spokesman Johan Buys said the little girl, who sustained injuries, had received treatment at the Ncedo Care Centre.

The incident was reported to police after the girl was seen running out of the suspect's shack in Soweto on Sea at 11am on Friday. (on Good Friday!!) 7 April

Captain Buys said that when the girl was questioned, she told police that she had been raped by the man.

The suspect was later arrested and is due to appear in court this week.

Evening Post: 7 April 1998.

EASTERN PROVINCE HERALD TUESDAY MARCH 31, 1998

Uitenhage man sexually assaulted

By SHAUN GILLHAM

A 26-YEAR-OLD mentally retarded man was sexually assaulted by two men in Uitenhage yesterday.

Uitenhage police spokesman Captain Trevor Appel said the mentally retarded man was taken to a house in Tuna Street, Uitenhage where he was allegedly sexually abused by two men.

Captain Appel said the suspects were known to the victim and the police.

He said the case came to light after the man left the Tuna Street house and told his father about the incident.

His father reported the matter to the police.

No arrests have been made yet.

ANNEX C.

(x)

ope alone does not guarantee the future. The success of community care dependent on the attitudes and reactions of people who have had little or contact with people who have a mental handicap. Some are sympathetic t many appear apathetic - feeling perhaps that there is little they can do. ie few who are antagonistic can make life in the community intolerable.

- Kids tease and jeer at people as they wait for a bus.
- Shoppers are afraid to lend a helping hand if they see a person in difficulties.
- Parents complain that the child with special needs is taking up too much of the teacher's time in the integrated classroom.
- Neighbours protest at the prospect of a group home opening in their locality.
- Employers quickly dismiss the idea of giving a job to a person with a mental handicap.
- Politicians have more pressing concerns on which to spend money.

CLOSED DOORS

McCartney, R. 1991 Closed Doors Issued. SSMH Glasgow, Scotland.

ANNEXURE D

QUESTIONNAIRE

INSTRUCTIONS:

- **A REQUEST IS MADE THAT YOU RESPOND TO THE FOLLOWING QUESTIONS AS STATED BELOW.**

- **KINDLY BE ADVISED THAT ALL INFORMATION WILL BE KEPT CONFIDENTIAL.**

SECTION A : DEMOGRAPHIC DATA : THE SCHOOL

1. Name of the School / Institution:

   .....

2. Total number of mentally-retarded persons in the school, according to the following:

   2.1 Mild
   Moderate
   Severe
   Profound

   2.2 Age-group: 6 - 17 Yrs
   18 - 21 Yrs

   2.3 Racial Groups: Blacks
   Coloured
   Asiatic
   White

   2.4 Sex: Boys
   Girls

3. Are the children: Boarding
   Day-schooling

4. Do the children/pupils pay school fees YES | NO

5. If yes, how much?

6. Is the school subsidized by the Government? YES | NO

7. If yes, indicate whether fully or partially

2/....

8. Indicate the categories and their numbers (i.e. how many of each) of the personnel working in the school:

9. Which of the following qualifications do you hold:
   - Primary teachers course
   - Senior teachers course
   - Diploma in mental-retardation (speciality)
   - Other

10. For how long have you been a teacher:
   - Less than 6 Months
   - 6 Months - 1 Year
   - 2 Years - 5 Years
   - 6 Years - 9 Years
   - 10 Years and over

11. Identify the multi-disciplinary team members that are found in the school:
   - Social-worker
   - Medical-Practitioner
   - Professional Nurse
   - Psychologist
   - Psychiatrist
   - Occupational therapist
   - Speech-therapist
   - Physiotherapist

12. If any professional nurse, what is her/his "speciality"?

13. Are the following facilities available in your school?
   - Community representative — YES | NO
     If yes, specify:

     _____
     _____

   - Enough manpower — YES | NO
     If no, specify the shortfall:

     _____
     _____

3/....

- Teachers with the following skills/ training:-
  - Basic Nursing, e.g. First Aid
  - Home-economics
  - Computer Literacy
  - Art and Designing
  - Hair-salon
  - Any other

- Teaching/training equipment for example (skill training):
  - Woodwork
  - Panelbeating
  - Motor-mechanics
  - Metal-work
  - Basket weaving
  - Any other

- Recreational facilities

- Transport

14. Does the school offer any academic classes, if yes, specify: YES / NO

---

15. What is the highest exit-level that a child must reach in your school?

16. Where is the child placed after this exit-level?

---

17. How many children are on the school's waiting list?

18. For how long have these children been on your waiting list?
    - 6 Months - 1 Year
    - 1 Year - 3 Years
    - 3 Years - 5 Years
    - 5 Years and over

19. Specify any other problems you encounter as principal/ teacher of the school in relation to:

- The situation of school: ----------

- Child abuse: ----------

- Absenteeism: ----------

- Any other: ----------

SECTION B : PARENT

20. Identifying the following:

- Age of child: [ ]
- Sex : [ ]
- Racial group: [ ]

21. How many children do you have? [ ]

22. Ordinal position of this particular child in your family. [ ]

23. Who is supporting your family?

- Food [ ]
- Clothing [ ]
- Education [ ]
- Shelter [ ]
- Medical Aid [ ]

24. When did you notice that the child is mentally retarded?

---

25. How did your child become mentally retarded?

---

26. How did you get your child to be admitted to this school?

---

27. Does your child have to pay school fees? YES | NO

If yes, how much?

28. Do you have to buy school-uniform for your child? YES | NO
If yes, how much do you spend on uniform?

29. Is your child getting a state-grant? YES | NO

If yes, how much?
If no, why?

---

30. Are you employed? YES | NO

If yes, specify type of job you are doing.

If no, why?

---

31. How does the child get to school?

---

32. Where does the child go to after school?
- Home
- Neighbour
- Stays outside until there is somebody home

33. Do you notice any skill-development, since the child is attending this school? YES | NO
If yes, specify what?

---

34. What do you wish to be provided with, that you think can help in the process of you caring for the child?

---

35. If you were to choose, would you prefer to keep your child at home, whilst attending the day-school, or have the child admitted to hospital?
Motivate your answer (why?)

SECTION C : HOSPITAL/HEALTH INSTITUTION

36. Name of institution/hospital:
- Tower
- Komani
- Kirkwood
- Fort England

37. Total number of mentally retarded patients in your ward/hospital:

38. Indicate the patients according to their:
- Sex
- Age
- Race

39. Types of mentally retarded patients in you institution/hospital and specify how many of each type:

TYPE	TOTAL NO.
- Mild	
- Moderate	
- Severe	
- Profound	

40. For how long have these patients been admitted to you ward/hospital:

- 6 months - 1 year
- 1 year - 3 years
- 3 years - 5 years
- 5 years and over

41. What are the qualifications/categories of staff that are working in the wards for mentally retarded persons:

	NO
- General nurse	
- Midwife	
- Community Health Nurse	
- Psychiatric Nurse	
Specialist in Mental Retardation	
- Assistant Nurse	
- Any Other	

P/...

42. What are the main functions rendered by each staff member in the process of them caring for the mentally retarded person in the ward?

---

43. Indicate the multi-disciplinary team members that are available in the institution/hospital:

- Psychologist
- Social-Worker
- Speech-Therapist
- Medical-Practitioner
- Psychiatrist
- Psychiatric-Nurse
- Physiotherapist
- Occupational Therapist
- Pharmacist
- Minister of Religion

4.4 Specify facilities available in your institution/hospital for the caring of mentally retarded persons, under the following headings:

- Manpower: ---

- Equipment for development of:
  - Vacational skills:

-

-

  - Stimulation programmes:

-

-

- Recreational: ---

- Finance (budget): ---

---

45. Under which sector does the institution belong?

Private [ ] State [ ]

46. In your opinion under which Department should the institution/hospital belong?

Health [ ] Education [ ]

Motivate your answer (why?)

---

47. If you were to choose, where would you like mentally retarded persons be cared for:

- Hospital [ ]
- Day Care Centre [ ]
- Special Day School [ ]
- Home [ ]

Motivate your answer (why?)

ANNEXURE E

QUESTIONNAIRE

- **YOU ARE REQUESTED TO RESPOND TO THE FOLLOWING QUESTIONS AS STATED BELOW.**
- **MAKE A TICK (✓) IN THE APPROPRIATE SPACE.**
- **BE ADVISED THAT ALL INFORMATION WILL BE KEPT CONFIDENTIAL**

SECTION A: DEMOGRAPHIC DATA : THE SCHOOL

1. School:

   Name: .....

   Officially opened; In: .....By: .....

   Under the Department of Health ☐
   Education ☐

2. Total number of mentally-retarded persons in the school: ☐

3. Specify their **numbers** according to the following:

   3.1 Classification: i.e. (how many)
   - Mild ☐
   - Moderate ☐
   - Severe ☐
   - Profound ☐

   3.2 Age-group: (how many)
   - 6 - 17 years ☐
   - 18 - 21 years ☐

   3.3 Racial groups: (how many)
   - Blacks ☐
   - Coloureds ☐
   - Asiatic ☐
   - White ☐

   3.4 Sex: (how many)
   - Boys ☐
   - Girls ☐

4. Are the children:
   - Boarding ☐
   - Day-schooling ☐

5. Do the children/pupils pay school-fees:
   - Yes ☐
   - No ☐

   If yes, how much? ☐

2/....

6. Is the school subsidized by the Government?
   - Yes
   - No

   If yes, indicate whether:
   - Fully
   - Partially

7. Indicate the categories of the personnel working in the school and how many of each category.

CATEGORY	NUMBER/S
.....	
.....	
.....	
.....	

8. Which of the following qualifications do you hold?
   - Primary teachers course
   - Senior teachers course
   - Diploma in Mental-retardation
   - Any other (specify)

   .....

9. If qualified in <u>diploma in mental-retardation</u>: <u>specify subjects</u> undertaken in this "speciality":

   .....
   .....
   .....

10. For how long have you been a teacher?
    - Less than 6 months
    - 6 months - 1 year
    - 2 years - 5 years
    - 6 years - 9 years
    - 10 years and over

11. For how long have you been a teacher for <u>mentally-retarded children</u>:
    - Less than 6 months
    - 6 months - 1 year
    - 2 years - 5 years
    - 6 years - 9 years
    - 10 years and over

12. Identify the multi-disciplinary team-members that are found in the school:

- Social-worker
- Medical-practitioner
- Professional-nurse
- Psychologist
- Psychiatrist
- Occupational-therapist
- Speech-therapist
- Physiotherapist

If any professional-nurse, what is her/his "speciality"?

.....

13. State whether the following are available in your school:

- Governing body - Yes / - No

If yes, how many members?

- Enough man-power - Yes / - No

If no, specify short-fall:

.....
.....

- Teachers with the following skills/training:

	YES	NO	HOW MANY
- Basic Nursing / First-Aid			
- Home-economics			
- Computer Literacy			
- Art			
- Designing			
- Hair-salon			
- Any other e.g. Internal decorating			

- Recreational facilities: Fields/Courts for e.g.

	YES	NO
- Rugby		
- Netball		
- Table-tennis		
- Tennis		
- Soccer		
- Cricket		
- Any other (specify)		

.....

.....

- Teaching/skill training equipment/facilities
- e.g. - Wood-work
  - Panel-beating
  - Motor-mechanics
  - Metal-work
  - Basket-weaving
  - Any other (specify)

.....

- Transport

	YES	NO	HOW MANY
- Bus			
- Combi			
- (Small car) Sedan			

- Any other (specify)

.....

- State the "use" of transport:

.....
.....

14. Does the school offer any academic classes:
    Yes
    No

    If yes, specify subjects given:

.....
.....

15. What is the highest exit-level that a child must reach in your school? ----------

16. State a specific skill that the child would have acquired at this exit-level:

.....
.....

17. Where is the child placed after this exit-level?

.....

If placed - state purpose/reasons for placement:

.....
.....

If not placed - state why?

.....

What happens to child thereafter:

.....

18. How many children are on the school's waiting list? [_____]

19. For how long have these children been on the waiting list:
- 6 months - 1 year [_____]
- 1 year - 5 years [_____]
- 5 years and over [_____]

If 5 years and over - any reason for waiting so long?

.....

What other options is the parent given to get her/his child helped somewhere?

.....

20. State any other problems that you encounter as a principal/teacher whilst caring for these mentally-retarded children in relation to the:

- School: .....
  .....
  .....

- Pupils: .....
  .....
  .....

- Parents: .....
  .....
  .....

- Facilities: .....
  .....
  .....

- Resources e.g. finance, material, etc.

  .....
  .....
  .....

- Any other problems:

  .....
  .....
  .....

21. State how involved is the community in the care of these children and school matters:

.....
.....
.....
.....
.....

SECTION B : PARENT

22. Furnish the following:

- Age of child
- Sex
- Racial group

23. How many children do you have?

24. Ordinal position of this particular child in your family:

.....

25. Who supports the family with the following:

- Food
- Clothing
- Education
- Shelter
- Medical aid

26. Who diagnosed your child as mentally retarded? ----------

When was this? ----------

27. How did you react when you heard that your child was mentally retarded:

.....
.....

28. What caused your child to be mentally retarded?

.....
.....

29. Who referred your child to this school?

.....

30. Does your child have to:

- pay school-fees? - Yes / - No

If yes, how much?

- buy school-uniform? - Yes / - No

If yes, how much do you spend on uniform?

31. Is your child getting a state-grant?

- Yes
- No

If yes, how much?

If no, why? .....
.....

32. Are you employed?

- Yes
- No

If yes, specify type of job you are doing:

.....
.....

If no, why? .....
.....

33. How does your child get to school?

.....

34. Where does the child go to after school?

- Home
- Neighbour
- Stays outside until there is somebody home

35. Do you notice any improvement/skill-development, since the child is attending this school?

- Yes
- No

If yes, what? .....
.....

36. Are you a member of any support-group related to the care of mentally retarded children?

- Yes
- No

If yes, which group? .....

How do you benefit from group?

.....
.....

37. What do you wish to be provided with, which you think can help in the process of you caring for the child?

.....
.....
.....
.....
.....
.....

38. If you were to choose, would you prefer to keep your child at home, whilst attending the day-school or have her/him admitted to hospital:

- Home, attending day-school
- Hospital

State why?

.....
.....
.....
.....
.....
.....

SECTION C : HOSPITAL/HEALTH INSTITUTION

39. Name of institution/hospital:
- Tower
- Komani
- Kirkwood
- Fort England

40. Total number of mentally retarded patients in your ward/hospital:

41 Indicate the patients according to their:
- Sex
- Age
- Race

42. Types of mentally retarded patients in your institution/hospital and specify how many of each type:

TYPE	TOTAL NO.
Mild	
Moderate	
Severe	
Profound	

43. For how long have these patients been admitted to yourward/hospital:

- 6 months - 1 year
- 1 year - 3 years
- 3 years - 5 years
- 5 years and over

44. What are the qualifications/categories of staff that are working in the wards for mentally retarded persons:

	NO
General nurse	
Midwife	
Community Health Nurse	
Psychiatric Nurse	
Specialist in Mental Retardation	
Assistant Nurse	
Any Other	

11/...

45. What are the main functions rendered by each staff member in the process of their caring for the mentally retarded person in the ward?

---

46. Indicate the multi-disciplinary team members that are available in the institution/hospital:

- Psychologist
- Social-Worker
- Speech-Therapist
- Medical-Practitioner
- Psychiatrist
- Psychiatric-Nurse
- Physiotherapist
- Occupational Therapist
- Pharmacist
- Minister of Religion

47. Specify facilities available in your institution/hospital for the caring of mentally retarded persons, under the following headings:

- Manpower: ---

- Equipment for development of:
  - Vocational skills:

  - Stimulation programmes:

- Recreational: ---

- Finance (budget): ---

---

48. Under which sector does the institution belong?

Private [ ] State [ ]

49. In your opinion under which Department should the care of a moderate mentally retarded person belong?

Health [ ] Education [ ]

Motivate your answer (why?)

---

50. If you were to choose, where would you like mentally retarded persons be cared for:

- Hospital [ ]
- Day Care Centre [ ]
- Special Day School [ ]
- Home [ ]

Motivate your answer (why?)

Icandelo B : uMzali

Interpretation of the English questionnaire into Xhosa:

22. Nika le nkcazelo ilandelayo:
    - ubudala bomntwana
    - ubume - yintombi/nkwenkwe
    - uhlanga

23. Unabantwana abangaphi?

24. Lo mntwana ngowesingaphi? .....

25. Ngubani onakekela usapho malunga nezimfuno zilandelayo:
    - ukutya
    - impahla yokunxiba
    - imfundo yabantwana
    - uphahla (indlu yokuhlala)
    - unakekelo mpilo

26. Wava ngabani ukuba ingqondo yomntwana wakho ibuthathaka/khubazekile?

    .....

    (i) Kwakunini ngoko? .....

27. Wayamkela njani le ngxelo ingentla? .....

    .....

28. Kwathiwa ibangwa yintoni lengqondo ibuthathaka/ ikhubazekileyo?

    .....

29. Wathunyelwa ngubani kwesisikolo umntwana wakho?

    .....

30. Kwesisikolo umntwana wakho akuso:
- Kukhona imali eqinggiweyo ayibhatalayo?

Ewe ☐
Hayi ☐

- Okokuba ewe, malini? ☐
nini? ngeveki? ☐
mpelanyanga? ☐
ngonyaka? ☐

- Uyasithenga isinxibo sesikolo (uniform)?
Ewe ☐
Hayi ☐

- Okokuba ewe, yimalini oyichithayo ukuthenga leuniform? ☐

31. Umntwana wakho uyayifumana indodla?
Ewe ☐
Hayi ☐

- Okokuba ewe, malini? ☐

- Okokuba hayi, kutheni? ☐

.....

.....

32. Uyaphangela wena mzali?
Ewe ☐
Hayi ☐

- Okokuba ewe, nika ngokufutshane uhlobo lomsebenzi owenzayo:

.....

.....

- Okokuba hayi, kutheni? .....

.....

33. Uyangantoni umntwana wakho esikolweni?

.....

34. Sakuba siphumile isikolo uyaphi umntwana?
- Ekhaya
- Ebumelwaneni
- ulinda phandle de kufike umntu ekhaya

35. Kukho mnyinyiva, nguquko yobuchule bokwenzanto owuqaphelayo okoko lomntwana wakho wahamba kwesi sikolo?

.....

.....

36. Ulilungu laliphi iqumru elixhasanayo labazali abanakekela abantwana babo abanggondo zibuthathaka/ khubazekileyo:

Ewe
Hayi

- Okokuba ewe, eliphi iqumru? .....
- Yintoni oyizuzayo ngokuba lilungu leliqumru?

.....

37. Ungwenela ukwenzelwa ntoni, ocinga ukuba ingaluncedo ekunakekeleni kwakho lo mntwana:

.....

38. Okokuba ubunokukhetha, ubungathanda ukumgcina ekhaya umntwana, loxa ehamba isikolo sasemini okanye ayekugcinwa esibhedlele?
- ekhaya, ehamba isikolo sasemini
- esibhedlela

ANNEXURE F

SECTION C : HOSPITAL/HEALTH INSTITUTION

39. Name of institution/hospital:
- Tower
- Komani
- Kirkwood ✓
- Fort England

40. Total number of mentally retarded patients in your ward/hospital: 350

41. Indicate the patients according to their:
- Sex M & F
- Age 5 - 60
- Race ALL RACES

42. Types of mentally retarded patients in your institution/hospital and specify how many of each type:

TYPE	TOTAL NO.
Mild	150
Moderate	55
Severe	120
Profound	25

43. For how long have these patients been admitted to your ward/hospital:
- 0 months - 1 year
- 2 years - 3 years
- 4 years - 5 years
- 6 years and over ✓

44. What are the qualifications/categories of staff that are working in the wards for mentally retarded persons:

	NO
General nurse	
Midwife ✓	
Community Health Nurse ✓	
Psychiatric Nurse ✓	
Speciality in Mental Retardation ✓	✓
Assistant Nurse ✓	
Any Other	

KIRKWOOD CARE CENTRE
P.O. BOX 279
KIRKWOOD
5120

45. What are the main functions rendered by each staff member in the process of them caring for the ~~mentally~~ retarded person in the ward?

THERAPEUTIC PROGRAMMES, BEHAVIOUR MODIFICATION. BASIC NURSING CARE. VOCATIONAL SKILLS TRAINING. ACTIVITIES OF DAILY LIVING. (ADL) SPIRITUAL ACTIVITIES.

46. Indicate the multi-disciplinary team members that are available in the institution/hospital:

- Psychologist	
- Social-Worker	✓
- Speech-Therapist	
- Medical-Practitioner	✓
- Psychiatrist	✓
- Psychiatric-Nurse	✓
- Physiotherapist	✓
- Occupational Therapist	✓
- Pharmacist	✓
- Minister of Religion	✓

47. Specify facilities available in your institution/hospital for the caring of mentally retarded persons, under the following headings:

- Manpower: ----------
- Equipment for development of:
  - Vocational skills:

    EQUIPMENT IS PROVIDED IN DIFFERENT AREAS LIKE OT. DEPARTMENT → CRAFT ROOM, INDUSTRIAL SUBCONTRACT WORK, STIMULATION ROOM, WARDS → BEDMAKING
  - Stimulation programmes:

    SENSORY STIMULATION PROGRAMMES → PERCEPTUAL STIMULATION FOR CHILDREN DEVELOPMENTAL PLAY ACTIVITIES, EG BALLS, SWINGS
- Recreational: INDOOR AND OUTDOOR GAMES - SOCCER BA NETBALL CARDS DRAFTS LUDO SNAKES & LADDERS, FINGER BOARD. MUSIC CENTRES VIDEO AND TV.
- Finance (budget): ----------

SECTION C : HOSPITAL/HEALTH INSTITUTION

39. Name of institution/hospital:
- Tower
- Komani
- Kirkwood
- Fort England

✓

40. Total number of mentally retarded patients in your ward/hospital: 26

41. Indicate the patients according to their:
- Sex
- Age
- Race

M	F
15	11
B	

6y - 1 9 → 6
7 - 2 10 - 1
8 - 2 11 - 4
12 - 1 13 - 18 = 10

N = 2
C = nil

42. Types of mentally retarded patients in your institution/hospital and specify how many of each type:

TYPE	TOTAL NO.
	NIL
	5
	14
	7

- Mild
- Moderate
- Severe
- Profound

43. For how long have these patients been admitted to your ward/hospital:

7
4
6
9

- 0 months - 1 year
- 2 years - 3 years
- 4 years - 5 years
- 6 years and over

44. What are the qualifications/categories of staff that are working in the wards for mentally retarded persons:

	NO
	3
	3
	Nil
	3
	Nil
	8
S.A.S.O	2

- General nurse
- Midwife
- Community Health Nurse
- Psychiatric Nurse
- Speciality in mental retardation
- Assistant Nurse
- Any other

SASO → Specialized Auxiliary Service Officers

[illegible] HOSPITAL
FORT BEAUFORT

LR [illegible]

45. What are the main functions rendered by each staff member in the process of them caring for the mentally retarded person in the ward?

Provision of basic needs, stimulation and active and passive exercises, positioning.

46. Indicate the multi-disciplinary team members that are available in the institution/hospital:

- Psychologist	
- Social-Worker	✓
- Speech-Therapist	
- Medical-Practitioner	✓
- Psychiatrist	
- Psychiatric-Nurse	✓
- Physiotherapist	
- Occupational Therapist	
- Pharmacist	✓
- Minister of Religion	✓

47. Specify facilities available in your institution/hospital for the caring of mentally retarded persons, under the following headings:

- Manpower: Shortage
- Equipment for development of:
  - Vocational skills: None
  - Stimulation programmes: Puzzles - music - dancing - sh
  - Recreational: short walks, watching matches
- Finance (budget): Department of health

TOWER HOSPITAL
FORT BEAUFORT

48. Under which sector does the institution belong?

Private [ ] State [✓]

49. In your opinion under which Department should the care of moderate mentally retarded person belong?

Health [✓] Education [✓]

Motivate your answer (why?)

They need both as intersectoral collaboration is encouraged when caring for mentally disabled people. The profound need to be nursed in the community.

50. If you were to choose, where would you like mentally retarded persons be cared for:

- Hospital [ ]
- Day Care Centre [✓]
- Special Day School [ ]
- Home [ ]

Motivate your answer (why?)

They should be under the care of their parents and professional staff so as to get parental love with professional assistance and to be with their siblings. unlike in hospital situation where they are isolated from their families and end up institutionalized.

TOWER HOSPITAL
FORT BEAUFORT

LR Nkwanti C/Dr

ANNEXURE G.

LUTHANDO-LUVUYO SCHOOL UNIFORM (TUNICS) AT THANDABANTU STORE

PRICE LIST GIRLS TUNICS

SIZES	PRICES
5 – 6	R119.95
7 – 8	R125.95
9 – 10	R129.95
11 – 12	R135.99
13 – 14	R145.99
15 – 16	R149.95
17 – 18	R155.99
19 – 20	R157.95

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Port Elizabeth
6001

PO Box 21915
Port Elizabeth 6000

Telephone 041 - 570110
Fax 041 - 570177

Bijee

CLOTHING
MANUFACTURERS

REF: MCP/nw

30 APRIL 1999

ATT: MARY MAPONYANA

TEL: 4662738

TO: LUTHANDO LUVUYO SPECIAL SCHOOL

FAX: 4664809

Dear Mary

RE: QUOTATION

The writer has pleasure in submitting the following quote:

Full Tracksuits

SIZE	PRICE EXCL. V.A.T.	PRICE INCL. V.A.T.
22 - 24	R 150.00	R 160.12
26 - 28	R 161.00	R 183.52
30 - 32	R 168.00	R 191.52
34 - S	R 182.00	R 207.48
M - L	R 195.00	R 222.30
XL - XXL	R 207.00	R 235.98
XXXL	R 213.00	R 242.82

TERMS: We require a 50 % deposit on placing of order
Balance on delivery .

The above prices include basic embroidery and are valid until further notice

Kind regards

M.C. PIETERSEN
MANAGING

LANGUAGE EDITING:

Mrs Helen Allen

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