

**A MODEL FOR EMPOWERMENT OF FAMILIES WITH
MENTALLY HANDICAPPED CHILDREN**

by

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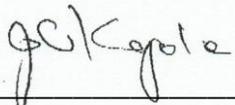
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NOVEMBER 2009

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DECLARATION

I declare that **A MODEL FOR EMPOWERMENT OF FAMILIES WITH MENTALLY HANDICAPPED CHILDREN** is my own work and that all the sources used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.



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A MODEL FOR EMPOWERMENT OF FAMILIES WITH MENTALLY HANDICAPPED CHILDREN

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ABSTRACT

The purpose of this study was to develop an empowerment model for families of mentally handicapped children in Moletši district in Limpopo Province. To achieve this purpose, the study consisted of four steps, namely exploring the meaning of empowerment in the context of families with mentally handicapped children; developing and describing a model for empowerment of such families; formulating guidelines for the implementation of the model, and evaluating the implementation of the model. A qualitative, explorative, descriptive and contextual theory-generative design was used.

The population of the study was all families who had mentally handicapped children in Moletši district of the Polokwane and Aganang municipalities. Semi-structured interviews, assessment guides and case studies were conducted with the families to evaluate the effectiveness of the model and whether the families reached self-efficacy in the care, treatment and rehabilitation of their mentally handicapped children.

Non-probability, purposive sampling was used in order to obtain relevant information from the correct participants. Concepts were identified and analysed, which led to the development of the model for empowerment of families with mentally handicapped children. The model was applied in practice, where the families' problems were identified and planned for, and the plans were put into action by means of case studies, and monitoring and evaluation was done through observation, interviews, discussion and meetings.

The results revealed that the families proved to be independent and reached self-efficacy in the care, treatment and rehabilitation of their mentally handicapped children. The model is a unique contribution to nursing education, research, administration and practice and sets guidelines for a new field in the practice of psychiatric nursing.

Key terms:

Empowerment; Down syndrome; families; mentally handicapped child; model paradigm; theory.

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Dedication

With love and gratitude to my husband, Choene Charles Kgole, for his constant love, support and encouragement, and unending patience and empathy

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List of abbreviations

CBE	Community-based education
DOH	Department of Health
DICAG	Disabled Children Action Group
HSREC	Health Studies Research Ethics Committee
NCAW	National Council of African Women
IPC	International Pentecostal Church
NGO	Non-governmental organization
PBE	Problem-based education
PHC	Primary health care
RDP	Reconstruction Development Programme
UNDP	United Nations Development Programme
UK	United Kingdom
URCSA	Uniting Reformed Church of Southern Africa
USA	United States of America
ZCC	Zion Christian Church

List of annexures

- Annexure A Request for permission to conduct the study
- Permission obtained from Department of Health and Social Development to conduct the study
- Permission obtained from Unisa, Health Studies Research and Ethics Committee (Clearance Certificate) to conduct the study
- Annexure B Request for consent to conduct the study
- Annexure C Request for assistance in a research
- Annexure D Evaluation tool for psychiatric nurses who took part in empowerment of families with mentally handicapped children and evaluation of the family members after the implementation of the empowerment model
- Annexure E Family and mental health assessment, interviews and summaries of case studies

CHAPTER 1

Background and orientation to the study

1.1 INTRODUCTION

Few families are equipped to cope with the birth of a mentally handicapped child. The family's social, psychological, spiritual, physical, and academic functioning becomes impaired, due to the stress and lack of support for mentally handicapped children (Blacher 1998:491; Dossetor, Nicol, Stretch & Rajkhowa 1994:490). Families with mentally handicapped children experience strong emotional reactions, including shock, disbelief, denial, blame, guilt feelings, depression, anger and anxiety, and bargaining as a means of delaying acceptance of the handicap. Family members reach acceptance at different times, depending on the severity of the handicap, availability of support, and their individual psychological and social make-up (Ross & Deverell 2004:37). Ross and Deverell (2004:75) point out that the family's reactions are to be expected since their dreams and hopes for the child are shattered by the presence of the mental handicap.

Rose (1997:19) emphasises that families with mentally handicapped children are faced with many challenges. They need emotional, financial, occupational, social, religious and informational support to care for, treat and rehabilitate their mentally handicapped children. Barr (1995:3) maintains that families of mentally handicapped children should enjoy a high priority for empowerment.

Regarding the role of family psycho-educational support groups, Van Hammond (1995:38) found that group members shared similar problems, discovered that they were not the only persons with problems, felt a common bond, and promised to accept their mentally handicapped children in their families as well as in the community. This indicates that empowerment of the families is needed for the survival of their mentally handicapped children. In the United States of America (USA), Storey (2003:2) found that national and grassroots support eliminated some of the stresses that families experience so that the unique needs of the mentally handicapped children could be met.

If one member is ill, the whole family is affected. Therefore, if there is a mentally handicapped child in the family, the entire family is affected and feels obliged to care for, treat and rehabilitate their mentally handicapped child (Department of Health [DOH] 1997:2).

South Africa (Republic) (1996:7) stipulates that everyone's dignity should be respected and protected. The Constitution states further that every child "has a right to family care or alternative care and if the child is removed from the home the child has the right to basic nutrition, basic health care services and social services". The child also has the right to be protected against abuse and exploitation. This would then imply that mechanisms should be in place to assist families to care for, treat and rehabilitate their mentally handicapped children. Mentally handicapped children should be cared for like any other children.

1.2. RATIONALE FOR THE STUDY

According to the United Nations Development Programme (UNDP), 5.2% of the global population suffered from moderate to severe mental disability (DOH 1997:3). Out of 5.2% of the global population 7.7% was from developing countries and 4.5% was from developed countries. The 1995 survey on prevalence of mental disability indicated the disability in South Africa to be 5%.

In 1997, the DOH presented the *White Paper on the Integrated National Disability Strategy for South Africa* to make provision for the rights and needs of disabled persons, including mentally disabled persons and children. Offices were established in all nine provinces, namely Limpopo, Gauteng, Northern Cape, Eastern Cape, Western Cape, North-West, Free State, KwaZulu-Natal, and Mpumalanga. These offices were established to take care of the welfare of disabled people, including training, social security, protection of their rights, inclusion in community participation, and employment (DOH 1997:23).

Government departments and state bodies are responsible for ensuring that disabled people have access to services and opportunities like other South Africans, for example, mentally disabled people in South Africa have the right to be employed if they have the necessary knowledge and skills.

In South Africa, the South African Mental Health Federation, Down Syndrome Forum of South Africa, South African Epilepsy League, Occupational Therapy Association of South Africa, Disabled Children Action Group (DICAG), and other organisations cater for the mentally handicapped (Bradley 2000:193). Such organisations are responsible for public education and awareness campaigns and programmes, care, treatment and rehabilitation of the mentally handicapped, social security, employment, housing, sport and recreation and research on disability.

Previously, families with disabled members, including mentally handicapped children, had no access to the mainstream services rendered. Mentally disabled persons were regarded as problems and burdens that should be cared for by their families. The Department of Health and Social Development was obliged to care, treat and rehabilitate these mentally disabled persons. Many individuals still perceive mentally handicapped children as burdens to the families due to lack of knowledge to care for, treat and rehabilitate them (DOH 1997:7).

In Waltham, United Kingdom (UK), Kraus and Singer (2003:3) found that people who had mentally handicapped siblings had the following feelings:

- Guilty about not having a disability
- Embarrassed about the siblings' disability
- Ashamed to invite friends to their homes and feared that they might develop the handicap
- Angry and jealous about the care and extra attention given to them
- Overburdened with the responsibility of caring for their siblings

These reactions, experiences and feelings indicate that family members need support in order to cope with their mentally handicapped children and possibly make their children's life meaningful and independent.

Chen and Tang (1997:253) examined the stress and social support among Chinese mothers of adult mentally retarded children and found that family members need health education (informational support) about mental retardation and its causes, as well as ways to care for, support and respect them and their rights.

These findings and her experience as a psychiatric nurse motivated the researcher to develop an empowerment model for families to support, educate or train them to care for, treat and rehabilitate their mentally handicapped children. The community should also be motivated to participate in the care, treatment and rehabilitation of their children.

1.3 SETTING

Moletši district, which falls under the Polokwane and Aganang municipalities in Limpopo province, is a rural district and consists of 108 villages. Being a rural district, Moletši gets assistance from and works together with the local chief and *indunas* in the provision of health care.

Two hospitals, namely WF Knobel Hospital and Seshego Hospital, and five clinics, namely Moletši, Mmotong, Matamanyane, Semenya and Monywaneng Clinics, are responsible for health care provision in Moletši. Moletši Clinic is the referral clinic for the other clinics, and had only five professional nurses, of which one had psychiatric nursing and four enrolled nurses in 2005. In April 2005, 150 mentally ill (who suffered from conditions such Schizophrenic, depressive, manic, eating disorder) people from 15 villages were on the clinic records, and of these 50 were mentally handicapped (who suffered from diseases such Down Syndrome, Hyperactivity, Autism and behavioural disorders). The researcher discovered that the one psychiatric nurse was the only psychiatric professional nurse on the staff, which means that the nurse-patient ratio was 1:150. Only one psychiatric nurse had insight into mental illness and mental handicap, and the families of the 150 patients needed informational support from health professionals.

1.4 PROBLEM STATEMENT

The University of Limpopo, Turfloop Campus, identified 77 mentally handicapped children in 25 villages of Moletši district. Their parents, grandmothers, siblings and neighbours cared for these children. The University of Limpopo supports the families of mentally handicapped children by providing psychiatric nursing students, who conduct home visits, to identify the needs of the families and their mentally handicapped children and equip families with knowledge and skills to care for, treat and rehabilitate these children. The researcher accompanied the University students on their home visits.

Some of the mentally handicapped children were found roaming in the streets; some were at home alone since the parents were out at work, and some were hidden because the parents were afraid of the stigma of mental handicap. Some mentally handicapped children were kept at normal government schools because the families had nowhere to take their children and for the children's safety against rape, abuse or exploitation.

Health education days are held yearly to teach the families, the Moletši community and the family supporters. Fundraising days are held to raise funds for needy families with mentally handicapped children.

The families needed informational and other support in order to take the children to the correct services. This situation indicated the need for the empowerment of families to care for, treat and rehabilitate their mentally handicapped children. As a result, the researcher established Moletši Centre for Mentally Handicapped Children in order to meet the needs of the children. This became a community project, which is funded and supported by community volunteers.

In 2000, the researcher conducted a study on the experiences of parents of mentally handicapped children regarding support services in the Moletši district. The parents indicated a lack of support services, money for transport, and knowledge with regard to mental handicap (Kgole 2000:46).

The present study, therefore, wished to generate an empowerment model to support families with mentally handicapped children as a solution to the existing problems of lack of empowerment for the families in the Moletši district (see chapter 3 for description).

Acuda (1993:55) found a lack of health professionals in Sub-Saharan Africa with children under the age of 15 years forming 50% of the total population. Acuda reported that 10-24% children under 15 years of age in countries/areas of Sub-Saharan such as Botswana, and Namibia Africa, had mental health disorders.

In South Africa, Shipton (1999:3) found that many mentally handicapped children were not correctly diagnosed or cared for.

In most instances, the environment in which they were cared for was not conducive to recovery due to a lack of health professionals and specialisation in the specific community.

1.5 PURPOSE OF THE STUDY

The main purpose of this study was to develop and describe an empowerment model for families of mentally handicapped children in Moletši district in Limpopo Province.

1.6 OBJECTIVES

To achieve the purpose, the study wished to

- explore the meaning of empowerment in the context of families with mentally handicapped children (step 1)
- describe a model for empowerment of families with mentally handicapped children (step 2)
- formulate and describe guidelines for the implementation of the model in practice (step 3)
- evaluate the implementation of the model for empowerment of families with mentally handicapped children (step 4)

1.7 PARADIGMATIC PERSPECTIVE OF THE STUDY

A paradigm is “a research tradition that is established in a certain discipline” (Mouton 2002:203). Creswell (1994:74) describes a paradigm as a collection of logically connected concepts and the proposition of a theoretical framework on which an investigation is based. All research studies follow a paradigm (Creswell 1994:74). Researchers choose certain assumptions from the paradigm in order to conduct a study accordingly (Cindi 2006:10). The paradigm provides an orientation to guide the research approach to the phenomenon under study.

Researchers conduct research on the basis of their values, which direct their activities and thinking. Research is also based on certain assumptions from theories or from everyday life.

Assumptions are statements that are taken for granted without any scientific proof and may be personal beliefs and values (Burns & Grove 2001:721). The paradigm influences the direction of the researcher's thinking and activities, and the development and actualisation of the process (Maputle 2004:6). In line with this argument Morse and Field (1995:243) are of the opinion that the paradigm guides the researcher in the investigation of study phenomena. In this study the selected paradigm guided the research towards the empowerment of families with mentally handicapped children.

The paradigm that the researcher chose is Newman's model, as it is a holistic approach to health care, is person-centred and it believes that the community and family consists of psychological, physical, social, cultural and spiritual aspects. Newman's model also believes that there are positive and negative external and internal factors that affect a human being. This paradigm is relevant in this study as the factor that negatively affects the family is the child's mental handicap. The families of mentally handicapped children should be empowered physically, culturally, socially, psychologically and spiritually. The family also needs empowerment at primary, secondary, and tertiary level of prevention.

According to Botes (1995:13), there are three types of assumptions, namely meta-theoretical, theoretical and methodological assumptions.

1.7.1 Meta-theoretical (ontological) assumptions

Meta-theoretical assumptions deal with people and society. They have an influence on research decisions made but are not testable. They do not give any epistemic pronouncement. Meta-theoretical assumptions are reconcilable with theoretical assumptions though they may not be grounded on theory (Mouton 2002:207). George (2002:349) refers to Newman's model, which identifies four major concepts in nursing's paradigm, namely human being/person, environment, health and nursing.

1.7.1.1 *Human being/person/client*

Newman defines a human being as a physiological, social, cultural, spiritual and open system that is continuously in interaction with the internal and external environment and this environment is continuously exposed to stressors. The stressors found in the environment affect a person's stability and illness (George 2002:349).

The client system may be an individual family or community. In this study, the client system or individuals were the families of mentally handicapped children in the Moletši district.

1.7.1.2 Environment

The environment is the totality of the internal and external influences that affect a person's development and life (George 2002:349). The environment in this research refers to families of mentally handicap children in Moletši district in Limpopo province. See 1.3, study setting for a comprehensive description of the environment of this study.

1.7.1.3 Health

Health refers to a person's degree of stability and is understood as a continuum between wellness and illness. Once a person's needs are met and stressors relieved, stability is attained. Health is attained if physiological, social, psychological, spiritual and cultural stability is attained (George 2002:349). In this study, the families of mentally handicapped children needed to be empowered to meet the needs of their children.

1.7.1.4 Nursing

The main goal of nursing is to assist people to attain and maintain stability by assessing their environment, and planning and developing strategies to restore stability (Stanhope & Lancaster 2000:208).

This study wished to assess the family environment in totality to identify the problems, and plan and implement strategies to attain and maintain the stability of the family. Stability referred to the autonomy and efficacy of families of mentally handicapped children in the care, treatment and rehabilitation of their children.

1.7.2 Theoretical (epistemological) assumptions

Theoretical assumptions offer epistemic pronouncements about the research field and are testable. These pronouncements lead to a better understanding of the research problem.

Theoretical assumptions make statements about the research field and shape the conceptual framework of the research study. Researchers cannot state their theoretical assumptions without undertaking a thorough study of existing theoretical pronouncements on their subject (Botes 1995:14).

In this study the researcher used Neuman's systems model as it is broad and has an open structure (George 2002:348). The open structure makes it applicable to individuals, families, groups and communities. This model is highly utilised in community health nursing. Neuman's personal philosophy was basically helping each other to live and in this study the health professionals assist the families of mentally handicapped children to care for, treat and rehabilitate their children and by so doing, helping their children to live. The model is relevant to the study because it is based on clinical experiences from communities and a variety of health care programmes, such as Child Rehabilitation programmes, Child and Adolescent services, Health Education services and covers primary, secondary and tertiary levels of prevention (George 2002:340).

According to Neuman's systems model, the community, including the family, consists of psychological, physical, social, cultural and spiritual aspects. Neuman defines the environment of the person, family and community as all the internal and external factors that affect them positively and negatively. Neuman believes in a holistic approach to care and the model is person centred (Stanhope & Lancaster 2000:144).

1.7.3 Methodological assumptions

Methodological assumptions direct research design because they are based on researchers' world-view, values and beliefs concerning the nature and structure of science. Methodological assumptions are concerned with the purpose, methods and criteria for the trustworthiness of research (Polit & Hungler 1997:304). This study follows a functional approach proposed by (Botes 1995:12), which assumes that research findings should be used to advance practice of nursing. In line with this view, the

researcher's aim was to develop a model for empowerment of families with mentally handicapped children. The research design and methods are outlined below.

1.7.3.1 Research design and methodology

The researcher used a theory-generative research design which is qualitative, exploratory, descriptive and contextual in nature. The study involved four steps of theory generation outlined below.

1.7.3.1.1 Exploration of the meaning of the concept "empowerment" in the context of the family of mentally handicapped children

The researcher used concept analysis to break down the concept of empowerment into its defining attributes. Attributes were derived from dictionaries and the literature review. The researcher identified antecedents and consequences of empowerment, developed the process of the model, derived theoretical definitions, and identified and explained model and other cases.

1.7.3.1.2 Description of the model for empowerment of families with mentally handicapped children

The researcher described the model, the purpose, assumptions and context of the model. Concepts in the model were defined and relationships explained in the context of the model. The description of the model included its structure and phases. Five independent specialists in model formulation evaluated the empowerment model for clarity, simplicity, generality, accessibility, and significance/importance (Chinn & Kramer 1995:140).

1.7.3.1.3 Formulation and description of guidelines for the implementation of the model in practice

The researcher used a deductive reasoning strategy to deduce guidelines from the model and literature. See chapter 5 for a comprehensive description of guidelines formulated by the researcher in this study.

1.7.3.1.4 Evaluation of the implementation of the model for families with mentally handicapped children

The researcher implemented the guidelines formulated in step 3 as part of her fieldwork in order to determine whether the empowerment model was effective to offer support for the families with mentally handicapped children. Case studies, family and child assessment guides and interviews were utilised as methods for data collection. The research approach used to implement the model in practice is outlined below starting with the research population.

- **Population**

A research population includes all members who are under study; that is, the totality of all the participants or members that conform to a designated set of specifications (Polit & Hungler 1997:224). In this study the research population included all the families with mentally handicapped children in the Moletši district of the Polokwane and Aganang municipalities.

A population sample refers to the number of elements or units of the population under study (Polit & Hungler 1997:229). In this study the sample consisted of the families whose children attending Moletši Clinic.

In order to participate in the study, only families who live with their mentally handicapped children and whose children attended Moletši Clinic were included in the sample. The rationale was that these families would have insight into the needs of their mentally handicapped children.

- **Sample and sampling technique**

Sampling refers to a way of choosing a sample from the population under study in order to obtain relevant information on the phenomenon under study. In this study, non-probability, purposive sampling was used to ensure that the respondents were selected based on their knowledge of the phenomenon. Purposeful sampling is done when researchers select the sample based on existing knowledge of the population and the purpose of the research (Babbie & Mouton 2002:166; Uys & Basson 1995:93).

Purposive sampling was used because the researcher wished to obtain detailed information from the families of mentally handicapped children, who have first-hand experience of their children's problems.

- **Data collection**

Data was collected by means of a semi-structured approach, which afforded the researcher flexibility. In a semi-structured approach, researchers do not set specific questions to be asked in a certain order, but start with a general question and allow participants to talk freely and narrate their concerns or stories. This approach allows interaction and conversation. The researcher preferred this method because the participants could describe the empowerment they used with and for their mentally handicapped children (Maree 2007:29; Polit & Hungler 1995:271). The researcher subsequently identified themes from the data collected.

The researcher used case studies and interviews for data collection. The interviews were tape-recorded with permission of the participants and the interviews were later transcribed verbatim (see chapter 2 for a full description of data collection).

- **Data analysis**

Data analysis is conducted to reduce, organise and give meaning to the data. Data analysis usually begins when data collection begins. The analysis techniques implemented are determined primarily by the research objectives, questions or hypothesis (Burns & Grove 2001:43; Matson & Mulick 1991:60). In this study, the researcher transcribed the interviews verbatim and analysed the data using Tesch's (1990) eight-step method of data analysis (Creswell 1994:155) (see chapter 2).

- **Ethical consideration**

Ethics deals with matters of right and wrong. *Collins English Dictionary* (1995:533) defines ethics as "a social, religious, or civil code of behaviour considered correct, especially that of a particular group, profession, or individual".

The researcher obtained permission from the Department of Health and Social Development because Moletši Clinic falls under the Department of Health and Social Development (see annexure A).

In this study, the researcher respected the respondents' rights to confidentiality and anonymity, informed consent, and privacy (Cormack 1996:31; Wilson 1998:247). The researcher explained the purpose and nature of the study to the respondents before obtaining written informed consent from them (see annexure B). The respondents were informed that participation was voluntary and they could withdraw from the study at any stage should they so wish (Cormack 1996:31; Polit & Hungler 1995:35; Wilson 1998:247). The respondents were given sufficient time to review the consent letter before they and the researcher signed it (Polit & Hungler 1995:378). In addition, the researcher gave her contact address as well as fax and telephone numbers to them.

1.8 TRUSTWORTHINESS OF THE STUDY

Holloway and Wheeler (2002:250) explain that the quality of a research instrument is determined by its validity and reliability. Validity is the degree to which an instrument measures what it is supposed to measure (Uys & Basson 1995:80). Reliability is the degree of consistency or dependability with which the instrument measures the attribute it is designed to measure. If the instrument is reliable, the results will be the same each time the test is repeated (Polit & Hungler 1997:308).

Trustworthiness is a measure to ensure validity. Trustworthiness is the process whereby the researcher confirms that the findings accurately reflect the respondents' experiences and views and not the researcher's perceptions (Polit & Beck 2004:36). The researcher used and Guba Lincoln's (1989) model to evaluate the trustworthiness of the data (Krefting 1991:214).

Lincoln and Guba identify four criteria for trustworthiness, namely, truth value, applicability, consistency and neutrality (Guba & Lincoln 1989:124; Robinson & Gmeiner 1998:4) (see chapter 2 for description).

1.9 DEFINITION OF CONCEPTS

For the purpose of this study, the following concepts are used as defined below:

1.9.1 Mental handicap

Uys and Middleton (2002:492) define mental handicap as subnormal intellectual functioning in general, which is related to impairment in adaptive behaviour and occurs during the developmental period.

American Association of Mental Retardation (2000:240) and Clarke and McGraw (1996:80) classify mental handicap as mild, moderate, severe, and profound mental handicap. Mentally handicapped persons comprise 2% of the population of South Africa. Mental handicap is classified according to the individual's Intelligence Quotient (IQ) level and its manifestation takes place before the age of 18. Mental handicap is classified on IQ and adaptive skills as follows: mild handicap (50 – 70); moderate handicap (35 – 49); severe handicap (20 – 34), and profound handicap (below 20) (American Association of Mental Retardation 2000:241; Kaplan & Sadock 1998:480).

- ***Mild mental handicap.*** Mild handicap is the first level of handicap. The child who is mildly mentally handicapped has difficulty in school adaptation, may not achieve Grade 6, but can achieve social and vocational knowledge and skills and is educable. Mildly handicapped children can develop social and communication skills, can master academic skills in special classes, but can master occupational skills well (Burack & Zigler 1998:70; Uys & Middleton 2002:494).
- ***Moderate mental handicap.*** Moderate handicap is the second level of handicap and the children need to be assisted in social adjustment. A mildly mentally handicapped child is trainable and not educable, can develop some vocational skills and can function better if placed in a sheltered workshop. Moderately mentally handicapped children cannot benefit from the academic setting, can have poor self-awareness, can benefit from social and occupational skills training, and can be put in sheltered employment in special workshops (American Association of Mental Retardation 2000:250).

- **Severe mental handicap.** Severe mental handicap is the third level of handicap and these children can only be trained in minimal skills (e.g., self-help skills like personal hygiene and toilet training). They are not educable.
- They can be taught communication skills in order to communicate their needs (Polloway, Patton, Smith & Buck 1997:4; Uys & Middleton 2002:495).
- **Profound mental handicap.** Profound mental handicap is the last level and these children are neither educable nor trainable. They need continuous and complete nursing care for the rest of their lives. Profoundly handicapped persons can do nothing for themselves, and need constant care throughout their lives because of their poor sensory and motor development.

The main objective of all training activities for mentally handicapped children is to support them to be self-supporting when they become adults. The wish is to assist them to be employed in the open labour market with support when it becomes necessary. Orem's self-care theory (George 2002:310) advocates comprehensive self-care, which includes individuals' physical, psychological and social aspects. Mentally handicapped children should be able to care for their personal hygiene themselves, able to communicate with others effectively, initiate and manage social relationships, and able to use their leisure time with the assistance of therapists (Dunn & LaFrenure 1993:1732; Kaplan & Sadock 1998:1270).

There are several causes for mental handicap, including hereditary or genetic disorders (e.g., chromosomal disorder, inborn errors of metabolism); overexposure to radiation; maternal infections such as Rubella and Syphilis in the first trimester of pregnancy; malnutrition during pregnancy; birth trauma and difficult deliveries like forceps delivery and injuries during birth; post-natal infections that complicate into encephalitis and meningitis; Rh-incompatibility, and childhood infections like encephalitis (Alexander 1998:50; Kaplan & Sadock 1998:1139; Richardson & Koller 1996:47; Warner 1996:629).

1.9.2 Family

Collins English Dictionary (1995:558) defines a family as “a primary social group consisting of parents and their offspring, the principal function of which is provision for its members; a group of persons related by blood; all the persons living together in one household” and (the) extended family as “a social unit that contains the nuclear family together with blood relatives, often spanning three or more generations” *Collins English Dictionary* (1995:548). The nuclear family is “a primary social unit consisting of parents and their offspring” (*Collins English Dictionary* 1995:1071). Stuart and Sundeen (1995:787) describe the family as the smallest unit of society that possesses the origin of its characteristic structure and its pattern of relationships and communication. Stuart and Sundeen (1995:787) refer further to the traditional or extended family, which consists of the parents, their children, and other relatives from both paternal and maternal families; the modern or nuclear family consisting of the parents and their own children, and, finally, single-parent and blended families. In this study, *family* referred to all the types of family defined above.

1.9.3. Child

Collins English Dictionary (1995:281) defines a child as “a boy or girl between birth and puberty”. In terms of the *Child Care Act, 74 of 1983*, a child is “any person who is under the age of 18 years”. In this study, *child* referred to a boy or girl between birth and 18 years old.

1.9.4. Model

Chinn and Kramer (1995:75) describe a model as “a symbol that attempts to represent empirical experiences. The model is not a real thing but a way of representing a concept or phenomenon in an objective manner. A model may be represented in a mathematical form, by means of words or by a material, which is physical in nature in the health profession and this model may be used in the planning and intervention of specific health problems.”

This study wished to develop a model to be used for empowerment of families with mentally handicapped children.

1.9.5. Theory

Collins English Dictionary (1995:1598) defines a theory as “a system of rules, procedures, and assumptions used to produce a result; a set of hypotheses related by logical or mathematical arguments to explain and predict a wide variety of connected phenomena in general terms”. Wendy (1994:4) describes a theory as a set of coherently interrelated concepts that assist in explaining and predicting phenomena to be discussed or researched. Furthermore, a theory may be inductive, that is, from specific to general in nature, and forms a frame of reference for the phenomenon to be investigated. The theory may also be deductive, that is, from general to specific (Wendy 1994:4).

The overall purpose of theory is to make research results or findings meaningful and interpretable. The theory also allows the researcher to limit the observations and arrange them in an orderly system (Polit & Hungler 1995:107).

1.10 OUTLINE OF THE STUDY

Chapter 1 outlines the problem, purpose and objectives of the study, the research design and methodology, ethical considerations, trustworthiness and defines key concepts.

Chapter 2 describes the research design and methodology, including the population, data collection and analysis.

Chapter 3 discusses the development of a model to empower families with mentally handicapped children.

Chapter 4 describes the model *for* facilitation of autonomy/independence and competence of families of mentally handicapped children to support them in the attainment of self-efficacy.

Chapter 5 discusses the guidelines for empowering the families with mentally handicapped children.

Chapter 6 discusses the findings and evaluation of the implementation of the model for empowerment of families with mentally handicapped children.

Chapter 7 concludes the study, briefly discusses its limitations, and makes recommendations for nursing practice and further research, nursing administration and nursing education.

1.12 CONCLUSION

This chapter introduced the research problem, purpose, the objectives and significance of the study; paradigmatic perspective of research, the theory-generative research design, methodology, the setting, problem statement and ethical considerations; defined key concepts used. Data analysis, and measures to ensure trustworthiness were discussed and the study layout was outlined. Chapter 2 gives a comprehensive description of the research design and methodology.

CHAPTER 2

Research design and methodology

2.1 INTRODUCTION

Chapter 1 described the background, purpose and objectives of the study. This chapter discusses the research design and methodology followed by the researcher. In this chapter a comprehensive description of the four theory-generative research design steps is presented. These include: (1) exploration of the meaning of “empowerment”; (2) description of a model structure and process; (3) formulation of guidelines for the implementation of the model in practice, and (4) the evaluation of the implementation of the model in practice (Chinn & Kramer 1995:27; King, Morris & FitzGibbon 1990:40). These four steps of theory-generation were used to generate a model that would offer support to families of mentally handicap children. The chapter starts by describing the purpose and objectives of study, this is followed by the research design and methods used throughout the thesis.

2.2 PURPOSE OF STUDY

As indicated in chapter 1, the main purpose of this study was to generate and describe an empowerment model for support of families with mentally handicapped children in the Moletši district in Limpopo province in South Africa.

2.3 OBJECTIVES AND STEPS OF THEORY GENERATION

To achieve the main purpose, the study wished to fulfill the following objectives through the four steps of theory generation:

Step 1: Explore the meaning of empowerment in the context of families with mentally handicapped children. This objective is attained in chapter 3 of this study.

Step 2: Describe a model for empowerment of families of mentally handicapped children. This objective is comprehensively dealt with in chapter 4.

Step 3: Formulate and describe guidelines for the implementation of the model in practice. This objective is dealt with comprehensively in chapter 5.

Step 4: Evaluate the implementation of the model for empowerment of families with mentally handicapped children. This objective is dealt with in chapter 6 of this thesis.

2.4 RESEARCH DESIGN

The researcher followed a theory-generative design that is qualitative, explorative, descriptive and contextual. In view of the main purpose of this research which is to develop a model, it is fundamental to describe the theory-generative research design, types of theories, and stages of theory-generation before discussing the research methodology.

2.4.1 Theory-generative design

The focus of a theory-generative research design includes concept identification, analysis and definition (Chinn & Kramer 1995:106; Walker & Avant 1995:39). Chinn & Kramer (1995:143) confirm that when the researcher wishes to design a study to generate a model, he or she should have made observations openly in order to see things in a new perspective. In line with this view, the main concept of the model “empowerment” emanated from the preliminary study conducted by the researcher on the experiences of families with mentally handicapped children in Limpopo (Kgole 2000). The findings of this study revealed that parents experienced rejection from health professionals, were unable to get physical, social and psychological support for their mentally handicapped children (Kgole 2000). It became imperative for the researcher to develop a model that would empower these families to support their mentally handicapped children. Theory-generative research design has been chosen for this study for the value of generating logical and meaningful body of knowledge for the discipline of mental health nursing. In an effort to fully comprehend this type of design, the researcher described various types of theories applicable to the discipline of nursing and these are described briefly below.

2.4.1.1 Types of theories

Authors use different typologies / terminologies to describe theory. One typology found in the literature is “levels of theory” (Walker & Avant 1995:5). Another description is scope or breadth (Chinn & Kramer 1995:120). The latter authors state that it may be important to describe the breadth or scope of the theory because the scope gives an indication of the usefulness in practice and research purpose. The scope of theory means the range of the phenomena to which the theory applies. In line with this discussion four levels of theory generation are outlined below, namely: (1) meta theory, (2) grand theories, (3) midrange theory, and (4) practice theory.

- **Meta theory**

This level of theorising looks at broad issues related to theory in a discipline. Its purpose is not concerned with the production of grand, middle range or practice theory. It mainly focuses on philosophical and methodological questions related to the development of theory base for a discipline – and in this case, nursing. According to Walker and Avant (1995:5-6) there are 3 most debated issues at this level, namely: (1) analysing the purpose and kind of theory, (2) proposing and critiquing the sources and methods of theory development, and (3) proposing the criteria most suited for evaluating theory in that discipline. In this study meta theory has been applied in various ways as described below:

- (1) In chapter 1 as philosophical assumptions on which the study is based.
- (2) The purpose of this study was to develop a practice theory that is aimed at empowering families of mentally handicap children in Limpopo.
- (3) The researcher uses a method proposed by Chinn and Kramer (1995:120) to evaluate or critique the model once developed.

- **Grand theory**

This level of theorising is also abstract and looks at broad issues related to goals, purpose and structure of practice in a discipline. In nursing, grand theories have helped sort out nursing from the practice of medicine by showing the presence of distinct nursing perspectives (Walker & Avant 1995:9).

Grand or macro theory covers large areas of concerns within a discipline or section. Grand theory is considered a very broad-scope theory in most sections of work (Chinn & Kramer 1995:120). It explains large segments of people's experiences and is considered useful in health and behavioural sciences. Clark and Hull's learning theory and of Talcott Parsons' behavioural theory are examples of grand theories (Polit & Hungler 1997:108). Other theories with a broad range include molar theories, which deal with the purpose of research broadly or cover a relatively broader scope of the range of phenomenon in question. Holistic theory, which deals with phenomena in totality for every discipline, is another broad-range theory (Polit & Hungler 1997:108).

Chinn and Kramer (1995:120) also identify theories that are narrow in scope like micro theories, molecular theories and atomistic theories. The range and the scope of the theory depend on the type of discipline or environment. However, a theory that is micro for one area may be macro for another area. The grand theory applied in this study is the Neuman's systems model as it looks at phenomena holistically (George 2002:348), and this is in line with the characteristics of grand theories outlined in this section.

- **Midrange theories**

While the above-mentioned theory is difficult to test, middle-range theories are simpler in that they contain limited numbers of variables. For this reason they are testable and are useful in research and practice. These theories range midway between the micro and macro theories. They have an average scope. Because of its limited scope, middle-range theory helps cover the gap between grand theories and practice (Walker & Avant 1995:11). Examples are theories explaining the phenomena of stress, and infant wellness (Polit & Hungler 1997:108).

- **Practice theories**

At this level of theorising, the focus is on the desired goal and the actions needed in order to attain it (Walker & Avant 1995:12). Given this characteristic it can be said that the type of theory envisaged in this study, is practice theory. This kind of theory prescribes the nursing actions to be implemented in each nursing situation, as well as expected outcome of those nursing interventions.

This study is conducted for the purpose of generating an empowerment model for support of families with mentally handicapped children to care, treat and rehabilitate their children. This model is aimed at improving the role of psychiatric-mental health nurses in their encounters with such families.

2.4.1.2 Stages of theory development

While the previous sub-section discussed levels and types of theories, this sub-section discusses the stages of theory generation. Dickoff, James and Wiedenbach (1968:198) (cited in Meleis 1997:142), propose that a theory exists on the following four levels:

Level 1: **Factor isolating** this deal with the naming or classification of the phenomenon under study.

Level 2: **Factor relating** this means to associate and correlate factors in such a manner that they become part of the whole phenomenon.

Level 3: **Situation relating** this describes and anticipates how the situations are related.

Level 4: **Situation producing**, which requires information about ways in which the situations are related as the theory will be used as a guide.

Dickoff et al (1968:198), (cited in Meleis 1997:141) identify three ingredients of situation producing theory: “(1) goal content, (2) prescription, and (3) survey list”. Goal content explains the purpose of the theory, while the prescription and the survey list are used to compose the core of the conceptual framework. Prescriptions refer to directions given and the survey list is made up of all the main concepts to be used in the development of a theory. Prescription also helps in the achievement of the outcomes of the theory.

Dickoff et al’s (1968:198), (cited in Meleis 1997:140) stages of theory development can be compared with Chinn and Kramer’s (1995:27) stages, that for theory to have practice value, four processes are essential to accomplish theory generation.

The following table details the researcher's stages of theory generation as compared to those of Dickoff et al (1968), (cited in Meleis 1997:143) and Chinn and Kramer (1995) (see table 2.1 for an outline of theory generative strategies followed by the researcher in this study).

Table 2.1 Stages for theory generation

Dickoff et al (1968)	Chinn and Kramer (1995:120)	Kgole's stages of theory generation used in this study
Factor isolating theory: First level or naming theory; conceptual ideas.	Creating conceptual meaning. Identification and definition of concepts.	Concept Analysis: <ul style="list-style-type: none"> • Concept identification • Concept definition • Concept classification
Factor relating theory: Second level situation depiction. Concepts are no longer in isolation. Higher level of complexity	The meaning created is structured and conceptualised. Multiple concepts are linked in a loose structure.	Description of model structure and process: <ul style="list-style-type: none"> • Model description • Model evaluation
Situation relating theory: Third level predictive theory with the aim of allowing for prediction of relationships between situations that are depictable.	Generation and testing of theoretic relations: They include: <ul style="list-style-type: none"> • Empirical and grounding; • Emerging relationships • Empiric indicators; and • Validating relationships 	Description of guidelines to operationalise the model in practice.
Situation producing theories: Fourth level theories, which are predictive in nature. Goal content specified as aim of activity. Prescriptions for activity to realise goal content. Survey list as supplement.	Deliberate application of theory. Clinical setting is selected. Outcome variables are determined for practice. A method of study is implemented.	Evaluation of the implementation of the model in practice of psychiatric-mental health nurses in a specified clinical area.

2.4.2 Qualitative aspect of the design

Since the main concept of the model that is developed in this study was identified through a qualitative research approach, it is important to describe the qualitative aspect of this research. Qualitative researchers start by talking to or observing participants who possess first-hand information and experience of the phenomenon being researched. The qualitative approach allows for description of and insight into different human experiences (Burnard 1992:68; Seale, Gobo, Gubrium & Silverman 2004:39).

A qualitative approach gives a full view of the phenomenon under study because it is loosely structured and this allows “for the expression of a full range of beliefs, feelings and behaviours” (Polit & Beck 2004:99; Silverman 2001:60).

Qualitative research is subjective and systematic in nature and is a way of exploring the richness and complexity of the phenomenon under study. According to Brink and Wood (1998:337), a qualitative design is directed at uncovering new insights, meanings and understandings. The knowledge gained from qualitative research can assist the development of theories and models and researchers can maximise their knowledge through qualitative research. Qualitative research is interested in the lived lives of people; is descriptive; involves fieldwork, and is inductive in nature. The researcher is the primary data-collection instrument and uses a narrative approach in writing research findings. Methods of collection of information in qualitative studies include case studies, interviews and participant observation (Myers 1997:1; Silverman 2000:69).

In this study, the main concept “empowerment” was identified through a preliminary qualitative study conducted by the researcher among family members with mentally handicap children. This would enable the researcher to formulate a blueprint empowerment model for use in support of families with mentally handicapped children in the Moletši district of Polokwane and Aganang municipalities and elsewhere. Once the model for empowerment of families of mentally handicapped children was generated and described, the researcher used qualitative research in the form of case studies to evaluate the effectiveness of the model in attaining its goal.

2.4.3 Exploratory aspect of the design

As part of conducting qualitative research, exploration is important to identify how the phenomenon manifests itself in reality. As such, the researcher utilised this aspect of the design to fully understand the application of empowerment in the context of families with mentally handicapped children. Exploratory research investigates a problem about which little is known. The main purpose of exploratory research is the development and clarification of ideas and the formulation of questions and hypotheses for more precise investigations later. This type of research involves gathering a great deal of information from a small sample (Neuman 2000:510).

Exploratory research is aimed at exploring dimensions of a phenomenon, how it is manifested and other related matters or factors (De Vos, Strydom, Fouche & Delport 2002:337; Uys & Basson 1995:25).

This study explored the dimensions of empowerment of family members, namely ways in which they were empowered to care for, treat and rehabilitate their mentally handicapped children.

2.4.4 Descriptive aspect of the design

In addition to exploratory design, the researcher utilised a descriptive design as part of a theory generative process. A study is descriptive when it intends to describe a phenomenon accurately within its specific context (Leedy 1990:30; Mouton 2002:102).

This study is concerned with description at various levels as mentioned below:

- The description of the empowerment model for families with mentally handicapped children.
- The description of guidelines to operationalise the model in the practice of psychiatric-mental health nurses.
- The description of cases and findings associated with the deliberate application of the model in an endeavor to empower families with mentally handicapped children.

2.4.5 Contextual aspect of the design

Due to the fact that the theory generated in this study is for a specified context in South Africa, it became necessary for the researcher to apply a contextual aspect in the design. Babbie and Mouton (2002:270) referred to the contextual research method as understanding the events within the concrete, natural context in which they happen.

According to Botes (1995:13), the research context is only valid within a certain time-space and is not value free. The research design is contextual in that it is bound to the unique context of families with mentally handicapped children in Limpopo province.

2.5 REASONING STRATEGIES

The use of reasoning strategies is essential in the process of theory development. In this study, the reasoning strategies used are discussed in the manner in which they are applied throughout the four theory generative stages followed.

These strategies include inductive reasoning, deductive reasoning, analysis and synthesis. The reasoning strategies are intellectual tools applied by the researcher in an effort to generate the proposed model for empowerment of families of mentally handicapped children. The reasoning strategies that assisted the researcher to formulate the model to empower these families of mentally handicapped children are outlined below.

2.5.1 Deductive reasoning

In deductive reasoning, logic is applied from general to particular. In deductive logic, two or more premises are used as a rational statement to draw a conclusion. Deductive reasoning is the process of developing specific predictions for general principles (Maputle 2004:17; Polit & Hungler 1997:455). Morse and Field (1995:70) pointed out that deductive theory is derived from previous knowledge in order to deduce potential relationships.

In this study, deductive reasoning was useful in the following instances:

- The main concept for the model “empowerment” was deduced from the findings of a preliminary study conducted by the researcher.
- In the development of the model once constructs had been identified.
- In drawing guidelines for the implementation of the model.
- During literature review to develop the model and during literature control after data analysis.
- In conclusions and recommendations drawn from the data analysis.

2.5.2 Analysis

In theory generation it is necessary to apply analysis strategy throughout the process. In this type of reasoning the theorist engages in activities of dissection, breaking down and reduction of a complex whole into its parts for purposes of (1) clarity, refinement, and better understating; (2) sharpening of concepts; statements or theories and (3) examining the relationship of each of the parts to each other and to the whole (Walker & Avant 1995:28).

In this study, strategy of analysis was used during:

- The breaking down of the concept “empowerment” to identify it’s defining attributes.
- The analysis of case study data after the deliberate application of the model among families with mentally handicapped children to identify themes associated with the empowerment of these families.

2.5.3 Synthesis

Once analysis of concept is achieved, it is necessary to synthesise attributes into a definition. Synthesis is the process of combining elements of data into a whole. Synthesis is a method of developing concepts based on researchers’ clinical observations (Polit & Hungler 1997:460). This process is useful in the development of theory and allows the theorist to use the experience from the clinical areas as a point of departure. In this study synthesis was used alternately with analysis during data analysis and concept analysis to help in:

- Definition of the concept of empowerment in the context of families with mentally handicapped children.
- Pulling together concepts that form the model of empowerment in a coherent structure and process detailed in chapter 4.
- Formulation of themes, categories, and sub-categories from the case study data collected during the implementation of the model in practice.

- In drawing conclusions and recommendations based on the findings of fieldwork conducted by the researcher during model implementation (Holloway & Freshwaters 2007:71).

2.5.4 Derivation

The strategy of derivation requires the researcher to first conduct an intensive literature review on the topic of interest. Thereafter, creativity and imagination is used to make an analogy or metaphor in drawing, borrowing and redefining a concept, statement or theory from one context (for example, one specialist field) to another (e.g. nursing).

It is mostly applied to areas which no theory base exists or to modernise an old theory (Walker & Avant 1995:29).

In this study the procedure for conducting concept derivation is that suggested by Walker and Avant (1995:70-73):

- The researcher conducted extensive literature review to develop a model of empowerment by familiarising herself with existing literature on the topic of empowerment in relation to families with mentally handicapped children.
- The search of literature covered a number of other fields that utilise the concept of empowerment.
- The concept of empowerment was then redefined in terms of supporting parents of children that are mentally handicapped.

2.5.5 Inductive reasoning

In inductive reasoning logic is applied from particular to general. It reasons from the specific observation to the rules that are more general. Morse and Field (1995:8) describe inductive reasoning as directed towards bringing the knowledge into the general view. Since it is descriptive, it helps in naming phenomena and positioning relationships between concepts and statements. This reasoning strategy fits well in theory generation since theories and models are created from collected data.

In this study, inductive reasoning strategy was used during the last stage of theory generation to test the model of empowerment in the practice of psychiatric-mental health nurses in their support of families of mentally handicapped children.

2.6 RESEARCH METHODOLOGY

Research methodology is a technique used to structure a study, and to gather and analyse information in a systematic fashion (Polit & Beck 2004:731). As indicated in the introduction of this chapter, the research methodology followed by the researcher in this study is consistent with four steps of theory generation described in table 2.1 above.

2.6.1 Step 1. Exploration of the meaning of the concept “empowerment” in the context of the family of mentally handicapped children

This step involved the identification, definition and classification of concepts. This is termed concept analysis and assisted in clarifying the concept “empowerment”, examining its attributes, and developing and evaluating the theory. Attributes were derived from dictionaries, literature sources and archives. The antecedents and consequences of empowerment were identified, the model developed, theoretical definitions derived, model case and other types of cases were formulated and described.

The process of concept analysis is creative as it identifies and clarifies the mental images that compose the concepts within the theory. These concepts help in the development of theory (Chinn & Kramer 1995:31). Chinn and Kramer (1995:83) point out that conceptual meaning gives a tentative definition of a concept and a group of tentative criteria to find out if the concept exists in a particular situation. In this study, this step is dealt with in **step 1** namely: (1) concept identification, (2) concept definition, (3) concept classification and (4) formulation of model, contrary and borderline cases as indicated in the following sub-sections.

2.6.1.1 Concept identification

The identification of a concept with which researchers work is the first step in the process of creating conceptual meaning and the first concept may change as meanings

evolve (Chinn & Kramer 1995:84). Researchers should identify a word that communicates an image that approximates the idea they want to put forward. The words used to put forward a special meaning are termed “technical” or “professional” terms. In this study, the researcher identified the concept “empowerment”, which communicated the idea that she wanted to put forward.

2.6.1.2 Concept definition

The main concept is identified and this becomes the concept that researchers use to communicate the phenomenon to be researched (Chinn & Kramer 1995:31).

In this study, the main concept used to communicate the phenomenon under study was “empowerment”. Once the key concepts were identified, the researcher started to identify the defining attributes of the concept as outlined by Chinn and Kramer (1995:31). In order to comprehensively define the concept, it is necessary to trace the origin of the words. Various data sources were utilised to identify the meaning of the concept by analysing definitions from the dictionaries, existing theories, and extended literature reviews. Once the defining attributes were identified, synthesis strategy was used to formulate the central definition of empowerment as it is applied in this study.

The researcher constructed cases that represented the experience being explored. This is another useful way of creating conceptual meanings. Scenarios for illustrating the researcher’s experiences were constructed. Chinn and Kramer (1995:84) identify model, contrary, related and borderline cases.

- **Model case**

If researchers present a model case they will be describing an instance of an experience. Therefore the model case represents the phenomenon under study and model cases assist in the definition of concepts. Chinn and Kramer (1995:86) emphasise that it is difficult to construct model cases from abstract concepts. As soon as model cases are formulated the researcher can identify the criteria emerging or forming. Criteria involve the ideas about which features are important and the reason why, and their qualitative characteristics. Chinn and Kramer (1995:85) point out that other cases may be developed in order to come to a final decision with regard to the attributes of model case.

- **Contrary cases**

Contrary cases are cases that are truly not representative of the concept of the phenomenon being studied. They represent something different. Contrary cases assist with the clarification of a concept under study as they say what something is not, rather than describing what it is (Chinn & Kramer 1995:86).

- **Related cases**

Related cases are different but use similar concepts. A different word may be used but the experiences have many characteristics in common with the one the researcher has chosen for the research study. They help the researcher to understand the manner in which the concept under study can fit into the broader scope of meanings. Related cases do not have the critical attributes required to define the main concept (Chinn & Kramer 1995:86).

- **Borderline cases**

Borderline cases are instances of false application of the concept because they contain few critical attributes. Inconsistency is common in borderline cases (Chinn & Kramer 1995:86). See chapter 3 for the model case and other cases formulated by the researcher.

2.6.1.3 Classification of main concepts

Once the concepts are defined, it is necessary to classify them in a meaningful manner that gives them structure. In the study the main concept “empowerment” was put in relation to other concepts that form a model for the empowerment of families with mentally handicapped children. This according to Chinn and Kramer (1995:35) gives the model structure. The researcher used the survey list as proposed by Dickoff et al (1968:423) (cited in Meleis 1997:14) to classify the concepts of the model. A survey list constitutes the third ingredient of a situation-producing theory. Activity has six aspects and those aspects of activity to be highlighted in the survey are six ways of looking at one thing in the hope of revealing different features as point of view shifts (Dickoff et al

1968:422) (cited in Meleis 1997:140). The survey list to classify the concepts of the model as follows:

- The agent (caregiver): Who or what performs the activity?
- The recipient (patient): Who becomes the recipient of the activity?
- The context (framework): In what context is the activity performed?
- The procedure (process): What is guiding the technique of the activity?
- The dynamics: What becomes the energy source of the activity?
- The terminus (goal): What is the outcome of the activity?

See chapter 3 for the application of the survey list as proposed by Dickoff et al (1968) (cited in Meleis 1997:139).

2.6.2 Step 2. Description of the model for empowerment of families with mentally handicapped children

The next step was to *describe* and *evaluate* the empowerment model, which included outlining what the model entails.

2.6.2.1 Model description

The purpose of the model was to support, motivate and equip the families of mentally handicapped children with skills. Assumptions underpinning the model were also described. The context of the model referred to the situation and circumstances under which the model was applied. Concepts in the model were defined and relationships in the context of the model described. In the description of the model, the researcher used the strategies for theory description as proposed by Chinn and Kramer (1995:84) in the following manner:

- What is the purpose of the model?
- What are the concepts that form the model?
- How the concepts were defined and what is the nature of their relationships?
- What are the phases and structure of the model?
- What assumptions underlie the model?

The structure of the model included to the overall organisation of the model, the representation of ideas and concepts, and the linking between different concepts (Chinn & Kramer 1995:112). The development and process of the model was divided into phases (see chapter 4 for the full description of the model).

2.6.2.2 Model evaluation

It is important to evaluate theory once described.

In this study model evaluation refers to the critical reflection of the model, which is essential to determine how well the model might be used in practice and research, and how it might be further developed. Three independent experts in theory development evaluated the model. Chinn and Kramer's (1995:127) criteria were used to evaluate the model, namely clarity, simplicity, generality, accessibility, and importance.

- **Clarity**

Clarity of the model pertains to how well the model can be understood, how the ideas in the model were conceptualised, and whether consistency was maintained or not. Concepts that were not clear were identified and re-conceptualised in the model (Madelá-Mntla, Poggenpoel & Gmeiner 1999:73).

- **Simplicity**

Simplicity of the model means that the model is not complicated but easy to follow. In a simple model concepts can be combined without losing meaning (Madelá-Mntla et al 1999:73).

- **Generality**

Generality of the model refers to the size of the model, that is, the breadth and the scope that the model covers, which depends on the scope of the concept of the model and the main purpose (Madelá-Mntla et al 1999:73)

- **Accessibility**

Accessibility of the model refers to whether the concepts are broad or narrow, the specificity or generality of the definitions in the theory or model, whether the definitions of the concepts in the theory are a true reflection of the concepts, and whether the concepts are practical and reflect real nursing practice (Chinn & Kramer 1995:136).

- **Importance**

The importance of the model refers to the significance or the extent to which the theory can be utilised to achieve the goals of the nursing profession theoretically and practically. This means that the model can be used to achieve goals in nursing education, administration and research (Chinn & Kramer 1995:136; Madela-Mntla et al 1999:73).

2.6.3 Step 3. Formulation and description of guidelines to operationalise the model in practice

The researcher formulated guidelines for the implementation of the model according to its different phases. According to Chinn and Kramer (1995:101), the researcher should start by selecting the clinical setting, determining the outcomes, implementing the method by applying the theory in practice, observing the results and making recommendations. In this study the researcher used deductive reasoning to arrive at the guidelines to operationalise the model proposed in this study. The guidelines in chapter 5 propose practical strategies to assist mental health professionals to care, treat and rehabilitate the mentally handicapped children.

2.6.4 Step 4. Evaluating the implementation of the empowerment model for families with mentally handicapped children

According to Chinn and Kramer (1995:102), the deliberate application of the theory is the final step of theory development. Strategies that were used in the evaluation of implementation of the model for families with mentally handicapped included case studies, assessment guides, and semi-structured interviews.

The researcher applied the theory in practice to carefully assess and understand the effect of its utilisation on the quality of nursing practice and the quality of life of a specific group, namely the families of mentally handicapped children. Applying the theory achieved the practical goals. In this study, the researcher applied the model for empowerment of families of mentally handicapped children to three families to assess if the model of empowerment would achieve the desired outcome. In this study Moletši district was chosen as a clinical setting of choice to the researcher.

The Moletši district has seven Clinics, namely three from Aganang municipality and four from Polokwane municipality. Moletši Clinic was the only clinic used for the application of the theory.

The deliberate application of theory consists of three subcomponents, namely: (1) selecting the clinical setting, (2) determining the outcomes, and (3) implementing a formal method of study.

2.6.4.1 Selecting the clinical setting

The clinical area selected may be any setting where nursing practice takes place in which the theoretical relationships can be observed by the implementers of the theory (Chinn & Kramer 1995:101). In this study, the clinical area selected was Moletši Clinic and three instead of five families with mentally handicapped children and who attend the clinic were chosen for case studies.

2.6.4.2 Determining the outcomes

It is necessary to determine the outcomes of the application of the theory to explore how the theory that was applied to nursing practice or any other practice area can affect the practice of nursing (Chinn & Kramer 1995:101). In this study the purpose of the model is well described in chapter 4, under 4.3.1 purpose of the model.

2.6.4.3 Implementing a formal method of study

During this stage of the deliberate application of the theory, evaluation research methods are used. The tool for evaluation needs to be drawn or designed in order to

provide evidence of the effect of the new approach “on the technical and professional aspects of the practice of nursing care, and on the practice setting” on the sampled people receiving the care. The setting automatically becomes the centre of attraction for observation (Chinn & Kramer 1995:102).

In this study the theory was for the empowerment of families with mentally handicapped children. Three families were chosen for conducting case studies.

The pre-morbid functioning and quality of the empowerment of families with mentally handicapped children provided before the theory was used. The assessment included the perceptions of nurses and other caregivers and families who are taught the skills that encourage and nurture the development of empowerment. Two schedules were prepared to collect data about the life of the mentally handicapped child and the family as a whole in order to identify the forms of empowerment that the family would need from mental health professionals.

2.6.4.4 Research population

A research population includes all the participants or members that conform to a designated set of specifications (Parahoo 1997:56; Polit & Hungler 1997:233). Researchers usually identify or sample the population that is accessible (Polit & Beck 2004:290). In this study, the research population included all families who have mentally handicapped children in the Moletši district of the Polokwane and Aganang municipalities.

2.6.4.5 Sampling technique

A sample is a portion selected from the population to represent the entire population under study (Polit & Hungler 1997:236). Sampling refers to a way of choosing a sample from the population under study. In this study, the researcher used purposive or judgmental non-probability sampling to obtain in-depth information from the participants who knew the details of the phenomenon under study and could talk about it (Uys & Basson 1995:93). The researcher used her knowledge of the population to handpick the sample. Three families whose children attended Moletši Clinic were selected for case studies and interviews since these families had the experience of caring for their

mentally handicapped children. In this study only families who lived with their mentally handicapped children and whose children attended Moletši Clinic were included in the sample as these families had insight into their children's needs.

2.6.4.6 Data-collection techniques

The researcher chose case studies, assessment guides and interviews as data-collection instruments in order to obtain in-depth information that would assist in the empowerment of families with mentally handicapped children by means of the application of the model. These methods are cost-effective and efficient because a lot of data could be obtained from participants within a short space of time (De Vos et al 2002:298; Morse 1989:37; Mouton 2002:156; Polit & Hungler 1997:272; Streubert & Carpenter 1999:23). Collecting information by means of case studies and interviews is effective in obtaining opinions in order to design new or further programs or guidelines.

- **Case study**

Babbie (2001:286) describes a case study as one of the best research methods in qualitative research as it consists of the in-depth study of a particular case and assists in yielding explanatory insights. Cases may be individuals, groups, institutions, social groups and programmes. Case study research involves analysis, not just writing up clinical cases or describing events, and qualitative and quantitative research methods can be used (Yin 2003:14). The starting point for case study is to make certain that the information for each individual case is as complete as possible (Patton 1990:384; Polit & Hungler 1997:98).

According to Bormley (1990:302) (cited in Zucker 2001:1), a case study is a “systematic and in-depth inquiry into an event or a set of related events which aims to describe and explain the phenomena of interest”. The data collected through case study may be derived from archival records, documentation, interviews, direct observations, artefacts and participant observations (Zucker 2001:1). In this study, the data collected by the researcher was derived from interviews with families of mentally handicapped children. Denzin and Lincoln (2003:143) refer to case study as “story telling” due to the complexity of the information collected from a person, group or programme.

Shergill (2006:1) defines a case study as a detached account of a single individual. The case study record includes personal history, background presentation, tests and interviews.

When doing case study research it is important to clarify the study question, develop propositions, use a recognised method of selecting cases, consider data analysis whilst collecting data and write the report (Bradley & Wiles 1999:5; Yin 2003:18).

Patton (1990:387) refers to case study as an important method for evaluating research operationalisation and the effectiveness of community programmes. Evaluation assists researchers to make decisions on how they can develop and improve the situation after identifying what is going on in the programmes. In this study, the researcher and the families identified the gaps in the care, treatment and rehabilitation of their mentally handicapped children.

Patton (1990:388) identifies three phases in the process of constructing a case study, namely assembling raw case data, constructing a case record, and writing a case study narrative.

Assembling raw case data

The data consists of all the information collected about the person or programme for which a case study has to be written. In this study, the researcher collected detailed information about the selected families of mentally handicapped children, including their pre-functioning state.

Constructing a case record

In this phase all the raw case data was organised, classified, and edited into a manageable and accessible package.

Writing a case study narrative

In this phase all the information about the person or the group under study was put in narrative form and the case study became a readable,

descriptive picture of a person, group or programme that provides all the information necessary to understand it.

The case study presents a holistic portrayal of a person, group or programme or institution (Patton 1990:389; Shergill 2006:1). In this study, the case study presented the physical, social, psychological, religious and cultural information, old and new methods of empowerment of families with mentally handicapped children, and the effects of implemented methods of empowerment.

- **Interview**

During the conduct of case studies, the researcher also carried out interviews to explore the experience of the empowerment process. Interviews refer to verbal communication between researchers and participants in order to extract information on the phenomenon under study. Burns and Grove (2001:353) refer to an interview as a self-report. An Interview, as a method of data collection, was initially utilised by social workers and it is a way people understand the events and experiences of their lives. Health-related issues are explored by means of interviews (Holloway 1997:94).

Prior to the interviews, the researcher explored the clinic and families' pre-morbid functioning in empowerment. The professional nurses were asked to describe the ways in which they empowered the families with mentally handicapped children. The families were asked about the ways they used to care for, treat and rehabilitate their mentally handicapped children at home. At the end of the application of the model, this information would enable the researcher to compare the care, treatment and rehabilitation before empowerment and after empowerment. After obtaining permission from the Department of Health and Social Development, the chief and the *indunas* (*head men*), the researcher made appointments (date and time) with the families.

The case studies and interviews took place at Moletši Clinic. The venue or setting was a private room that was pleasant, private and enabled interaction to take place freely. In order to neutralise any mistrust and tension, the researcher established rapport with the participants by putting them at ease to enable them to express their honest and deep-seated anxieties (Mouton & Marais 1994:93). The researcher showed the participants her identification card and informed them who she was, the institution she came from,

the purpose and confidentiality of the study, and that they were not chosen for harassment but because a small portion of the population was needed (Bailey 1994:186).

The researcher was adaptable, friendly and responsive to the participants at all times. The participants were encouraged to elaborate in answer to the questions and their permission sought for the use of a tape recorder during the interviews. The researcher emphasised that she would clarify any aspects that were not clear and answer participants' questions (Burns & Grove 2001:355; Polit & Hungler 1997:287).

According to Burns and Grove (2001:354), the role of researchers during interviews is to employ therapeutic communication techniques and encourage participants to continue until data is saturated. Techniques of communication include reflection, clarification, questioning, nodding (indicating interest), maintaining eye contact, and listening attentively (indicating that the information is regarded important).

The researcher and the clinic psychiatric nurse organised visits to families to get more information about the home environment, neighbourhood, home circumstances and the functioning of the family set-up. The researcher also visited the families alone at home to obtain information about the details of the family set-up.

- **Family and child assessment guides**

Over and above the use of interviews, the researcher also utilised assessment guides. The researcher filled family assessment guides to get information from the three families as well as assessment guides to get information about birth history and problems of the three mentally handicapped children.

2.6.4.7 Data analysis

Data analysis commenced at the same time as data collection, as is characteristic in qualitative research. The researcher listened carefully to discover meanings and identified the themes from what the participants related (Polit & Hungler 1997:271).

At the conclusion of data collection the researcher immersed herself in the data and reflected on what had been discovered. The cyclic nature of questioning and verifying is important in qualitative research.

This helps researchers cluster information and discover the meanings intended in what they have observed and heard (Streubert & Carpenter 1999:28). Streubert and Carpenter (1999:28) pointed out that heightened awareness of the data is developed once total immersion in the data has taken place.

The researcher analysed the data by clustering similar data or ideas into themes and categories, which are structured meaning units of data. The researcher developed categories and corresponding codes to sort and organise the data. Themes were identified by noting salient categories of meaning held by the participants in the setting. Then the researcher manually searched for patterns and structures that connected the themes (Polit & Beck 2004:571).

The researcher followed Tesch's (1990) (in Creswell 1994:155) eight-step method of data analysis, namely:

- (1) Listen to the tape to get the sense of the whole, internalise the content and transcribe the content verbatim. Then read carefully through all the transcripts and get the sense of the whole.
- (2) Choose and take one interview randomly to review. Read through it in order to get the underlying meaning, asking questions such as: "What is it about?; What is the underlying meaning?; What does the data say?. Then write down notes at recognisable places so as not to forget.
- (3) After completing the task for all the documents, make a list, cluster the same topics together, and put them in columns as major topics, unique topics and other topics. As the process continues, analyse and synthesise the data.
- (4) Take the list and return to the data to allocate codes to the topics in an abbreviated form. Write the code next to the correct segment.

- (5) Find the most descriptive wording of topics and turn them into categories and reduce the total list of categories by grouping them into related entities. Draw lines between the categories to show interrelationships.
- (6) Make a final decision about abbreviations for each category and alphabetise the codes.
- (7) Assemble data belonging to each category in one place and perform a preliminary analysis.
- (8) Cluster major categories into the most appropriate theory.

The researcher sent the raw data to an independent coder, who was a colleague from the neighbouring university and had extensive knowledge of qualitative research methods. The researcher and the independent coder met in order to reach consensus on the themes, categories and sub-categories identified independently. In order to maintain confidentiality, only the researcher and the independent coder had access to the audiocassettes and transcriptions.

2.6.4.8 Ethical consideration

Ethics deals with matters of right and wrong. *Collins English Dictionary* (1995:533) defines ethics as “a social, religious, or civil code of behaviour considered correct, esp. that of a particular group, profession, or individual”. Accordingly, the researcher sought and obtained permission to conduct the study from the Department of Health and Social Development because the clinic falls under the Department (see annexure A). Approval and permission was also obtained from the Department of Health Studies, University of South Africa (see annexure A). Finally, the researcher obtained permission from the key figures of the Moletši community, namely the chief and the *indunas*. This communication was done verbally. The chief informed the ward counsellor, as he is one of the chief’s advisors.

Research that involves human beings as subjects should be conducted in an ethical manner to protect their rights. Polit and Beck (2004:167) emphasise that when people are used as study respondents, “care must be exercised in ensuring that the rights of

the respondents are protected". Accordingly, the researcher respected the respondents' right to informed consent, privacy, anonymity, confidentiality, and protection from harm and discomfort (beneficence) (Burns & Grove 2001:196; Cormack 1996:31; Wilson 1998:247).

- **Informed consent**

The researcher informed the participants of the purpose and significance of the study; their role as participants; the method of data collection, namely interviewing; the duration of the interview; the type of information needed, and what would be done with the findings. Written informed consent was obtained from the participants (see annexure B). The participants were given sufficient time to review the consent letter, which was then signed by the researcher and the participants (Polit & Hungler 1997:378).

Furthermore, the participants were given the option to withdraw from the study at any time, should they so wish. Confidentiality was ensured by not linking inputs to individual participants (Streubert & Carpenter 1999:38).

Scientific honesty on the part of the researcher was ensured through establishing a relationship of trust with the participants (Streubert & Carpenter 1999:36, 37).

- **Privacy**

Privacy is the freedom individuals have to determine the time, extent and general circumstances under which private information will be shared with or withheld from others (Burns & Grove 2001:158). The respondents' privacy was respected by conducting the interviews in private.

- **Anonymity and confidentiality**

The participants' anonymity and confidentiality were assured because their names were not disclosed hence no information could be linked to specific participants. The right to confidentiality was respected because the information was not disclosed to unauthorised individuals (Cormack 1996:31; Polit & Hungler 1997:35; Wilson 1998:247).

The researcher endeavoured to set aside presuppositions or personal biases throughout the study. This was done by returning to the participants for verification to ensure the accuracy of their inputs (Streubert & Carpenter 1999:41).

- **Protection from harm and discomfort (beneficence)**

The right to protection from discomfort and harm from the study is based on the ethical principle of beneficence. The principle of beneficence states that one should do good and above all do no harm (Burns & Grove 2001:165).

Discomfort and harm can be physical, emotional, economic, social or legal. In this study the researcher minimised the risk of exposing the respondents to discomfort or harm. The researcher gave her contact address as well as fax and telephone numbers to the participants.

Table 2.1 Measures to ensure trustworthiness of the study

CRITERION	STRATEGY	CRITERIA	APPLICATION
Truth-value	Credibility	<p>Prolonged engagement</p> <p>Triangulation</p> <p>Peer examination</p> <p>Reflexivity</p> <p>Structural coherence</p>	<p>The researcher worked in the area for five years and spent sufficient time with the participants/the families with mentally handicapped children during interviews and case studies in order to identify and internalise their needs.</p> <p>The researcher was trained and qualified as a psychiatric nursing specialist and taught Psychiatric Nursing for twenty years.</p> <p>A non-probability, purposive sample was chosen, case studies and interviews were conducted with families, an independent coder was used for data analysis, the study promoter confirmed the research findings, main concepts defined from various sources, attributes identified and reduced, core concepts defined to form model for empowerment of families.</p> <p>Experts in qualitative research, specialists in model formulation, colleagues, an independent coder, and the study promoter checked the study.</p> <p>The researcher kept the tape-recorded interviews and case study, defined concepts, discussed relationship statements, and used an independent coder.</p> <p>The study objectives guided the research design, data collection and theory formulation.</p>
Consistency	Dependability	Triangulation, peer examination and dense description methods were used	Detailed sources of empowerment consulted, purposive sample used and transcriptions of interviews kept.
Neutrality	Confirmability	Confirmability audit, triangulation and reflexivity were utilised	Confirmability audit done through literature search, case study and interviews and interview cassettes were kept.
Applicability	Transferability	<p>Selection of a sample</p> <p>Dense description</p>	<p>Purposive sampling was used and the steps in theory generation done.</p> <p>Detailed description of theory-generative research methods was provided.</p>

2.7 MEASURES TO ENSURE TRUSTWORTHINESS (DISCUSSION)

According to Lincoln and Guba (1985:294) trustworthiness is a method of establishing scientific rigor in qualitative research without sacrificing significance. Guba's model of trustworthiness (in Krefting 1991:214-222) was chosen as a frame of reference to ensure credible research practices throughout the research process. This model has four criteria of trustworthiness, namely: (1) truth value, (2) applicability, (3) consistency, and (4) neutrality. These criteria are realised through multiple strategies that are described below.

2.7.1 Truth-value

Truth-value is a measure that attempts to provide proof of the truthfulness of the findings of the study. Truth-value is based on confidence in the credibility of the study. It is proof that what transpired during the study is a true reflection of what the participants have communicated. Credibility establishes confidence in the truth of the findings, the study design and the setting in which research is conducted (Cindi 2006:25). Krefting (1991:214) proposes four strategies to enhance credibility, namely prolonged engagement, reflexivity/applicability, triangulation and peer examination. These are described in detail below.

2.7.1.1 *Prolonged engagement*

Prolonged engagement is proposed as a strategy to prevent distortions of the findings related to the researcher and field workers' presence at the research site or their involvement with the participants (Guba & Lincoln 1989:105). It entails spending an extended period of time with participants to allow the researcher to check perspectives. It additionally assists participants to become familiar to the researcher (Krefting 1991:218).

The researcher gained entry into the field prior to data collection. The researcher's entry was negotiated through the head man and the Department of Health and Welfare. The researcher first met with professional nurses at the clinic before working with families who had mentally handicapped children. The initial meetings were used to establish rapport with the family members.

The researcher spent enough time to interact closely with the participants, interviewed them during the case study, and observed them in their known and actual environment in the care, treatment and rehabilitation of their mentally handicapped children. Through prolonged engagement with the participants, a relationship of mutual trust and understanding and rapport was established. This prolonged engagement helped the researcher to identify problems, misunderstandings and weaknesses during data collection (Polit & Beck 2004:441).

Prolonged engagement was also applied during theory generation through extensive literature reviews conducted by the researcher in consultation with the study supervisor. The researcher critically analysed literature to identify the defining attributes of empowerment. This helped the researcher to fully understand the meaning of empowerment in the context of families with mentally handicapped children.

2.7.1.2 Triangulation

Triangulation is the process of utilising multiple referents to conclude what constitutes the truth of research findings. These multiple referents or methods are utilised to complement each other. In generating and refining the concepts of the model, the researcher used different sources, namely expert knowledge and skills from qualitative research specialists, dictionaries, existing theory and literature (James 2006:68). The completeness and depth of research findings can be ensured or confirmed through triangulation, including data, investigator, method and theoretical triangulation. In this study the researcher used colleagues, an independent coder, and specialists in qualitative research and model formulation to evaluate the research methods, the model and interpretations of the findings for credibility, dependability, confirmability and transferability (Mavundla, Poggenpoel & Gmeiner 2001:10; Polit & Beck 2004:444; Streubert & Carpenter 1999:300;).

2.7.1.3 Peer examination

Qualitative researchers promote credibility of the findings by means of peer examination.

The researcher used immediate colleagues, an independent coder, and specialists in qualitative research and model formulation to evaluate the research methods, model and interpretations of the findings for credibility (Clifford 1997:67; Madela-Mntla et al 1999:67). Additionally, regular discussions with the supervisor enhanced the neutrality of this research, complemented by formal and informal discussions with impartial colleagues regarding the research process and findings.

2.7.1.4 Member checking

Member checking was conducted throughout all four steps of theory generation to minimise misinterpretation of findings (Krefting 1991:219). It involved formal and informal discussions with families, psychiatric nurses, and theory generation experts to verify the definition of the main concept and findings in step 4. This also entailed member checking of the theory generation process. The researcher gave the tentative model to three experts for evaluation. The experts agreed that the model was necessary to improve the lives of children who are mentally handicapped. The involvement of an independent data coder in step four was also seen as a form of member checking.

2.7.1.5 Structural coherence

Structural coherence entails the integration of the masses of loosely connected data in the thesis to create a logical holistic picture (Krefting 1991:220). Evidence is structurally coherent when different parts of evidence verify each other, the parts fit and the facts are consistent (Guba & Lincoln 1989:106). In this study structural coherence was obtained through a well-structured four-step theory generative design and methods used. This also includes evidence of concept analysis, defining attributes identified, classification of concept into a model and the evidence associated with case study material collected from the three sampled families.

2.7.1.6 Referential adequacy

Referential adequacy was established through attaching documents as appendices to allow academic audiences to critically assess the ethical aspects adhered to and the interpretations that the researcher made through direct quotations and documents.

The appendices include samples of letters of informed consent, letters of permission to conduct this research, case study data and assessment guides.

2.7.2 Applicability

Apart from the truth value, the research also ensured applicability of study findings. Applicability was ensured by the strategy of transferability. Transferability means that the results of a study may have meaning to other areas with similar problems (Streubert & Carpenter 1999:29). Research findings can be applied in other settings and will yield the same results in different settings and this can be enabled by thick description of the context of data collection. Transferability is the extent to which results from the data can be transferred to other settings (Berg 1998:100; Polit & Beck 2004:444). Transferability means that research results will prove consistent if applied in a similar context. This strategy was achieved in the following manner:

2.7.2.1 Dense description

The researcher provided a dense description with a wide range of information about the participating families and the context to allow others to assess the transferability of the findings to their own contexts. The entire research process is described comprehensively. The researcher also provided direct verbatim quotes made by research participants during field work. This would allow transferability judgements to be made by others (Krefting 1991:220).

2.7.2.2 Nominated sample

A nominated sample refers to selection of research participants that are representative for the particular study population (Krefting 1991:220). Purposive sampling was the sampling method of choice in step four of the research process. Selection criteria guided the choice of families with mental handicapped children.

2.7.3 Consistency

Consistency is seen as an alternative to reliability in qualitative research (De Vos et al 2005:246).

It considers whether the findings would be consistent if the inquiry was replicated with the same subjects or in a similar context. The uniqueness of the human situation prescribes that qualitative researchers should seek variation in experience rather than identical repetition (Field & Morse in Krefting 1991:216). This is based on the idea that people will always differ in their perceptions, attitudes and experiences. Consistency is defined in terms of dependability, namely variability that can be ascribed to specific sources such as increasing insight on the part of the researcher, changes in the situations of the participants and looking at the range of experiences rather than an average experience (Krefting 1991:216).

In this study consistency was ensured by applying the strategy of dependability. Dependability is only achieved if the findings of a study are credible. Dependability is concerned with the stability of the data over a specified time and over conditions. Researchers can depend on research findings once there is truth-value in the results. A dependability audit was ensured through the involvement of experts in model formulation for the evaluation of the model before implementation. To meet the code-recode criterion, the researcher reached consensus with the independent coder on the collection and analysis of the data from the participants.

2.7.4 Neutrality

The fourth criterion of trustworthiness is neutrality. It captures the traditional concept of objectivity and whether the findings of the research could be confirmed by another study (De Vos et al 2002:347). Neutrality reflects the extent to which research procedures and findings are free from bias (Bailey 1994:59; Krefting 1991:216). The researcher ensured neutrality by applying the strategy of confirmability. The researcher left an audit trail. This is a record of activities that can be followed by another researcher. This works like an audit that is done in health services to identify a clear picture of what was done, and the reason why it was done. In this study another strategy used was that of peer review. In an attempt to peer review data collected, the researcher used an independent coder who was a specialist in qualitative research methods and theory generation to evaluate the process.

2.8 CONCLUSION

This chapter outlined the purpose and objectives of the study, the research design and methodology. Different theories and levels of theory development were also described. The measures for ensuring trustworthiness were also applied throughout the research process. Chapter 3 covers the development of an empowerment model for the families of mentally handicapped children for attainment of independence and self-efficacy.

CHAPTER 3

Development of an empowerment model for autonomy/independence of the families of mentally handicapped children

3.1 INTRODUCTION

Chapter 2 described the research design and methodology. This chapter focuses on the development of a model envisaged to assist in the empowerment of families with mentally handicapped children. In order to develop an empowerment model, the researcher examined definitions of and analysed the concept “empowerment” in education, sociology, economics, politics, nursing, psychology, and management sciences. For a better understanding of empowerment, the researcher classified all the concepts that work hand in hand with empowerment.

3.2 CONCEPT ANALYSIS

In order to define empowerment, the researcher started with concept analysis. Concepts are the building blocks or elements that form a theory. A concept is an idea or thought that is conceived in the mind and may be empirical or abstract in nature. Empirical concepts can be observed or experienced whereas abstract concepts cannot be observed (George 2002:3). Chinn and Kramer (1995:74) define a concept as “a mental formulation of experiences that people have. These experiences may be derived from research, clinical areas, and life experiences.” Walker and Avant (1995:24) refer to a concept as “a mental image of a phenomenon, an idea or a construct in the mind about a thing or action”. Concept analysis is a method that assists in the examination of attributes or characteristics of a concept. Concept analysis is rigorous in nature and the end results are always tentative as different researchers may describe different attributes for the same concept (Walker & Avant 1995:24).

3.3 PURPOSE AND USES OF CONCEPT ANALYSIS

Rossouw (2003:94) states that the purpose of analysis is to assist researchers to derive a theoretical definition of a concept by identifying the characteristics of the concept. The characteristics of the concept or the phenomenon to be researched can be derived from dictionaries and different literature sources. Concept analysis leads to the required degree of clarity of concepts that researchers are interested in (Smith 1994:21; Walker & Avant 1995:21). It promotes communication because the attributes of the concept to be used for the development of the theory become clearer. Smith (1994:24) points out that concepts are useful because they contribute to the development of knowledge and skills through their explanation and description. Moreover, they also assist in cases where the attributes of a concept are not clear. Through concept analysis researchers can differentiate between attributes with similar meanings, antonyms, related meanings and irrelevant meanings. Researchers are able to describe different words and their uses, clarify vague words that are overused and refine “ambiguous concepts in a theory” (Walker & Avant 1995:28). The results of concept analysis may assist in the evaluation of an instrument or a tool for assessing the theory. Concept analysis assists researchers to identify ways in which experiences are the same by categorising all the things that are similar about them. Reilly (1999:3) identifies three purposes of analysis, namely clarifying the meaning of the phenomenon, distinguishing between everyday and scientific usage of the phenomenon, and evaluating the phenomenon to be studied.

Concept analysis further enables researchers to classify experiences in a meaningful manner and draw relationships between two or more concepts, and the relationship that can be observed then forms a model or theory. Concept analysis can be used to explore philosophical foundations critically (Walker & Avant 1995:25). For the purpose of this study, the researcher identified concepts and these assisted in the development of a model for empowerment of families with mentally handicapped children.

3.4 STEPS OF CONCEPT ANALYSIS

The researcher followed Wilson’s (1963) (cited in Walker & Avant 1995:39) approach to the concept analysis of “empowerment”, namely:

- Identify/select the concept

- Determine the aims or purpose of the analysis
- Identify all uses of the concept
- Determine the defining attributes
- Construct a model case
- Construct borderline, related, contrary, inverted and illegitimate cases
- Identify antecedents and consequences
- Define empirical referents

3.4.1 Identify/select the concept

The researcher selected “empowerment” as the concept for analysis (selected concept). In defining empowerment, the researcher started with the definition of power. *Collins English Dictionary* (1995:1220) defines power as “ability or capacity to do something; a specific ability, capacity, or faculty; control, dominion or a position of control, dominion, or authority”.

Weber (1946) (cited in Page 1999:2) describes power as “the capability to make others to perform activities that one wants regardless of their own wishes and interests. It is viewed as influence and control and is unchanging or unchangeable. It is created in relationships between people or objects/things. Power means influence, domination, authority and shared power. Power, as a process that takes place in relationships, leads to the possibility of empowerment.” Jooste (2003:217) defines power as the feeling of being able to perform something legally and with authority. Power is the ability to mobilise resources that are needed to accomplish the job and empowerment is gaining access to these resources, support and information for growth and development (Kanter in Hawks 1992:610; Samiento, Laschinger & Iwasiw 2004:134). Miller, Goddard & Laschinger (2001:1882) refer to power as the capability of people to get things done and power is derived from the level or the rank or position that the person holds at that institution. Tebbitt (cited in Miller et al 2001:1881) defines empowerment as the process of creating and sustaining the work environment that “speaks to values that facilitate the employees’ choice to invest in and own personal actions and behaviours resulting in positive contributions to the mission statement of the organisation. Therefore empowerment of workers in any organisation is viewed as a critical element in the achievement of the mission, the vision and the strategic plans of any organisation.”

Empowerment is defined in various spheres of life and disciplines, and refers to the distribution of authority, sharing equal responsibility for the results, maximisation of one's contribution for success, and full participation in decision-making (Nokelainen & Ruohotie 2003:147; Page 1999:3).

Menon (2002:29) defines empowerment as the act of granting autonomy, a process of gaining control over events and outcomes or a feeling of being enabled. In Menon's (2002:28) health empowerment model, empowerment in health is an interactive system that consists of "the individual community member, health service providers, and the regulatory environment consisting of health policy and systems".

Individual community member. The individual community member is the potential recipient of health service. In this section the concern is the health and well-being of self and the family.

Health service providers. Health service providers include all services where health care is rendered like hospitals, clinics, health centres and the professionals who render health care like nurses, doctors, social workers, pharmacists, physiotherapists and occupational therapists.

Health policy and systems. These are all the policies formulated to run the health service organisation. They are used to regulate the practice of the health service, and include budgetary and health insurance policies.

All three systems overlap and are interdependent of each other. Empowerment should encompass the three elements of health care (Menon 2002:31).

Hawks (1992:610) emphasises that empowerment gives individuals more control over their own situations or lives by teaching them ways to acquire this control.

Page (1999:1) defines empowerment as a process that challenges the assumptions about power, succeeding, achieving or helping. It is a process of change. Empowerment is not static but an on-going process and cyclical in nature.

3.4.1.1 Empowerment as a relational concept

Nokelainen and Ruohotie (2003:148) view empowerment as a relational concept. Individuals have a personal sense of power and a sense of control in relation to other people. Empowerment can also mean sharing power with or distributing power and control to subordinates. This is a power-sharing relationship of empowerment and “is based on the idea that creating interdependent and meaningful relations with others improves individual motivation, gives a sense of meaningfulness, and advances self-understanding”. Empowerment is therefore a social process as it occurs in relationships between the empowerer and the empowered.

3.4.1.2 Empowerment as a motivational construct

Empowerment is a motivational construct because during the process of empowerment the cognitive aspect, the perception and the emotions of the individual or group concerned are emphasised. Psychological motivation is viewed as intrinsic motivation as individuals become self-motivated and self-directed. Empowerment is related to self-efficacy beliefs and to outcome expectations (Nokelainen & Ruohotie 2003:149).

3.4.1.3 Empowerment as management of change

Sprezer, DeJanasz and Quinn (1999) (cited in Nokelainen & Ruohotie 2003:149) state that there is a relationship between empowerment and management of change, that managers are expected to evolve innovative ideas, get support from their seniors and encourage members of the organisation to strive towards a common goal. Nokelainen and Ruohotie (2003:145) refer to Herrenskohl, Judson and Heffner’s (1999) tool to test different dimensions utilised to determine whether an individual is empowered.

Byham (1994:5) defines empowerment as knowledge of the boundaries of authority and responsibility, making decisions that are meaningful, and being respected as a thinking being.

According Ross and Deverell’s (2004:291) community development model, the principle of empowerment forms part of community development and means giving power to community members to participate in decision-making on matters affecting the

community. For empowerment to materialise, community members need knowledge and skills in order to make the correct decisions. Once empowerment takes place at individual, family and community levels, people will work together to achieve the set goals.

3.4.1.4 Definitions of empowerment

The researcher consulted definitions of “empowerment” from management, education, nursing management, sociology, economics, sociology and psychology.

3.4.1.4.1 Managerial/organisational empowerment

In management, empowerment refers to the processes that allow employees to take part of the decision-making of the organisation (Wilkinson 1998:42). Subordinates are sometimes given greater discretion as well as a certain percentage in the control of the organisation. Wilkinson (1998:42) and Thompson and Herman (1995:4) refer to empowerment in the work situation as pseudo-empowerment, however, because the workers are not given real power.

From a management perspective, empowerment is leading people to learn how to lead themselves. If people can lead themselves they are empowered. Empowerment is a form of leadership. The leader must have the ability to see how to empower someone, formulate a plan and implement it. The leader must be conscious and committed and review the empowerment process to evaluate if there is any positive change (Wilkinson 1998:13). Empowerment is a dynamic process of interaction between the leader, who is the empowerer, and the follower, who is the individuals to be empowered (Jooste 2003:321).

3.4.1.4.2 Nursing educational empowerment

In the nursing profession, the concept of empowerment has been adopted in personnel management, nursing research, nursing education, and the development of patient care (Kuokkanen, Leino-Kilpi & Katajisto 2002:328).

Empowered nurses develop and respect the moral principles of the profession; are future-minded, creative, innovative, and broadminded; have nursing expertise and personal integrity; are sociable, and display competency in their work.

The nursing education system in South Africa is changing from an acute to a community setting and nursing students must be equipped with the methods and skills to function in the community setting. Empowerment should revolve around health promotion concepts like identification of community's health care needs and how to address these community needs (Gaines, Jenkins & Ashe 2005:522). The absence of empowerment in nursing is characterised by powerlessness, helplessness, alienation, oppression, loss of a sense of control over one's life, and dependency.

Jooste and Booyens (1998:24) define empowerment as an enabling process that enables nurses to use their potentials and competencies. Jooste (2003:231) identifies the main characteristics of empowerment as follows:

- The contribution that the management structures make to the empowerment of nurses by training them in supervisory skills, providing an open atmosphere for discussion, free communication, and opportunities to be innovative.
- Participative decision-making on the empowerment of nurses.
- Attributes that characterise a nursing manager or any manager in any organisation include fairness, acting as a role model, having a relationship of trust with followers, and being caring, hard working, an expert in the field, trustworthy, and open to criticism.
- Motivation and token system strategies that contribute to empowerment.
- The role of power sharing in the empowerment of nurses.
- The skills and the responsibilities of managers towards the empowerment of nurses.

Jooste (2003:226) maintains that leaders/managers should use the following empowering strategies to promote participative decision-making on management issues in the work situation:

- Teach team building to top- and middle-level management so that teams at the lower levels can become strong.

- Follow a collaborative approach.
- Delegate authority to lower levels so that leaders have less work in supervision and that the lower levels are encouraged to take part in decision-making until they become competent.
- Adopt a bottom-up approach where the followers should spell out their expectations.
- Encourage a democratic rather than an autocratic approach to leadership.
- Leaders need to communicate with the followers and make the necessary information available.

Jooste (2003:227) further identifies the following elements for empowerment: self-motivation; self-enrichment, which will lead to personal and professional development; acknowledgement in the form of performance appraisal for promotion; material and non-material incentives and tokens, and constructive feedback. These elements further increase self-motivation and self-worth.

Hawks (1992:616) emphasises experiential and transformational learning theories and methods for empowerment of student nurses. Laschinger, Finnegan, Shamian and Wilk (2001:261) use Kanter's theory of organisational empowerment to illustrate the impact of structural and psychological empowerment of nurses in their job setting. According to Kanter, individuals react rationally to the existing situation in which they find themselves. In the nursing situation, then, if the working situation is so structured that employees feel they are empowered, they will respond by facing the challenges in the organisation and this will lead to the improvement of the organisation and the employees will react positively to the needs of the organisation.

For empowerment to be effective, those who are empowered should gain access to information on the needs and expectations of the organisation; be supported by those responsible for empowering them, that is, the empowerers or the leaders of the organisation; be given latitude to use the available resources to do their delegated tasks or work, and continuously be given opportunities for development like crash courses or in-service training. Guidance, leadership, monitoring, and evaluation are important in the empowerment of workers (Laschinger et al 2001:261).

Kanter associates empowerment with important outcomes of organisations like hospitals and nursing educational issues such as practising autonomy, taking part in decision-making on major issues of the organisation. Individuals take control of their destiny and perform to the limit of their competence. Involvement in the organisation prevents burnout and develops confidence in management and the organisation (Laschinger et al 2001:260). Structural empowerment or the working conditions should be planned in a manner that enhances psychological empowerment. Therefore psychological empowerment automatically becomes the outcome of implementing Kanter's theory. Spreitzer (cited in Laschinger et al 2001:261) identifies four components of structural empowerment, namely meaning, competence, self-determination, and impact.

Meaning. This refers to a positive and relevant relationship between the needs of the job and the employees' beliefs, values and needs.

Competence. This refers to the employees' capabilities to perform the work.

Impact. Impact is the sense or capacity of an individual to have an influence over important outcomes of the organisation.

Self-determination. Self-determination means individuals' feeling of control over their job.

Laschinger and Wong (1999:308) found that staff nurses' empowerment and collective accountability had a positive effect on their perceived productivity and self-rated work effectiveness.

Samiento et al (2004:134) applied Kanter's theory to nurse educators' workplace empowerment, burnout, and job satisfaction at a nursing college in Canada. The study found that a conducive or positive workplace yields positive results in the employees or those being empowered, because the participants felt empowered through attendance of conferences, exposure to new challenges in nursing education, open channels of communication, collaboration and networking with peers.

Miller et al (2001:1887) evaluated physical therapists' perception of empowerment using Kanter's theory of structural power of organisations. According to Kanter, for empowerment to be effective, management should create a working environment that enables employees to gain access to the support, information, and resources necessary to accomplish the work delegated to them (Miller et al 2001:1881). This offers employees opportunities to develop continuously in their work setting. Consequently, it is essential to create an environment that will provide access to the structures or tools that will empower nurses to accomplish their job and achieve the set goals.

3.4.1.4.3 Social empowerment

Kuokkanen et al (2002:328-335) found that empowerment contributes to nurses' mobilisation and concern for the realisation of full potential of social, physical, economic and psychological development. In this study, mobilisation focused on the empowerment of families for the physical, social, psychological and economic care of their mentally handicapped children.

3.4.1.4.4 Psychological empowerment

According to Gutierrez (1990:151) (cited in Ross & Deverell 2004:186), empowerment involves a "process of increasing personal, interpersonal, or political power so that individuals can take actions to improve their life situations". Four associated psychological changes are necessary for individuals to move from the stage of apathy and despair to action, namely increasing self-efficacy, making group consciousness strong, reducing self-blame, and taking personal responsibility for change and taking an active role in the community. Increasing self-efficacy refers to developing a sense of personal power or mastery over life's events. Psychological empowerment makes people more capable, assume personal responsibility to change their environment, develop a sense of sharing, and make an active effort to solve their problems.

3.4.1.4.5 Socio-economic empowerment

Anthony (2003:7) defines economic empowerment as access to credit for meeting consumption and the production needs, "involvement in economically productive activity, control over income, access to and control over productive assets like land, and

autonomy over personal choices”. Women’s economic empowerment is a useful strategy because it promotes shared knowledge and self-help, encourages solidarity among women, and promotes mutual trust and women’s participation and bargaining power in local institutions.

Personal empowerment refers to personal development through which individuals reach self-realisation or self-identity.

3.4.1.4.6 Empowerment models and theories

According to Dredf (2004:10) and Ross and Deverell (2004:291) empowerment is one of the principles of community development and means giving power to community members to participate in decision-making on matters that affect the community. For empowerment to materialise, community members need knowledge and skills in order to make the correct decisions. Once empowerment takes place at individual, family and community levels, people work together to achieve set goals.

Empowerment theory addresses “the forces of discrimination and oppression of individuals and groups” (Bradley 2006:3). Bradley (2006:3) maintains that problems occur when society fails to meet the needs of its members adequately. Bradley (2006:3) describes empowerment as an individual or group’s capability to control human and material resources. The consequences of empowerment include a personal sense of power and self-efficacy.

Empowerment is achieved in five steps (Bradley 2006:4; Townsend 2003:13; Wilkinson 1998:51), namely:

- Awareness of the need to change
- Desire to participate and support the change
- Knowledge of how to change
- Ability to implement the change on a day-to-day basis
- Reinforcement to keep the change in place

3.4.1.4.7 The Casey family resource centres model of empowerment and leadership

In 2001 the Smith College in the USA introduced the Casey family resource centres empowerment and leadership model, and found that “a clear progression of participant involvement” was essential for real empowerment to take place (Drisco 2003:26). The staff members discovered that the participants lived far from each other and were therefore isolated, which then prevented them from achieving their goals. The staff then embarked on outreach projects in order to inform the people about the goals and activities of the family resource centres. When this was not sufficiently effective, friends and families were utilised to encourage them to come to the centres. The children were incorporated and later parents and extended families were introduced to the family resource centres.

3.4.1.5 Enabling stages of Casey family resource centres

The Casey family resource centres model is introduced in three steps, namely preparation, early stage of empowerment and later stage of empowerment. According to Drisco (2003:27), the first step is preparation to make sure that the families are “thought of and also valued as members of their neighbourhood”. The family resource centre recruits staff members who are able to speak the local languages to enable everyone to follow discussions. Childcare and food were among the first priorities.

The second step (early stage of empowerment) is to introduce health workers in the neighbouring areas to the family resource centres so that they begin to value the importance of the centres and view them as safe, empowerment strategies, and potential assistance in achieving goals. This leads to increased participation of both staff and people from the neighbouring areas (Drisco 2003:30).

Finally, in the later empowerment step, partnerships were formed with the participants in order to make decisions. The best strategy to reinforce empowerment and leadership skills was support and encouragement.

The Casey family resource centres model consisted of six phases: recruitment, engagement, involvement, retention, partnership and leadership (Drisco 2003:31). Figure 3.1 depicts the six phases of the Casey family resource centres model.

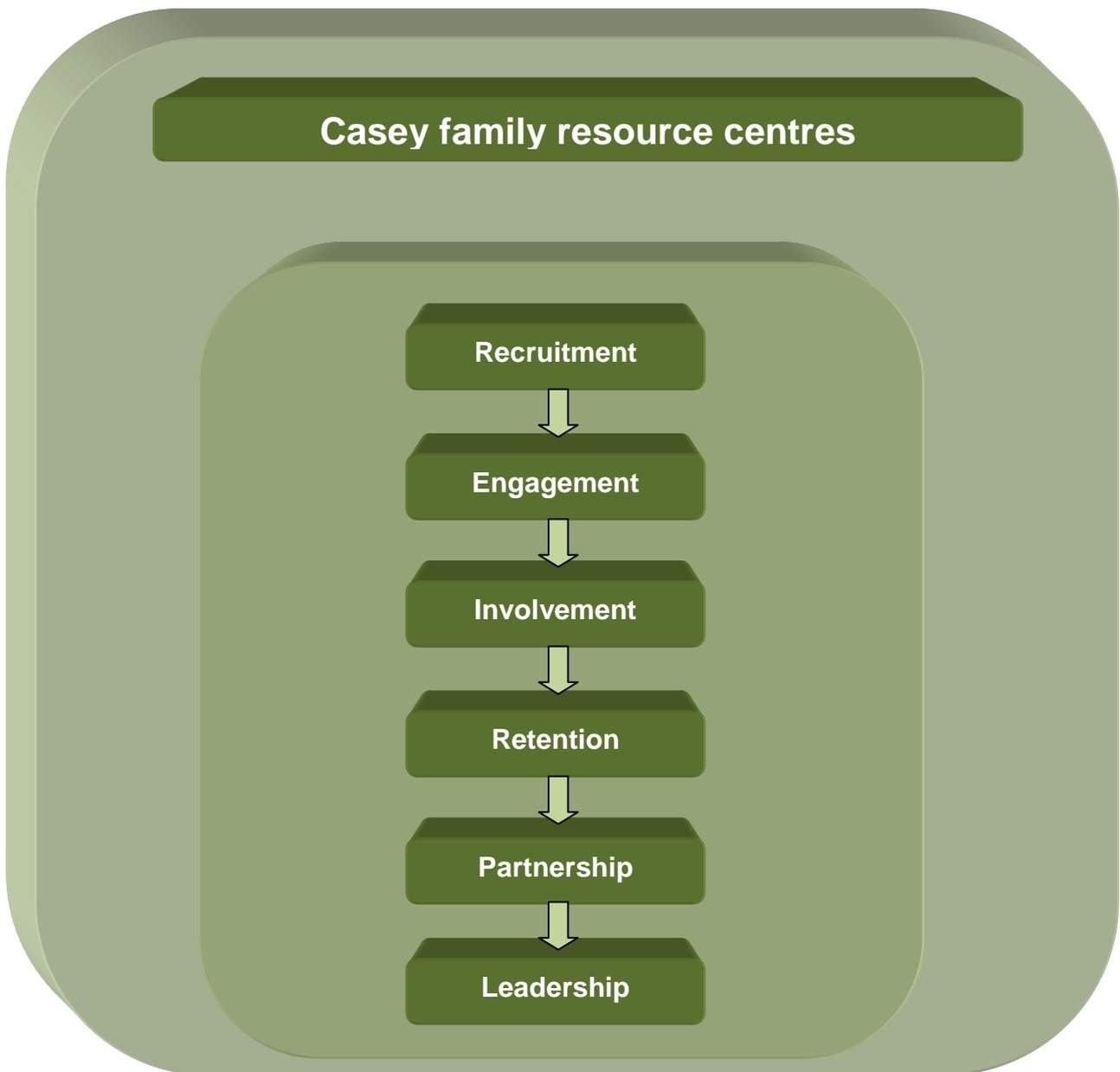


Figure 3.1 *Phases of the Casey family resource centres model*

Source: Drisco (2003:31)

Recruitment. This is the period when the health care workers start to identify the needs in the community and families and start to recruit them to come and attend health care services.

Engagement. The families and the community start to be involved.

Involvement. The community and the families start to take an active part in their health care activities. Those who are empowered form part of the health team.

Retention. Those who are empowered remain in the group and internalise the norms and values of the group.

Partnership. A partnership forms between the empowerers and the community members. There is a working and supportive relationship.

Leadership. This is when those who are empowered take charge of their health and become responsible.

3.4.1.6 Process and methods of empowerment

Empowerment has four phases related to the power that people gain to handle conflicts and problems and their participation in solving the problems at hand, namely mobilisation; search for social support; better understanding, and conviction (Stark 2002:29).

Mobilisation

This is the time when individuals start to realise that they have a crisis or problem and gain confidence in whoever leads them or makes decisions for them. People start to look for their own possibilities of solving the problems or of influencing the situation.

Search for social support

In the second phase, people search for social support from others who have similar problems or the same interests. After finding out how others handle their conflicts, they take action by assessing their capabilities and take their first public action.

Better understanding

In this stage people have gained knowledge and reached a better understanding from others. The experience that they gain through taking action enables them to define their roles in the groups.

Conviction

In this stage people have developed skills in handling conflicts and come to the conviction that they can influence the social content. This attitude of conviction assists in supporting other people with the same processes. People who reach the stage of conviction may act as 'catalysators' for a broader empowerment and encourage others to participate actively and start building social power from below.

3.4.1.7 Family empowerment

In order to address equity in educational opportunities, teachers and professionals should adopt a comprehensive approach to empowering families in dealing with the health and social needs of children in the communities like nutrition, health care, housing, and occupational functioning. Schools and communities are responsible for seeking ways of empowerment to support families so that the future of all their children with or without handicaps can be hopeful.

Methods of empowerment include parenting education and programmes, early child education, empowerment through leadership and team development, collaborative services, and impact points (Byham 1994:20; Green, Friesen, Gordon, Everhart & Gettamen 2003:27).

Parenting and how parents and children bond with and relate to each other affects the children's future and socialisation (Dunn 1995:33-40; Brodin & Molosiwa 2000:10; Green et al 2003:30). Parenting programmes should be comprehensive and collaborative, and include health care, social services and family support services. Each child in the programme must have ongoing professional assistance. The programmes should be accessible and the service providers should consider the clients' cultural aspects as well. Moreover, parenting programmes should be controlled qualitatively with people who are accountable for their implementation (Brodin & Molosiwa 2000:10; Dunn 1995:33-40; Green et al 2003:30).

Other methods of empowerment include formation of school-linked and community partnerships for family empowerment (Brodin & Molosiwa 2000:10; Dunn 1995:33-40).

In this study, empowerment pertained to the process through which families or family members are taught or assisted to take care of their mentally handicapped children physically, mentally, and socially to encourage independence and self-reliance.

Huff and Johnson (1998:376) explain empowerment as an intent and process of helping or assisting people who need help at individual, group, family and community level to make use of the resources in and around their environment. "To empower people is to help them find strengths and worth within themselves" (Huff & Johnson 1998:376). People feel empowered when they find that they are able to take control over their lives and feel competent and worthy to do something for themselves. In this study, the participants felt empowered once they were able to care for their children independently with little assistance.

The dynamics of empowerment are a reflection of the interaction between individuals and their localised environment. In this study, the localised environment was the family setting where the parents and siblings of the mentally handicapped children live; the individuals were the people residing in the house including the mentally handicapped child; reflection was the process of empowerment, and the interaction was the outcome of the empowerment process. Empowerment is about being helped while learning to do things.

The following are ways of empowering families, parents, and guardians of children with disabilities, including mental handicap (Buntix 1993:11; Harrold & Lubetsky 1995:4; Van Hammond 1995:37).

- Children and young adults with disabilities should be provided with free and appropriate public education.
- Make sure that young adults and children with disability get the necessary educational support and other services that they need for completion of their educational needs.
- Give parents and guardians and families of disabled children access to accurate information, specialised training, and peer-to-peer support in their communities.
- Make sure that parents, guardians, and families of children and young adults with disabilities are full participants in their education in all spheres where their needs are supported.

- Build on the existing regional service delivery systems in order to give technical assistance to the resources available for the families of children and young adults with disabilities.

3.4.2 Attributes of “empowerment”

In determining the attributes of concepts researchers make notes of the characteristics as they read; that is, the characteristics of the concepts that appear over and over again. This list of characteristics is referred to as defining or critical attributes of the concept. The attributes are not immutable as they may change as the understanding of the concept improves. The purpose is to try to show or display “the cluster of attributes that are the most frequently associated with the concept and that allow the analyst the broadest insight into the concept (Gilmour 2001:85; Pearsal 1999:43; Tulloch 1990:39; Walker & Avant 1995:41). A researcher may have many possible meanings and will have to decide to choose the ones that will be most useful in the study, depending on the aim of the study. A researcher may decide to take more than one meaning and continue with the analysis. The final decision lies with the researcher (Walker & Avant 1995:41). In this study, the researcher started with the attributes of “power” and then those of “empowerment”, and analysed more than one meaning further.

For example, antonyms to “empowerment” included disempowerment, helplessness, alienation, oppression, dependency, loss of sense of control, and powerlessness.

3.4.3 Construction of a model case

Walker and Avant (1995:42) refer to a model case as “a real-life example of the use of the concept that includes all the critical attributes of the concept”. A model case should be an absolute example of the concept and must absolutely represent the case. It may be from a real-life situation or researchers may construct it. As researchers develop a list of attributes for the concept they simultaneously develop the model case attributes (Walker & Avant 1995:42)

Example of a model case

A married woman aged 35 had three children aged 16, 14 and 11. The eleven-year-old child was moderately mentally handicapped. Her family was undermined and rejected by the community members due to the stigma of mental handicap. The mother worked at a restaurant and the father was a labourer working at a distant workshop in an industrial area. They both experienced absenteeism from the workplace due to the demands of taking the child to different health professionals, seeking help because they did not have the knowledge and skills to care for their mentally handicapped child. The family experienced financial problems because of high medical bills to meet the child's needs. The siblings experienced problems with their schoolwork and did not attend school regularly.

The couple asked for help from the psychiatric nurse working in the community clinic. The nurse visited the family to assess the family needs in totality with the assistance of the family who took part in the identification of their needs, problems and expectations. The family and the nurse identified that the family did not have information on mental handicap and how to treat, care for and rehabilitate their mentally handicapped child. The family did not know the resources available and where they could get support. The psychiatric nurse and the family together formulated a plan of action and formed a relationship of sharing, honesty, respect and trust and the environment became enabling.

The psychiatric nurse explained the concept of mental handicap, its causes and manifestations, the support that should be given to the mentally handicapped child, and the involvement of the family in training the child. The nurse taught the family about the rights of mentally handicapped children, and also how to make homemade toys. The education was given in sessions until the family had a good grasp of mental handicap. The family was given handouts to make the sessions clearer.

The psychiatric nurse referred the family to the relevant mental health professionals, starting with a psychologist for further assessment, classification of the child's mental handicap and specialised procedures. The child started to show signs of epilepsy and the psychiatric nurse referred the child to a psychiatrist for treatment. The family was also referred to a social worker since they had financial problems and financial assistance in the form of a monthly disability grant was issued to the child. The social worker referred the child to the occupational therapist and the child was taught leatherwork because that was the child's area of interest. The family was encouraged to take part actively and learn the skills that were taught to their mentally handicapped child and the child started to be independent, became innovative and performed skills on his own.

During the health education days arranged during March, mental handicap awareness month, by the Department of Health and Social Welfare and the nearby university the

family was invited to come and listen to the health education lectures on mental handicap, including the responsibilities of the families in the treatment, care and rehabilitation of mentally handicapped children. At the talks, the family met other families of mentally handicapped children and shared and learned to solve similar problems related to the care of their children. In this way, the families started empowering themselves with guidance from mental health practitioners. The families were encouraged to form self-help, parent and buddy groups to support one another and share happy moments with their children, like going to the cinema, taking trips, going on picnics, and celebrate important days like birthdays, Christmas, and family days. The family took the lead because they had internalised issues about the care of the mentally handicapped. The families of mentally handicapped children started to function independently with confidence.

The families developed long- and short-term goals for their support group, one of which was to establish a day-care centre for their children so that they could go to work. The empowered family support groups established a day-care centre for the mentally handicapped children and the family members were included in the executive committee and some of the caregivers were family members of the children. The families were so committed that they registered the centre as a non-governmental organisation (NGO) with the Department of Social Development and were issued with a fund raising number, authorising the centre to raise funds. They took ownership of the centre and also registered it with the Department of Education, Health and Social Welfare for a subsidy in order to meet the needs of the children. The psychiatric nurse invited the Department of Labour and the Department of Agriculture to capacitate the children and their families with knowledge and skills for gardening and handwork like knitting, weaving, leather work, cooking and other skills to enable the families to raise funds in order to sustain the project for the mentally handicapped children. The families expressed satisfaction and feelings of independence, self-efficiency, and self-fulfilment. The centre boosted their self-esteem and they felt that they had achieved their goal. Furthermore, they recruited nearby places to establish such day-care centres for the mentally handicapped children in their community. The families became experts in the care of their mentally handicapped children.

Both the psychiatric nurse and the families monitored and evaluated the success of the implementation and found that the families had developed skills and knowledge, and become autonomous, independent and self-efficient in taking care of their mentally handicapped children.

3.4.4 Construction of borderline, related, contrary, inverted and illegitimate cases

Borderline, related, contrary, inverted and illegitimate cases vary in their attributes of the concept (Walker & Avant 1995:43-45).

Borderline cases have some but not all the attributes of the concept.

Example of a borderline case

A 30-year-old woman had a daughter of 12 who was severely mentally handicapped. The neighbours and their children always ridiculed the child and they said she played like an animal. This problem worried the mother due to lack of skills and knowledge and she took the child to the nearby clinic for assessment. The nurse at the clinic assessed the child and explained to the mother that the child appeared to have a serious problem and warranted assessment by the psychiatrist. The nurse referred the mother to the psychiatrist who examined the child and discovered that the child was severely mentally handicapped and needed training in basic skills like toilet training and personal hygiene. The psychiatrist informed the mother of the causes, manifestations and type of treatment, care and rehabilitation needed by the child. The mother was referred back to the clinic where she and her child were taught the self-help skills. The sister at the clinic supported the mother, equipped the mother with the knowledge and skills, and referred the child to the available resources but the child did not improve. The psychiatric nurse only assessed the child with the mother and did not continue with a plan of action, therefore the implementation and evaluation of the empowerment process was unsuccessful.

Contrary cases. Contrary cases are cases or instances that do not contain all the critical attributes of the concept being analysed. They are not consistent and assist researchers to identify why the instance does not represent the model cases.

Example of a contrary case

A young teacher worked at a rural school and her husband worked at a firm 90 kilometres from home. The woman gave birth to a baby boy in the absence of her husband. According to the mother, the child displayed questionable behaviour. She took the child to the nearest clinic and they told her that the boy was a 'mongol'. The mother was very frightened because she understood the child was an animal. She took the child to a doctor who said he was too busy to examine the child and referred her to a psychologist. The psychologist said it was too early to diagnose the child and the mother must go home and wait and see, and referred the child to the nearby health centre. She found that nurses were very busy and gave her an appointment to come after a week. She went to the social worker who told her to come and see her after two years as it was too early to diagnose the child. The mother said she went home and looked for a carer for the child so that she could go to work. The family was not given access to support, resources and information necessary for empowerment. Consequently, they could not develop independence and self-efficacy.

Related case. These cases do not contain the critical attributes even though there is a relationship between the instances of the concepts and the concept being studied. Related cases assist researchers to understand the relationship between the concept under study and the other concepts that surround it. Although these cases are closely related to and nearly the same as the concept under study, closer examination reveals differences (Walker & Avant 1995:45).

Inverted cases refer to cases derived from other fields like home economics.

Illegitimate cases are not usually used because there are terms that are not properly used or out of context.

All the cases are important to enable researchers to make the best judgement about the attributes that represent the concept being studied (Walker & Avant 1995:43).

3.4.5 Identification of antecedents and consequences

Walker and Avant (1995:45) maintain that it is essential to identify the antecedents and consequences of the concept as they assist in further refining the critical attributes.

Attributes refer to the events that should take place before the phenomenon under study or the concept. Antecedents and consequences assist in identifying the social context in which the selected concept is used and assist in identifying the underlying assumptions about the concept under study. Consequences also help in the identification of the areas or ideas that are neglected and the relationships that generate future research. According to Drisco (2003:20), the steps needed for empowerment to take place include “enabling”, that is, building of capacities and confidence, which should be based on the person’s intrinsic goals and purposes.

3.4.5.1 Antecedents of empowerment

Before empowerment can occur, the environment for it must be conducive, that is, therapeutic, nurturing and caring (Hawks 1992:611). A caring and nurturing environment requires a relationship of trust between the empowerers and those to be empowered in order to portray honesty. Trust and empowerment will develop with ease if openness, open communication and genuineness flow in both directions; that is between those who are empowered and the empowerers. Both parties in the empowerment process should accept one another as they are, have mutual respect, act responsibly during their interactions and share common goals and aspirations.

Latino (1998:20) identifies the following steps to ensure empowerment:

- Establish long-term goals and a clear vision for empowerment. The direction will be defined and clear goals set.
- Choose the people to be empowered and define or identify what they need to be empowered to do.
- Recognise the existing experience of the people to be empowered and build on it.
- Train those to take the empowering role and responsibility. They should develop a desire to be responsible for their own excellent performance.
- Develop genuine trust between the empowerer and those to be empowered. An environment of trust and openness and free sharing should be encouraged.
- Build a relationship of trust. In case of a company, the trust should be created between management and employees.

- Convey a true sense of stewardship for the organisation's future or success to the people to be empowered.

Page (1999:5) regards mutual respect between participants, facilitators, committee members and others involved in the empowerment process as the crucial prerequisite of empowerment.

3.4.5.2 Consequences of empowerment

Empowered organisations work with long-term goals which they operationalise into short-term goals with the focus on the formulation of goals to the outside world (Stark 2002:30). In the case of families and communities, the people acquire skills and knowledge to support, educate and care for their families comprehensively. According to Byham (1994:2), organisations that empower their employees produce meaningful changes and become competitive and the customers become happy.

Byham (1994:5) found that empowerment brings about responsibility, meaning, interest, and challenge and those empowered become excited as they had achieved. Once people are empowered they can adapt to the changing environment. "Empowerment makes the day go quickly, puts a lift in your walk and at the end of the day produces feelings of pride and accomplishment" (Byham 1994:6). Empowerment creates energy for mental and physical well-being. People who are empowered feel ownership of and commitment to what they do, produce quality work, become productive and enjoy fulfilling and rewarding work. Motivational energy may result from the process of empowerment.

Empowered individuals display increased job satisfaction, feel independent and accept responsibility, are committed to their job in order to attain the set goals, improve their leadership and communication skills and the work becomes meaningful to them (Hawks 1992:611). Samiento et al (2004:136) point out that empowerment leads to perceived control over the practice of nursing and reduces role or job stress.

Empowered individuals in the health care setting, such as nursing, develop the ability to apply themselves to the ever-changing environment, self-efficacy, self-esteem and confidence (Lewis & Urmston 2000:17). They develop the ability to participate in decision-making forums, accept responsibility and become self-reliant.

3.4.6 Definition of empirical referents

The final step in concept analysis is the determination of the empirical referents for the critical attributes. Empirical referents refer to “classes or categories of actual phenomena that by their existence or presence demonstrate the occurrence of the concept itself” (Walker & Avant 1995:46). The categories relate to the critical attributes of the concept and in some cases the empirical referents are the same as the critical attributes that are identified. Table 3.1 lists the critical attributes of empowerment.

Table 3.1 Defining attributes of empowerment

Empowerer	Empowered	Process	Context	Outcome
Make able/enable	Assess own capabilities	Cyclical	Enabling environment	Active/full participation
Facilitate	Gain access to information, resources and support	Social	Regulatory environment	Feeling enabled
Capacitate		Sharing		Effectiveness
Support		Interactive	Open atmosphere	Self-efficacy
Role model	Realise own crisis/needs	Developmental	Free communication	Self-fulfilment
Assist/help	Gain/acquire knowledge and skills	Enabling		Competence
Expert	Development	On-going		Success
Share responsibilities				Handle life’s problems
Commitment	Evaluation			Autonomy
Evaluate				Independence
Influence				Gain control
Encourage				Decision-making
Creates enabling environment				Innovativeness
Accountable				

3.4.7 Definition of empowerment

Empowerment is a cyclical process of shared social interaction taking place between the empowerer (psychiatric nurse/mental health professional) and the empowered (family members of the mentally handicapped child). In this process the psychiatric nurse who is regarded as an expert empowers the family members who are regarded as lacking knowledge and skills. In this process both the empowerer (psychiatric nurse/mental health professional) and the empowered (family members of the mentally handicapped child) participate actively in the creation of awareness, which leads to the formulation of a plan of action. Resources are mobilised to meet the identified needs and lastly monitoring and evaluation is done. The process leads to the family's independence, competency and self-efficacy (Byham 1994:5; Samiento et al 2004:136).

3.4.8 Classification of main concepts

The researcher used Dickoff et al's (1968:422) (cited in Meleis 1997:140) list to classify the concepts of the model, including the agent, recipient (patient), context (framework), procedure, dynamics and terminus.

3.4.8.1 Agent

Collins English Dictionary (1995:28) defines an agent as "a person who acts on behalf of another person, group, business, government, etc; a person or thing that acts or has the power to act; the means by which something occurs or is achieved; instrument". An agent explains who or what performs the activity (Chabedi 1998:40; Meleis 1997:140). The agents are the empowerers, who are the mental health professionals, trained in psychiatry, and include psychiatric nurses, psychiatrists, and allied health professionals like occupational therapists, social workers, psychologists and physiotherapists. These mental health professionals establish a relationship with families of mentally handicapped children and empower them with skills and knowledge so that they can be capacitated and enabled to gain independence and become competent efficient in the care, treatment and rehabilitation of their mentally handicapped children, be self-sufficient, self-reliant and be able to make decisions on their own.

3.4.8.2 Recipient

A recipient is “a person who or thing that receives” (*Collins English Dictionary* 1995:1294). In this study, the recipients were those who qualified for empowerment and were authorised to take part in the empowerment process to reach a stage of independence and autonomy to solve problems. The recipients were families of mentally handicapped children, who needed sharing of information, resources and support from the professionals in order to deal with problems and participate actively in the care of their children.

3.4.8.3 Context

In a theory the agent and the recipient have to be specific in terms of the content within which both are involved in the process (Dickoff et al 1968) (cited in Meleis 1997:142; Chabedi 1998:41). The context is the situation in which the study takes place. The context of this study was the families residing in the Moletši district of Polokwane and Aganang municipalities.

3.4.8.4 Procedure

Dickoff et al (1968) (cited in Meleis 1997:142) and Chabedi (1998:42) refer to the procedure as steps that need to be taken to bring about the desired intention/goal. Procedure is the technique of the activity and forms the guidelines for the theory. It indicates the protocol of the activities to be followed in the theory.

The procedure involves a two-way process between the empowerers (health professionals) and those who need empowerment (the families of mentally handicapped children). Empowerment is a relational and interactive process. The empowering environment needs to be enabling. Elements needed for empowerment to take place include identification of empowerment, sharing of common goals, active involvement in accessing knowledge and skills, resources and information, and support to achieve independence, self-care and autonomy and become competent and self-efficient in dealing with the problems of mental handicap.

3.4.8.5 Dynamics

Dynamics is the energy source for the activity (Chabedi 1998:43; Meleis 1997:140). The dynamics of empowerment takes place between the empowerers (mental health professionals) and the empowered (the families of mentally handicapped children). The dynamics involves aspects that facilitate the social process of the relationship of the empowerer and the empowered that achieve the goals and the purpose of empowerment. In this study, the families needed information for growth and development; access to resources and support in the care, treatment and rehabilitation of their mentally handicapped children; full participation in decision-making, and to be rewarded for the positive performance. Such involvement in the empowerment process enabled the families to become autonomous, competent and self-efficient.

3.4.8.6 Terminus

The terminus refers to the situation to be produced at the end of the process; that is, the end point of an activity. The terminus brings about a feeling of satisfaction in the performance of the activity (Chabedi 1998:43; Meleis 1997:141). Terminus refers to the outcome, the achieved goals or the end results of the process. In this study terminus is the achieved goals for empowering families with mentally handicapped children.

In this study, capacitation of families with mentally handicapped children was done to encourage taking of responsibility to promote knowledge and skills, autonomy/independence in order to achieve competency and self-efficacy. Self-efficacy forms the terminus of the empowerment process.

Figure 3.2 illustrates the conceptual model of the process of empowerment.

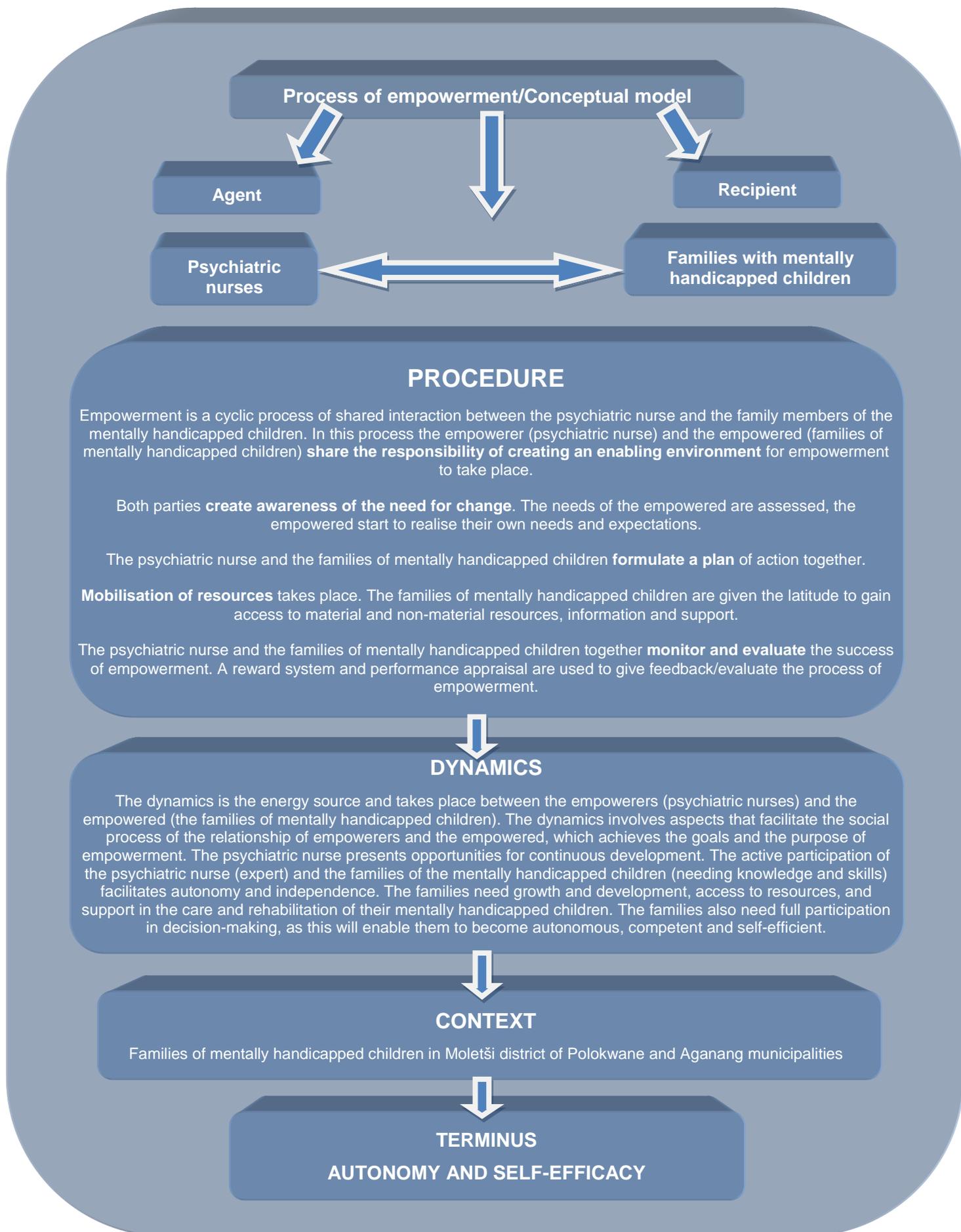


Figure 3.2 Conceptual model of the process of empowerment

3.5 CONCLUSION

This chapter discussed the purpose and uses of concept analysis, processes, attributes and theoretical definition of “empowerment”, and the development of a model to empower families with mentally handicapped children. Antecedents and consequences of empowerment were discussed. Conceptual model of the process of empowerment was discussed. Chapter 4 will describe the empowerment model for facilitation of autonomy/independence of families with mentally handicapped children to support them in the attainment of competency and efficacy.

CHAPTER 4

An empowerment model for facilitation of autonomy/independence and competence of families of mentally handicapped children to support them in the attainment of self-efficacy

4.1 INTRODUCTION

Chapter 3 focuses on the development of a model envisaged to assist in the empowerment of families with mentally handicapped children. The researcher used Chinn and Kramer's (1995:76) concepts in the development of the model. Chapter 4 describes the empowerment model for facilitation of autonomy/independence of families with mentally handicapped children to support them in the attainment of competency and efficacy.

4.2 OVERVIEW OF THE MODEL

From the literature it became clear that for empowerment to take place, the empowerers (mental health professionals) and the empowered (families of mentally handicapped children) need to share the responsibilities and be actively involved in creating awareness of their needs, formulating a plan, mobilising resources, creating an enabling environment and planning empowerment strategies.

The families need to be motivated to participate actively in the empowerment process to develop skills and knowledge to be able to treat, care for and rehabilitate their mentally handicapped children. Figure 4.1 graphically represents the model.

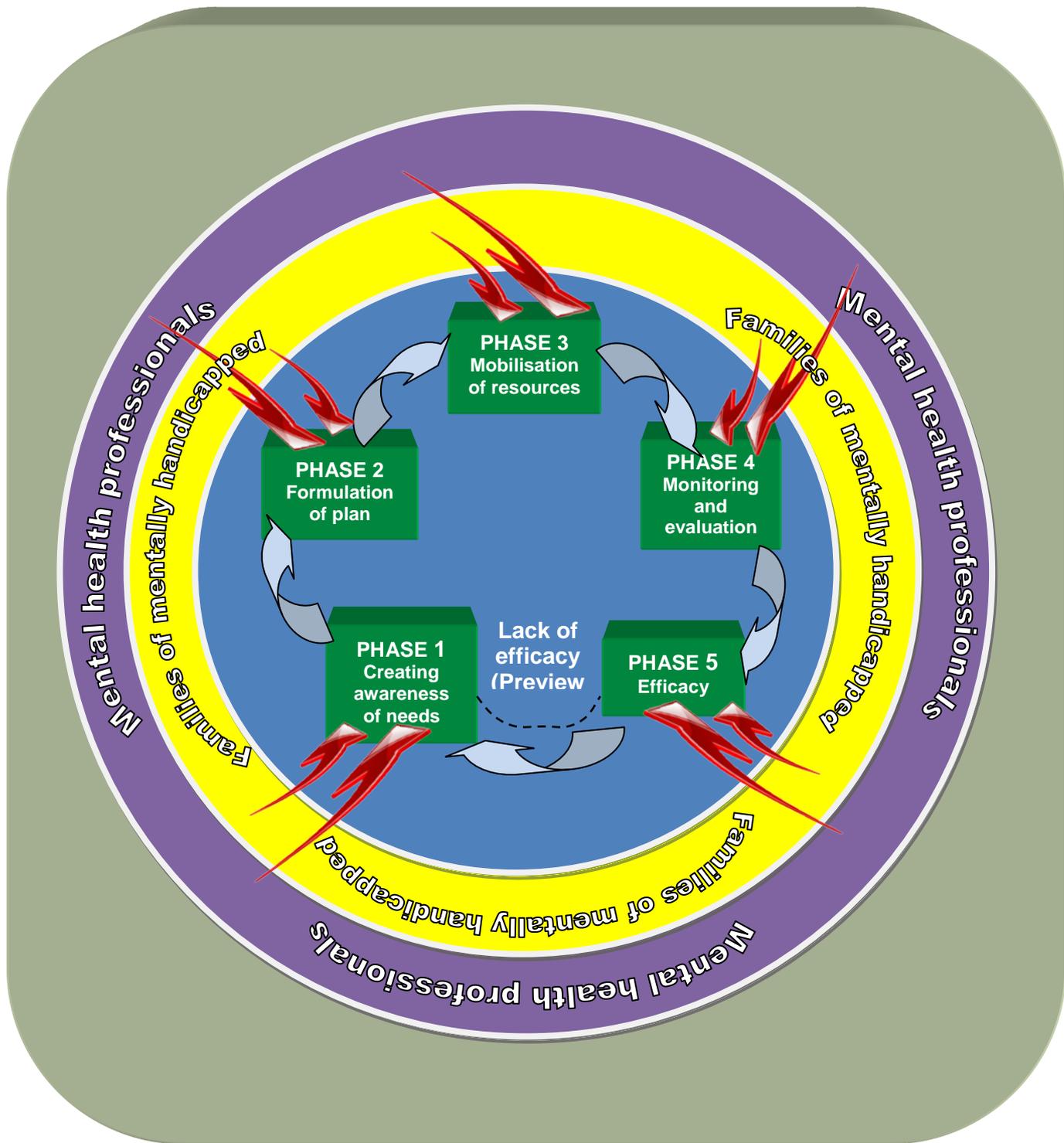


Figure 4.1 Model for empowerment of families with mentally handicapped children

4.3 STRUCTURE OF THE MODEL

The structure of the model refers to the overall organisation of the model, how ideas and concepts of the model are represented and the linking between different concepts. Chinn and Kramer (1995:112) point out that “the structure of the theory gives the overall form to the conceptual relationship”. It also refers to the structural presentation and the process of the model (Chinn & Kramer 1995:117).

4.3.1 Purpose of the model

The purpose of a model is to identify the central problems of the phenomenon under investigation. The model gives a framework for thinking about a certain/specific phenomenon and guides the concerned people’s thinking and behaviour when dealing with the phenomenon to be investigated (Ekdawi & Conning 1994:17). This study dealt with the central problems of empowerment. The researcher simplified and systematised the empowerment of families of mentally handicapped children through the use of a model (Mouton & Marais 1994:141). Mental health professionals could use this model locally, regionally, provincially, nationally and internationally in the care, treatment and rehabilitation of mental health care users.

The purpose of the empowerment model is to support, motivate and equip families of mentally handicapped children with knowledge and skills. The model provides a frame of reference for health professionals in different spheres of health care, especially mental health professionals, who support individuals, families and the community towards autonomy to attain competency and self-efficacy in the provision of their own health care.

4.3.2 Assumptions

The researcher based the empowerment model on assumptions related to empowerment as a process that assists families of mentally handicapped children in the attainment of competency where the families act independently and are enabled to control their own life situation.

The primary assumption of the model is that families are born with potentials and capabilities to survive and are always in the process of becoming. Families are conscious of their needs and shortcomings. Once an expert makes them realise their shortcomings, they work together with the expert to correct their situations. Families take it upon themselves to correct the situation on their own in order to attain competency and self-efficacy.

In the health care field empowerment is a process of sharing equal responsibilities between the mental health care professionals and the mental health care users. Both the provider and the recipients of health care have to participate actively in the process of becoming or empowerment so that the recipients can acquire knowledge and skills to care for themselves and their families. In this study, the mental health care professionals capacitate the families of mentally handicapped children to treat, care for and rehabilitate their mentally handicapped children on their own and become efficient in the process.

The process of empowerment should equip the families with the information to change behaviours and attitudes with the aim of making them autonomous in the attainment of self-efficacy.

According to Ross and Deverell's (2004:291) community empowerment model, the principle of empowerment forms part of community development. For empowerment to materialise, community members need to be equipped with skills to enable correct decision-making. Once empowerment takes place at individual, family and community levels, the people will work together and achieve the set goals. Therefore the mental health care professionals and the family must work together to achieve the goal of facilitating efficacy on the part of the family with mentally handicapped children.

Empowerment is a social process that occurs at individual, family and community levels. In this study, empowerment occurred in relationship between the empowerer (mental health professionals) and the empowered (the families of mentally handicapped children). In the researcher's empowerment model, empowerment occurs in relationship to the mental health professionals and the families of mentally handicapped children and was a journey that grew from need assessment and moved to planning goals and involvement to reach independence and competency.

Empowerment is a process of change that challenges the power of succeeding, achieving and helping (Page 1999:1). Moreover, empowerment is not static but on-going and cyclical in nature.

Empowerment is a form of leadership and people learn how to lead themselves with the guidance and assistance of the empowerer (mental health professionals). The aim of learning how to lead themselves encourages families with mentally handicapped children to become self-motivated, self-directed and self-efficient. Independent and eventually becomes competent and self-efficient.

Empowerment is achieved in five steps (Bradley 2006:4; Townsend 2003:13; Wilkinson 1998:51):

- Awareness of the need to change
- Desire to participate and support the change
- Knowledge of how to change
- Ability to implement a change on a day-to-day basis
- Reinforcement to keep the change in place

The above steps are related to the process of the empowerment model in this study because awareness is related to need assessment; desire to participate and knowledge of how to change are related to planning and implementation, and ability to implement the change and reinforcement to keep the change in place are related to independence/autonomy, competence and self-efficacy.

4.3.3 Context of the model

The context of this model was rural Moletši, 20 kilometres from town (Polokwane). The health services like hospitals and clinics in Moletši are situated in Polokwane and Aganang municipalities. The clinics and hospitals have a shortage of health care professionals, particularly medical, psychological, social, occupational and mental health care providers. Psychiatric nurses form the largest percentage of mental health care professionals. In Moletši district psychiatric nurses are perceived as the pivot on which mental health care revolves.

They are present 24 hours around the clock whilst other mental health care professionals like psychiatrists, occupational therapists, psychologists, and social workers visit clinics once a month. The psychiatric nurses are the only mental health care professionals perceived to be able to support and motivate the families of mentally handicapped children to take ownership of the care and rehabilitation of their mentally handicapped children and eventually become autonomous and specialists in the care of their children.

In Moletsi, the researcher found that the majority of the families with mentally handicapped were needy; had little or no education due to poverty, and hid their children due to the stigma attached to mental handicap. The model would therefore emerge as a source of assistance to these families as they would be equipped with skills and knowledge to care for and rehabilitate their children. The families would be involved in the assessment of their needs and goal setting, developing skills to become competent in the care and rehabilitation of their mentally handicapped children.

4.3.4 Definitions of the concepts

The researcher defined and contextualised empowerment as the core concept and its related concepts as the theoretical definitions. Chinn and Kramer (1995:78) define a theoretical definition as “a statement of meaning that conveys the essential features of a concept so that it fits within the theory”.

4.3.4.1 Empowerment

Empowerment is a cyclical process of shared social interaction taking place between the empowerer (psychiatric nurse/mental health professional) and the empowered (family members of the mentally handicapped child). In this process the psychiatric nurse who is regarded as an expert empowers the family members who are regarded as lacking knowledge and skills. In this process both the empowerer (psychiatric nurse/mental health professional) and the empowered (family members of the mentally handicapped child) participate actively in the creation of awareness, which leads to the formulation of a plan of action. Resources are mobilised to meet the identified needs and lastly monitoring and evaluation are done. The process leads to the independence and self-efficacy of the family.

4.3.4.2 Family

Stuart and Sundeen (1995:787) and Fawcett (1991:5) describe the family as the smallest unit of the society/community that possesses the origin of its characteristics, structure and patterns of relationship as well as communication and whose members are closely related to one another. The traditional family in all the cultural groups consists of two parents (that is, mother and father), the children and other relatives from both the maternal and paternal families. The modern family, also called the nuclear family, consists of mother, father and the children. The family shares a specific physical and psychological space. Each member of the family has specific roles (Ross & Devereil 2004:258).

4.3.4.3 Mentally handicapped child

A mentally handicapped child has limitations in functioning, characterised by significantly sub-average intellectual functioning, and lacks intellectual, occupational, and social skills, and is unable to perform self-management tasks (Campbell 1996:629). The family is expected to identify the needs of their mentally handicapped child with the support of the mental health care providers; be equipped with skills and knowledge; participate actively in the acquisition of skills; gain confidence and autonomy or work independently, and develop self-help skills in the attainment of competency and self-efficacy in the care and rehabilitation of their mentally handicapped child.

4.3.4.4 Mental health care professionals

Mental health care professionals have been trained in basic as well as mental/psychiatric health care. These professionals come from diverse environments, like nursing, social work, occupational therapy, medicine and psychology. They are trained to become clinical specialists and motivate and encourage families to act independently and take ownership of their health practices. They act as facilitators, advocates and change-agents in mental health practices (Basavanthappa 2007:669).

4.3.4.5 *Autonomy/independent*

Autonomy means that a person is reasonably independent and self-governing in decision-making and practice. Autonomy goes with accountability and responsibility. Autonomy and independence may be used interchangeably (Menon 2002:29). The empowered (families of mentally handicapped children) should gain access to support, information, resources and skills to enable them to be responsible and accountable and practise self-care on their own or independently to attain competency and self-efficacy. Aspects that would prove that the families of mentally handicapped children had gained autonomy would include possessing infinite worth and dignity, having the right to make their own decisions about matters that affect their children, having the potential to choose wisely, and being responsible and accountable for their actions (Ross & Deverell 2004:247).

4.3.4.6 *Competence*

Spreitzer in Laschinger et al (2001:261) define competency as the confidence that individuals have in their abilities to perform the work. Competency pertains to achievement of goals that have been formulated for achievement.

Families of mentally handicapped children should be supported, given information and resources to enable them to become competent in the care of their children and become experts or specialists in the care of their mentally handicapped children.

4.3.4.7 *Support*

Support is the assistance or help that mental health care providers give to families of mentally handicapped children to use their previous knowledge and experiences as well as new information they have acquired and develop innovativeness to do things for themselves to attain competence. Support can be emotional, physical, occupational, economic, religious and psychological (Hawks 1992:616; Laschinger & Wong 1999:303). If families of mentally handicapped children fail to implement the self-care practices, the mental health care professionals will assist them to start the process from the beginning to enhance efficacy because empowerment is a continuous and cyclical

process. Mental health care professionals' support of families enables the families to gain control of their life situations.

4.3.4.8 Information

The empowered (the families of mentally handicapped children) gain access to information in the form of training, exposure to recent methods of treatment, care and rehabilitation of the mentally handicapped children. The families become capacitated with skills and knowledge to gain independence and self-care to attain competency and self-efficacy (Hawks 1992:616).

4.3.4.9 Resources

Resources refer to the means available to perform a certain activity. Resources may be material or non-material (human) in nature (Drisco 2003:27). Material resources include support in the form of financial assistance, and transportation of families of mentally handicapped children to health services. Human resources include mental health care professionals. In the empowerment process mental health care professionals should avail themselves and support the families of mentally handicapped children to create need awareness, formulate a plan of action, and create an enabling milieu to implement the process (active participation from both parties) and gain knowledge and skills to attain self-efficacy (Family Network 2004:5).

4.3.4.10 Self-fulfilment

Self-fulfilment occurs when individuals are able to fulfil their ambitions. The families of mentally handicapped children reach a stage of self-fulfilment after being supported with skills and knowledge for the care and rehabilitation of their children with the support of the mental health care professionals. Once the families of mentally handicapped children reach competency and self-efficacy, they automatically reach self-fulfilment (Antai-Otong 2008:83).

4.3.4.11 Power sharing

Power sharing is a two-way process (Nokelainen & Ruohotie 2003:148). In the empowerment process, the empowerers (mental health care professionals) act as facilitators and work hand in hand with the empowered (the families of mentally handicapped children). Both parties become actively involved. An interdependent and meaningful relationship is formed. This relationship improves motivation of the families of mentally handicapped children, gives them a sense of meaningfulness and advances self-understanding that will encourage autonomy.

4.3.4.12 Relational and interactive

Power sharing is a relational term and indicates a sharing of power between the empowerers (the mental health care professionals) and the empowered (the families of mentally handicapped children). The mental health professionals equip the families of mentally handicapped children with specialised skills, whilst the families also participate actively in the empowerment process to control their life situations by developing self-help skills. For empowerment to be successful, there should be a relationship of trust, respect, honesty, sharing, genuineness and acceptance (Menon 2002:28). The empowerer (mental health care professionals) and the empowered (families of the mentally handicapped children) should work together for self-efficacy to be attained.

4.3.4.13 Cyclic

Cyclic means recurring in cycles. Empowerment is cyclic in nature because if the empowerment process is unsuccessful or changes occur in the environment where empowerment takes place, the process is reviewed to enable the families of mentally handicapped children to attain self-efficacy (Page 1999:1).

4.3.4.14 Enabling

An enabling environment is a calm, encouraging and supportive environment that makes it possible for empowerment to take place successfully.

For empowerment to be successful, there should be a relationship of trust, respect, genuineness, and sharing between the mental health professionals and the families of mentally handicapped children (Jooste & Booyens 1998:25; Maccoby 1999:1).

4.3.4.15 Skill development

Skill development means the acquisition of skills like decision-making, communication and problem-solving skills that enable the families of mentally handicapped children to gain independence in the care and rehabilitation of their mentally handicapped children (Drisco 2003:27).

4.3.4.16 Process

A process is a course of action. It is a series of actions that follow in a specific sequence and is scientific in nature. The empowerment process follows a sequence of events, namely need assessment, goal setting and creation of an enabling environment, and involvement where the empowerer and the empowered share the responsibilities in achieving the set objectives, and independence and self-efficacy occurs (Page 1999:1).

4.3.4.17 Innovativeness

It is the responsibility of the mental health professionals to make resources, information and support available to the families of mentally handicapped children. The families have to be innovative or creative and start processes/activities on their own for the competent care and rehabilitation of their mentally handicapped children (Wilkinson 1998:53).

4.3.4.18 Motivation

The health care professionals need to continuously motivate and encourage the families towards independent and self-care activities due to the stigma attached to mental handicap in society. The parents should also have intrinsic motivation; that is, motivation from within themselves or self-motivation. This motivation gives them confidence, encourages them to perform self-help activities, makes them feel respected, reassured and accepted, and boosts their self-worth.

Positive reinforcement is one of the strategies to encourage families of mentally handicapped children to master and perform their self-help practices (Jooste 2003:22).

4.3.5 Relationship statements

Theories are basically sets of relational rules that contain concepts and specify how concepts relate to one another. Relationships of statements should be formulated, which serves to put concepts in relation with one another. Relationships of statement provide links between concepts in the family empowerment model and are based on theoretical definitions (Chinn & Kramer 1995:117; De Swardt 2004:75).

Autonomy, self-fulfilment and self-efficacy are the outcome of the empowerment process. The success, autonomy, self-fulfilment and self-efficacy developed by the families of mentally handicapped children facilitate, support and enable them to use the strategies for self-care/independent methods in order to attain competency. They avail information, support and resources to the families of mentally handicapped children.

Autonomy/independence and self-efficacy become possible if both the empowerers (mental health care professionals) and the empowered (families of mentally handicapped children) share the responsibility in the empowerment process. The mental health care practitioners avail the information, resources and support to the families of mentally handicapped children to encourage the families do things for themselves and become competent and self-efficient.

4.4 STRUCTURAL DESCRIPTION OF THE MODEL FOR EMPOWERMENT OF FAMILIES WITH MENTALLY HANDICAPPED CHILDREN

The model is cyclical in nature, which indicates that empowerment is a process that consists of events that follow one another. First, people must realise their needs. Secondly, they must formulate a plan for the identified needs. Thirdly, resources must be mobilised (implemented) guided by the goals and objectives of the plan. What is implemented must be evaluated and monitored so that if competency and self-efficacy are not achieved, the process is reviewed and starts all over again with needs identification. The model reflects two different pathways.

The first pathway is for the mental health professionals and the second is for the family with mentally handicapped children, who are the mental health care users. The two parties participate actively in all the phases. The model reflects five phases in the process of empowering the families of mentally handicapped children. The arrows in the model indicate movement from both parties to each phase, proving that empowerment is a power-sharing relationship. The circular shape of the model indicates that the empowerment process is continuous and moves from one phase to the next. The families of mentally handicapped children and the mental health care professionals are situated around the phases of the model, proving the impact of the parties on the empowerment process. The family should internalise the skills and knowledge and be enabled to function autonomously in order to attain efficacy.

The model reflects five phases that follow one another consecutively. The phases are continuous and each one is based on the previous one, and move in a circular pattern. The model shows arrows connected from both families and the mental health professionals to all the phases, indicating that both participate in the empowerment process and this becomes a power-sharing relationship. The broken arrow indicates the feedback mechanism if competency and self-efficacy were not up to standard and that reassessment takes place again with the mental health care professionals assisting the families of mentally handicapped children. The process will start again and the mental health care professionals will support the families of mentally handicapped children to attain autonomy, which will lead to competency and self-efficacy.

4.4.1 Colours used in the model structure

The researcher selected of the colours of the National Council of African Women for the model. A woman named Mina Soga founded the Council in 1937. These colours were chosen because the organisation aimed at empowering families, especially in poor communities (Hlatswayo 2006:2). The colours used are green, purple and gold.

GREEN symbolises growth. Growth refers to the act or process of growing, improvement, extension or increasing in size and value. The green symbolises a growth in knowledge and skills on the part of families with mentally handicapped children. Autonomy and efficacy are achieved in the treatment, care and rehabilitation of mentally handicapped children.

PURPLE symbolises peace. Peace refers to contentment, calmness, stillness, tranquillity, and harmony. As soon as the families of mentally handicapped children acquire skills and knowledge to achieve self-efficacy in the treatment, care and rehabilitation of their mentally handicapped children they feel at peace with the world because they have attained self-fulfilment and self-confidence. There is harmony in the families as a result of attaining the physical, psychological and social needs.

GOLD symbolises prosperity. Prosperity refers to success, prosperousness, good life, good times and well-being. The power-sharing relationship between the empowerer (mental health professional) and the empowered (families of mentally handicapped children) in the empowerment process yields success because the objectives of family empowerment are achieved as the families gain autonomy and efficacy in the care, treatment and rehabilitation of their mentally handicapped children.

4.5 PROCESS OF THE MODEL

The process of the model is divided into five phases.

Phase 1: Creating awareness of needs

Gaines et al (2005:522) and Drisco (2003:31) maintain that empowerment should revolve around health promotion, which starts with identifying the health care needs. Methods of assessment include observation and practical interviews (Ekdawi & Conning 1994:39; Stanhope & Lancaster 2000:288). The empowerers (mental health professionals) assist the empowered (families of mentally handicapped children) to identify their health needs and the family start to be aware of their needs and spell them out. The families of mentally handicapped children start to assess their own capabilities and their expectations. The mental health care professionals embark on a search for the needs, by interacting with the families in order to develop data. The process is referred to as data generation and includes information about their knowledge and skills, beliefs, norms and values, family support groups and influential persons. The families also become involved from the phase when the needs are identified because they start to realise that they have crises or problems.

The families develop knowledge and insight into the nature of their problems as well as their needs. Both parties work together and form a partnership to embark on the identification of needs and the families start to gain confidence in the mental health care professionals. In this first phase, the mental health care professionals and the families collect the readily available data and generate a database to use to formulate the plan of action for empowerment. During this stage:

Available data gathered is combined with generated data to make it composite. Problems and capabilities of the families are identified from the composite database. Data is interpreted/analysed, synthesised and themes identified. The families should be highly involved during the interpretation stage.

Phase 2: Formulating a plan

Both the mental health care professionals and the families of mentally handicapped children start to look for their own possibilities of solving the problems and needs, and plan how, when and who should address the needs of the empowered that are identified (Ross & Deverell 2004:289). The empowerers (mental health care professionals) and the empowered (families of mentally handicapped children) start to plan ways in which to address the needs and create an enabling environment for empowerment to take place. Both parties formulate short- and long-term goals based on the needs identified and start with the prioritisation of needs. The problems identified are analysed in the planning phase together with prioritisation of needs. During analysis, the empowerer and the empowered together identify the origin and impact of the problems and the time the identified needs can be dealt with. Each problem identified should be analysed and if specific expertise or specialisation is required, then those specialists should be involved in the process (Stanhope & Lancaster 2000:318).

Phase 3: Mobilising resources

In this phase both the empowerers and the empowered become involved and participate actively in the empowerment process. A working and supportive relationship forms between the empowerers (mental health care professionals) and the empowered (families of mentally handicapped children) and a partnership is formed (Drisco 2003:30). They both create an enabling environment.

This is the implementation stage when mental health professionals motivate the families of mentally handicapped children to participate in problem solving and the plan of action is put into action (Ross & Deverell 2004:281). The mental health professionals enable the families of the mentally handicapped children to access the information, skills, resources and support. The mental health care professionals (empowerers) capacitate the families of mentally handicapped children (the empowered) with recent (up to date) information about the treatment, care and rehabilitation of mentally handicapped children and the families share this special professional training with their peers. During the involvement process the families develop decision-making, communication and self-help skills that enable them to take ownership, become innovative and become experts in the care and rehabilitation of their mentally handicapped children. Involvement from both directions facilitates development of growth and self-help skills and the families become independent. During the process of involvement the empowered internalise the norms and values of empowerment. The families of mentally handicapped children realise that they have to take charge of their needs and become responsible and accountable to attain autonomy and self-efficacy and become experts in the care and rehabilitation of their children. Families of mentally handicapped children should be supported, given information and resources to enable them to become competent, self-efficient and become experts or specialists in the care of their mentally handicapped children. During the intervention stage the families of mentally handicapped children (the empowered) gain knowledge and skills, reach better understanding, are able to define their roles, experience self-confidence and self-fulfilment, are able to act independently and can take ownership of the care and rehabilitation of their children competently (Stark 2002:29). The mental health care professionals should be committed to the empowerment process to enable the families to attain self-efficacy.

Phase 4: Monitoring and evaluation

Monitoring and evaluation should, in fact, start from the planning phase, whether goals go hand in hand with the problems identified, objectives are measurable during the implementation stage, and implementation takes place according to the set objectives throughout the process (Stanhope & Lancaster 2000:260). Evaluation is the appraisal of the effects of the activities implemented and is performed to determine the effectiveness, adequacy, appropriateness and efficiency of the implementation.

Evaluation is basically the process of assessing progress by comparing the goals and objectives of the plan with the results or outcome of empowerment. Evaluation determines whether the goals and objectives of the empowerment process have been attained or not. The failure of the empowerment process will warrant the review of the process and the empowerer and the empowered will review the process and start reassessing the needs of the families of mentally handicapped children.

Phase 5: Autonomy and self-efficacy

Autonomy means that individuals are reasonably independent and self-governing in decision-making and practice. Autonomy goes with accountability and responsibility. Autonomy and independence may be used interchangeably. Efficacy is synonymous with effectiveness, efficacious, perceived competence and control (Driscoll 2003:3). *Collins English Dictionary* (1995:225) and Longman (2000:57) define efficacy as “competence, capability, effectiveness and success”. People with high self-efficacy believe that they are capable of accomplishing or performing an activity and are willing to pursue the activity in spite of difficulties that they may encounter. Increment of self-efficacy refers to the development of a sense of personal power or mastery over events in one’s life (Ross & Deverell 2004:187). The families of mentally handicapped children will reach self-efficacy and be able to care for their children independently with the assistance of the mental health care professionals.

The empowerment process will be evaluated for success. The outcome of the process will determine whether review of the process should be done or not. If the outcome of the process is positive and autonomy and self-efficacy were achieved, review will not be performed but if the empowerment process was not achieved or if positive results were not attained, that is, if families of mentally handicapped children have not attained autonomy and efficacy in the care and rehabilitation of their mentally handicapped children, the process will be reviewed as shown in the model.

4.6 EVALUATION OF THE MODEL FOR EMPOWERMENT OF FAMILIES WITH MENTALLY HANDICAPPED CHILDREN

Three independent experts in model development and qualitative research evaluated the model. The model was evaluated using Chinn and Kramer's (1995:127) criteria, namely clarity, simplicity, generality, accessibility, and significance (importance).

4.6.1 Clarity

Clarity of the model pertains to how well the model can be understood and how the ideas in the model were conceptualised, whether consistency was maintained or not. A clear model becomes meaningful to all researchers, especially experts in model development. Concepts that were not clear were identified and reconceptualised within the model (Madelá-Mntla et al 1999:73).

4.6.2 Simplicity

Simplicity means that the theory is not complicated but easy to follow. In a simple theory the number of elements especially the concepts, and how they are related is easy to grasp (Madelá-Mntla et al 1999:73). In a simple model concepts can be combined without losing meaning.

4.6.3 Generality

Generality of the model refers to the size of the model, that is, the breadth and scope that the model covers, which depends on the scope of the concept of the model and the main purpose in the specific theory or model (Madelá-Mntla et al 1999:73).

4.6.4 Accessibility

Accessibility of the model refers to whether the concepts are broad or narrow, the specificity or generality of the definitions in the theory or model, whether the definitions given for the concepts in the theory are a true reflection of the concepts and whether the concepts are practical and reflect real nursing practice (Chinn & Kramer 1995:136).

4.6.5 Significance/importance

The significance or importance of the model refers to the extent to which it can be utilised to achieve the goals of the nursing profession theoretically and practically. It means that the model can be used to achieve goals in nursing education, administration and research.

4.7 CONCLUSION

This chapter described the structure and process of the model for empowerment of families with mentally handicapped children, including the symbolism of the colours used. The five phases, which are creation of awareness, formulation of plan, mobilisation of resources, monitoring and evaluation, and self-efficacy of the model and its application were discussed in detail. Definition of concepts of the model and relationship statements were described. Chapter 5 discusses guidelines for the operationalisation of the model.

CHAPTER 5

Guidelines for the operationalisation of the model for empowerment of families with mentally handicapped children

5.1 INTRODUCTION

Chapter 4 described the process and structure of the model, and its evaluation according to Chinn and Kramer's (1995:136) criteria. This chapter presents guidelines for the operationalisation of the model.

The model is intended to assist mental health care professionals, especially psychiatric nurses, to be more effective in empowering and supporting families with mentally handicapped children. The researcher developed the model and the guidelines for its implementation on the basis of the literature review and her experience. The researcher is of the opinion that these guidelines will assist families of mentally handicapped children in the care, treatment and rehabilitation of their children, since they will also take part in their empowerment process.

5.2 GUIDELINES FOR THE FACILITATION OF EMPOWERMENT OF FAMILIES WITH MENTALLY HANDICAPPED CHILDREN

In this study, the family members of mentally handicapped children included the family caregivers since they were always with the children. The guidelines include the creation of awareness of needs, formulation of a plan of action, mobilisation and gaining access to support, resources and information, monitoring, and evaluation.

5.2.1 Creation of awareness of needs

Creating an awareness of needs serves to identify the profile of what the families were unable to perform so that the families could be empowered to care for, treat and rehabilitate their mentally handicapped children (Ward 1992:46).

The main purpose of this stage or phase of the model is to identify the needs, problems, weaknesses and shortcomings in the family care, treatment and rehabilitation of their mentally handicapped children.

Creation of awareness of needs is established through the strategies of establishing relationships and assessing the family for creating awareness of needs.

5.2.1.1 Establishment of relationships

The objective of this strategy is to establish a relationship between the mental health care professionals and the families of mentally handicapped children in order to further establish rapport between the two parties.

Rapport needs to be established between the professionals and the families of mentally handicapped children because it is the cornerstone of obtaining cooperation from the families of mentally handicapped children. The best possible interpersonal relationship should be established in order to neutralise the initial distrust during the interaction (Mouton & Marais 1994:93).

The empowerer (mental health care professionals) and the empowered (the families of mentally handicapped children) should initiate, develop and sustain a mutually satisfying one-to-one relationship (Becker 2005:154). In order to facilitate the establishment of a therapeutic relationship, the mental health care professional should:

- Be approachable and create a relationship of trust, honesty, openness, mutual respect, sharing, genuineness, responsibility, accountability, understanding and open communication that will enable free sharing of information between the mental health care professional and the family.

- Accept the families of mentally handicapped children unconditionally. Dispel myths and fears about mental handicap and be non-critical in order to win the confidence of the family members.
- Encourage the families to participate actively and express themselves in discussing and identifying their needs (Madelá-Mntla et al 1999:73). Listen attentively and treat all the family members as equals. This approach encourages freedom of speech on the part of family members.
- Be non-judgmental and consistent in all interaction in order to win the trust of the family members (Taylor 1990:79).
- Develop a truly therapeutic situation/environment for the families by providing them with new positive experiences and understanding their behaviours. This should become a therapeutic experience (Taylor 1990:41).

The mental health professionals should:

- Create an environment that is enabling and therapeutic to offer freedom of speech from the family members of mentally handicapped children (Taylor 1990:82). This therapeutic environment would foster trust and the family members would feel safe and comfortable.
- Promote this type of environment by being empathetic and listening actively (Townsend 2003:171).
- Create an interactive environment to promote freedom in sharing of ideas with the family members (Taylor 1990:77).

5.2.1.2 Assessment of the family for creating awareness of needs

After establishing a relationship, it is essential to perform an assessment of the family. The objective of this strategy is to assess the needs of the families to establish how the families functioned in the past in order to assist them to be independent (Ward 1992:46).

Assessment is the measurement of the extent of individuals' ability to perform their expected responsibilities independently and sufficiently in order to achieve self-adequacy. Assessment should be a collaborative process between the mental health care professionals and the families of mentally handicapped children.

The mental health care professionals with their specialised psychiatric knowledge and skills should take the ultimate responsibility for the diagnosis, treatment, care and rehabilitation of their children (Nash 1994:224; Ward 1992:53). In this study the families of mentally handicapped children were assessed to find out if they could treat, care for and rehabilitate their children competently on their own. The families were expected to participate actively in the assessment process (Chinkanda 1988:48; Ward 1992:43).

The families of mentally handicapped children must always be approached with dignity and respect to make them feel free to spell out their health problems and feel valued (Drisco 2003:27; Ward 1992:16).

The mental health care professionals assist the families of mentally handicapped children to identify their health needs and become aware of their needs and spell them out. The families are involved from the first step of the empowerment process to recognise their determination and efforts. They also start assessing their own capabilities and gain access to their expectations (Gregory 2004:32).

All the family members are assessed to enable the mental health care professionals to prevent impediments during the mobilisation of resources, support and information. The family social support networks are identified in order for the mental health care professionals to form links and partnerships with them, with the aim of collaborating in the empowerment of the families with mentally handicapped children (Stuart & Sundeen 1995:838). Identify the roles and relationships of the family, decision-making behaviours, the leader and the more influential members of the families in order to use the leader as a point of entry into the family (Foxcroft & Roodt 2007:39; Spradley 1991:349) (see annexure E).

5.2.2 Formulation of a plan of action

After identifying the needs, the mental health professionals together with the families formulate a plan of action for both parties to treat, care for and rehabilitate their mentally handicapped children independently.

The objective of formulating a plan of action is to organise and outline how the mental health care professionals would assist the families during the empowerment process.

The plan includes the objectives of the empowerment process, the intervention strategies that the primary carers would empower the entire family unit with, methods of monitoring and evaluating the empowerment process, and methods of evaluating the entire empowerment process to assess the necessity of re-planning, should the process prove ineffective (Lofland & Lofland 1995:39).

The plan formulated for empowerment of the family of mentally handicapped children is based on the identified needs of the family members including those of the mentally handicapped children. The plan has to be flexible, depending on the status quo of the problems that the families experience with their mentally handicapped children. The mental health care professionals serve as a liaison between the families and the available health services.

The mental health care professionals sit down with all the members of the families and draw up a list of identified needs of the family and of their mentally handicapped children. The plan is also based on the physical, social, cultural, religious, academic and psychological needs of the mentally handicapped children.

Planning for empowerment of families with mentally handicapped children entails preparing why, how, who, when, to whom, and where the empowerment process should take place.

Planning refers to the programme of actions to be formulated and followed in order to achieve the required outcomes. Goals and expected outcomes should be drawn up, indicating whether they are long- or short-term. These expected outcomes should be a collaborative effort between the mental health care professionals and the families of mentally handicapped children. In this study, the families of mentally handicapped children became aware of the need to change and desire to participate and support the change after being involved in the assessment of their needs, skills and aspirations (Haverman & Buntix 2002:20).

The mental health care professionals should find it easy to involve the families of mentally handicapped children in the formulation of outcomes. The outcomes should be written down, time frames set and priorities written down.

The data collected should be analysed and prioritised to facilitate a relevant plan of action, then the two parties develop a plan of action together. Strategies to enhance learning include printed materials, audiovisual, computer-assisted learning, demonstration, guest speakers, field trip, peer presentations and peer counselling.

5.2.3 Mobilisation and gaining access to support, resources and information

Families of mentally handicapped children should gain access to support, resources and information during the empowerment process.

The purpose of mobilisation and gaining access to support, resources and information is to enable the families of mentally handicapped children to gain access to the relevant knowledge and skills and be referred to the psychological, physical, social, religious and cultural resources to enable them to be independent and gain self-reliance in the care, treatment and rehabilitation of their children (Halliday 1994:4; James 2006:79).

According to Neuman's systems theory, the totality of the interrelationship between the physiological, psychological, spiritual, developmental and socio-cultural variables should be considered when enabling families of mentally handicapped children to gain access to information, support and resources (George 2002:54).

During the process of mobilisation of resources for the empowerment of families with mentally handicapped children, the mental health care professionals should also take into consideration promotion of the basic human needs of the mentally handicapped children and the physiological/physical, social, psychological, religious, cultural and developmental aspects of the entire family. The families have to be empowered to be responsible and promote the basic needs of their mentally handicapped children (Potter & Perry 2007:129).

5.2.3.1 Support

Support can be utilised in three ways, namely as an attitude, a specific intervention, and a role of the carer.

The main objective of support is to provide the families with a free environment that is non-threatening and non-judgmental to enable the families to develop knowledge and skills for the care, treatment and rehabilitation of their mentally handicapped children (Kane 2000:30).

5.2.3.1.1 Strategies for support of families with mentally handicapped children

Strategies for support of families with mentally handicapped children involve creating an enabling environment that will facilitate the empowerment process to lead to competency, autonomy and self-reliance.

Activities for support include the following actions of the mental health care professionals:

Create an attitude and atmosphere of sharing, being heard, accepted and understood. Support is valuing respect for the inherent worth of others. Hawks (1992:616) points out that support can be emotional, physical, occupational, economic, religious and psychological in nature.

Provide comfort, which has both an interpersonal and physical care dimension. It includes decreasing anxiety, enhancing self-esteem, reassurance, nurturing, boosting morale, educating, training and advocacy (Byrne & Sebastian 1994:4).

Training in self-help skills. The families of mentally handicapped children should be taught to teach their children how to use the toilet, wash and groom themselves, dress and undress, feed themselves and care for their immediate environment (Okun 1991:50).

Academic support. Involve the families in academic support like taking their mildly mentally handicapped children to special schools and literacy schools.

Social support. The families should support their children socially, including recreation, and teaching the children ordinary good manners and interpersonal skills. They should also approach social workers to arrange for social support in the form of financial security (Knox & Parmenter 1994:7; Uys & Middleton 2002:503).

5.2.3.2 Information

Mobilisation and provision of information to the families of mentally handicapped children is part of the purpose of the empowerment model (Hawks 1992:616). The objective of mobilisation of information is to capacitate the families of mentally handicapped children with the knowledge and skills to gain independence and self-care with the ultimate aim of attaining competency and self-efficacy.

The following strategies are utilised for providing information:

- Mental health care professionals give health education to the families on mental handicap, causes, manifestations, care, treatment and rehabilitation of mentally handicapped children.
- Teach the families leadership, decision-making, communication, problem-solving and assertive skills so that they can advocate for their mentally handicapped children boldly without failure (Drisco 2003:28). Learning leadership skills assists the families to become self-directed, self-motivated and self-efficient (Jooste 2003:28).
- Present lessons to the families and their significant others through printed materials, such as posters, pamphlets and leaflets; audio visually through television, radio, newspapers and films; as well as through peer group teaching and counselling by other families who have mentally handicapped children (Stanhope & Lancaster 2000:263).
- *Hold workshops and seminars* for families with mentally handicapped children, relatives, neighbours, friends and interested people who wish to offer support.
- *Arrange awareness campaigns* and youth development programmes.

The families should teach the mentally handicapped children activities of daily living such as washing clothes, fetching firewood and other activities, depending on their capabilities, interests and level of functioning and retardation (Wolf-Vereecken 1996:172).

5.2.3.3 Resources

Resources include different referral systems for referring mentally handicapped children for further treatment. The purpose of knowing resources is to be able to refer the family to the most appropriate service, so that they can acquire knowledge and skills.

Neuman's theory emphasises the totality of the interrelationship between individuals' physiological, psychological, spiritual, developmental and socio-cultural variables therefore individuals should be assisted in totality. Based on the above theoretical perspective the researcher based the empowerment of the family members with regard to mobilisation of resources, on physiological, socio-cultural, developmental, psychological and spiritual resources. Mental health professionals serve as liaison between the families of mentally handicapped children and available resources and services (George 2002:240).

- **Socio-cultural resources**

The families should encourage their mentally handicapped children to take part in social and recreational activities, such as picnics, games/sports, reading, music and dancing, depending on their interest, ability, religious denomination, and cultural values and beliefs.

- **Basic family training resources**

The families should be referred to the training resources, which are non-governmental organisations that are concerned with fundraising for the support of families with mentally handicapped children. Mental health care professionals, such as psychiatric nurses, social workers, occupational therapists, psychologists, education specialists, and psychiatrists, work as a team to raise money to care for, treat and rehabilitate mentally handicapped children (Bagnol 2002:1; Sadler 1995:1).

- **Ombudsman programme**

The families of mentally handicapped children should be referred to ombudsman programmes, which consist of individuals who act as volunteers in advocating for the

children and speak for the children's needs. Ombudsman programmes are mostly sponsored and coordinated by the Department of Health and Social Development with the help of community volunteers and mental health professionals. In the families where problems are encountered in the care, treatment and rehabilitation of mentally handicapped children, psychiatrists refer the children to group homes for living. The ombudsman is responsible for all developmentally disabled children who stay in the community-based intermediate care facilities and the community is encouraged to take part in caring for these children (Sandler, Warren & Raver 1995:2).

- **Family therapy**

Families who have family problems should be referred for family therapy. Family therapy is used to resolve conflicts and anxieties in the family due to the presence of a mentally handicapped child. The families are assisted to care for, treat and rehabilitate their mentally handicapped children (Fawcett 1991:381; Shives 2000:37).

- **Physiological/physical resources**

Families should be educated on the physical, social, psychological, cultural and religious resources available for them to develop knowledge and skills to care for, treat and rehabilitate their mentally handicapped children. The mental health care professionals enable the families of mentally handicapped children to gain access to material and non-material resources (Wieseler & Colond 1995:10).

- **Human rights programmes**

Mentally handicapped children whose rights are not respected are sent to the Human rights programmes. The Human Rights Commission of each province educate the communities about human rights through different programmes, be it Human rights programme, Childrens' rights programme and programme of the rights of other categories of human beings in the community.

Moletši district, being part of Limpopo province, gets exposed to these programmes. Bagnol (2002:1) points out that human rights programmes are committed to

empowerment of families of children with conditions associated with mental handicap, such as autism, cerebral palsy and other multiple disabilities.

- **Parent groups**

The mental health care professionals encourage families of mentally handicapped children to initiate support in the form of parent groups. These groups consist of families of mentally handicapped children from different villages who form a group because they have the same problems, namely mentally handicapped children. These groups arrange and hold regular meetings, share their problems and come up with solutions with regard to the care, treatment and rehabilitation of their mentally handicapped children. These parent groups initiate mutual support systems, families share ideas, help to relieve loneliness and isolation, solve problems and remove the stigma of mental handicap (Brodin & Molosiwa 2000:165; Spradley 1990:43)). The families start to realise that they are not the only families with mentally handicapped children and the necessity of family partnership formation.

5.2.3.4 Monitoring and evaluation

The purpose of monitoring and evaluating the empowerment of families with mentally handicapped children was to establish whether the objectives formulated had been achieved or not.

The mental health care professionals and the families of mentally handicapped children should monitor and evaluate whether both achieved the planned care, treatment and rehabilitation of their mentally handicapped children. Other aspects to be evaluated and monitored include the effectiveness of the process of family empowerment and the product or outcome of empowerment, whether self-efficacy is reached or not (Stanhope & Lancaster 2000:261).

- **The mental health care professionals and the families of mentally handicapped children**
 - Examine the families' and children's identified needs, and the plan of action to determine whether they were achieved or not.

- Check whether implementation or mobilisation of resources was done as planned and all the objectives were met; whether the implementation was followed as planned or whether there were gaps in the empowerment process.
- Identify the hidden challenges.
- Make recommendations for future care, treatment and rehabilitation of the mentally handicapped children, including referrals.
- Monitoring and evaluation of empowerment of families with mentally handicapped children should be done by means of interviews, participant observation, home visits, meetings and written reports.

- **Interviews**

The families should be interviewed to determine the effectiveness of the model. The families should explain the positive aspects and problems that they encountered during the application of the model and make suggestions for implementation of the model.

- **Participant observation**

The mental health care professionals should observe whether the families were able to provide the basic needs of the mentally handicapped children.

- **Home visits**

The mental health care professionals should visit the families regularly to observe, monitor and evaluate whether the families are improving or deteriorating.

- **Meetings**

The mental health care professionals should arrange regular meetings with the families of mentally handicapped children to sort out any problems the families might have in the implementation of the model.

- **Written reports**

The families should write reports and express their feelings with regard to the model and whether empowerment has been successful or not (Hawks 1992:611).

5.2.3.5 *Autonomy and efficacy*

The purpose of taking families with mentally handicapped children through this phase is to further evaluate and monitor the empowerment process to determine whether families actually become independent after the empowerment process. The mental health care professionals and the families both evaluate whether the families possess the skills and knowledge that prove the consequences of the empowerment process. In this phase the mental health care professionals should observe the way in which the families care for, treat and rehabilitate their mentally handicapped children. Empowered families should

- know the rights of their mentally handicapped children
- have knowledge of community facilities or resources for their children
- be able to explain how the community facilities are utilised
- differentiate between the right support or help and the wrong support or assistance
- be able to support other families who have the mentally handicapped children as they share the same problems
- understand that mentally handicapped children deserve the same dignity as all other children

The mental health care professionals should participate actively and be committed to the empowerment process to enable the families to attain independence, competency and self-efficacy in the care, treatment and rehabilitation of their mentally handicapped children.

5.3 CONCLUSION

Chapter 5 discussed the guidelines for the operationalisation of the model. The guidelines should include the information to be given to family members, resources to

be refer the family members and their mentally handicapped children and ways of supporting families with mentally handicapped children. Ways of monitoring the care, treatment and rehabilitation offered include meeting, interviews, home visits, participant observation and written reports. Chapter 6 discusses the findings of the research study and evaluation of the implementation of the model for empowerment of families with mentally handicapped children.

CHAPTER 6

Evaluation of the implementation of the model for empowerment of families with mentally handicapped children

6.1 INTRODUCTION

Chapter 5 developed and described the guidelines for the operationalisation/ implementation of the model of empowerment of families with mentally handicapped children. The application of the model revealed positive achievement of aims and objectives after mobilisation of resources. This chapter discusses the evaluation of implementation of the model of empowerment of families with mentally handicapped children, that is, guidelines in the practice of psychiatric nurses. The researcher adopted a case study approach using semi-structured interviews and assessment guides in the application of the model to evaluate its effectiveness in practice (Hansen 2006:95). Names used in the three case studies are fictitious for confidentiality and anonymity of families. The researcher analysed and synthesised the data from the semi-structured interviews and assessment guides. The findings are discussed according to the categories of the model, namely creation of awareness of needs; formulation of plan; mobilisation of resources; monitoring and evaluation, and self-efficacy.

6.2 FIELDWORK

The researcher made appointments with the participants to conduct the interviews with them at the clinic. In some cases, it took two appointments before the participants arrived. This necessitated a lot of travelling although the psychiatric nurse from the clinic assisted the researcher. The case studies were implemented using semi-structured interviews, lasting between 45 and 60 minutes, and assessment guides. The data was collected on alternate Fridays over a period of three months. The researcher found it challenging and enlightening to listen to the participants' experiences in caring for, treating and rehabilitating their mentally handicapped children.

The implementation and evaluation of the model convinced the researcher that the empowerment process should be utilised in the first and the final year of clinical training to determine whether the objectives had been achieved, and nurses achieved self-efficacy and could work independently in the clinics or hospitals. This would empower professional nurses who would ultimately become efficient and able to assess the needs of patients, plan for the care to be rendered, implement the care by mobilising resources, information and support, and monitor and evaluate the care rendered. The final outcome would be self-efficacy in the care, treatment and rehabilitation of mentally handicapped children.

The empowerment model could be used among the families at the voluntary centre that was established to empower families of mentally handicapped children to care for, treat and rehabilitate their children to facilitate independence and self-efficacy.

6.3 PREPARATION AND TRAINING FOR THE CASE STUDIES

In order to establish whether the empowerment model was effective, the researcher needed to know the pre-morbid functioning and quality of the empowerment of families with mentally handicapped children provided before the theory (model) was used; that is, how the nurses assisted and treated the families and the children (Chinn & Kramer 1995:21). Yin (2003:57) emphasises that good preparation of case studies should start with good listening, adaptability and flexibility, a grasp of the issues being studied, and lack of bias. Accordingly, the researcher established rapport with the parents and the nurses at the clinic in order to explain the nature, purpose and effects of the model on the care, treatment and rehabilitation of mentally handicapped children.

6.3.1 Preparation of nurses at the clinic

The researcher made an appointment to see the professional nurses at Moletši Clinic in order to arrange dates and times for the orientation and training in applying the model of empowerment. The researcher agreed to meet with the nurses at the clinic on Friday afternoons, when the clinic was not busy

The letters of permission from the Department of Health and Social Development and the University of South Africa, Health Studies Research Ethics Committee (HSREC)

(see Annexure A) were shown to prove that the researcher had permission to conduct research (Mouton & Marais 1994:98).

The researcher gave the psychiatric nurse from Moletši the clinic a letter requesting her assistance in the awareness of the needs, formulation of the plan, mobilisation of resources, and monitoring and evaluation to establish whether the model was effective and yielded independence and self-efficacy.

The researcher used an enlarged copy of the model that was clear and coloured to make it easy to understand. The researcher explained the purpose, context, phases and structure of the model, and that it would be applied to the families of mentally handicapped children to determine its effectiveness in producing independence and self-efficacy to the families of mentally handicapped children. The psychiatric nurse and the professional nurses at the clinic were allowed to make additions and suggestions for the model. The researcher gave them a one-day seminar on the care, treatment and rehabilitation of mentally handicapped children and support of their families.

6.3.2 Pre-morbid functioning of the clinic on empowerment

When asked how they empowered the families with mentally handicapped children, the nurses said they were short-staffed, catered for over eighteen villages, and did not have transport to do follow-ups of their families. Moreover, the families did not bring their children monthly as expected, but only for minor ailments. They had no opportunity outside of those times to educate the families about their mentally handicapped children and refer children with problems to the psychiatrist in hospital, especially children suffering from epilepsy.

The families were asked about the ways they cared for, treated and rehabilitated their mentally handicapped children at home so that at the end of application of the model the care, treatment and rehabilitation before empowerment and after empowerment could be compared (Chinn & Kramer 1995:21).

The purpose of the case study was to establish or identify the needs, problems, weaknesses and shortcomings in the families. The nurses together with the families

could then plan to meet the needs identified, mobilise resources together, and put the plan into action together.

The researcher, the nurses and the families of mentally handicapped children did combined evaluation to determine whether the needs were met and the families were able to care for, treat and rehabilitate their mentally handicapped children. This would indicate that they had become independent and achieved self-efficacy (Chinn & Kramer 1995:102).

6.3.3 Specific outcomes/objectives of case studies

The outcomes of the case studies were to

- identify the needs, problems, weaknesses and shortcomings
- formulate a plan of action to meet the needs
- mobilise and gain access to resources, support and information to meet the needs
- evaluate and monitor the effectiveness of the plan and whether the needs were met
- determine whether the model was effective and self-efficacy was met

If the process was not effective, the researcher and the clinic nurses should restart the process again (Miles & Huberman 1994:5).

6.3.4 Establishing a relationship

The researcher established rapport and built a relationship with the families through primary (parents, friends and siblings) and secondary (colleagues, friends, and relations) members and the nurses (Becker 2005:6). The researcher used simple Northern Sotho, the language preferred and understood by members of the families, and respected the families by using their real names. The researcher was open, established a sharing relationship, and allowed the families to identify and express their needs with regard to their mentally handicapped children. The model promotes a power-sharing relationship, so the researcher and the clinic nurses displayed a relationship of

mutual sharing and respected the families of mentally handicapped children (Baumann 1998:54; Kaplan & Sadock 1998:27).

The researcher explained that the purpose was to help them to identify their needs. The researcher accepted the families and encouraged them to express their needs since they were the ones who needed assistance. Accordingly, the researcher created an enabling environment by listening carefully, showing empathy, and communicating with the families of the mentally handicapped children (Baumann 2007:589; Margo 1994:15; Poggenpoel 1997:20). The families were encouraged to freely express and identify problems.

6.3.5 Preparation and training of the family

The researcher and the clinic nurse established good interpersonal relationships with the family members in order to eliminate mistrust. The researcher introduced herself to the participants, explained the nature, purpose and significance of the study, and informed them that participation was voluntary. The researcher assured the participants that all information (data) would remain confidential and anonymous, they would not be subject to harassment, and they were free to ask any questions or to decline to participate. The participants were also informed that a small portion of the population was needed for the study, and that the researcher wished to apply the model to determine its effectiveness in empowering parents to care for, treat and rehabilitate their mentally handicapped children. Their permission was sought to use a tape recorder in the interviews to ensure that the data was accurately reflected. The family members were put at ease to enable them to express their anxieties openly (Mouton & Marais 1994:93). The family members then read and signed informed consent to take part in the study (see annexure B).

Appointments were scheduled for the process to start and subsequent appointments to go through the process of the model. The families were given incentives in the form of food packages as tokens of appreciation.

6.4 SAMPLE

The sample of this research study was drawn from the families with mentally handicapped children who attended and collected their monthly medication at Moletši Clinic in Polokwane municipality.

The researcher used purposive sampling to deliberately identify and include families with mentally handicapped children for participation (Babbie 2001:67) (see chapter 2 for inclusion criteria). These families were believed to have first-hand information on the problems encountered in raising a mentally handicapped child.

The sample consisted of three families, who cared for, treated and rehabilitated their mentally handicapped children. With the exception of case study 1, where one member was married, all the family members lived in the same household. The families were at child-bearing and child-rearing stage. Case study 1 was a single-parent family, and case studies 2 and 3 were nuclear families.

One of the families spoke English as their first choice while the other two families only spoke Northern Sotho, which is an indigenous language spoken by local people in the study area, and hardly understood English.

The first family was a single family with five members, and the children were 34, 14, 8 and 4 years old. The second family was a nuclear family with five members, with children aged 14, 8 and 7. The third family was also a nuclear family with seven members, with children aged 33, 30, 27, 22, and 16. All the families had one mentally handicapped child living at home and were caring for, treating, supporting and rehabilitating the mentally handicapped ones.

After they had been informed of the objectives of the study, the families agreed to take part in in-depth semi-structured interviews and assessment guides, which were developed to conduct assessment of families with mentally handicapped children (see table 6.1).

Table 6.1 Participants' families

	Case study 1	Case study 2	Case study 3
Type, stage and composition of family	Single parent, mother unmarried, child bearing and rearing, a 34 year old girl, 3 boys aged 14, 8 and 4 years	Nuclear family, mother and father, child rearing, two boys and one girl, aged 14, 12 and 7 years of age	Nuclear family, mother, father, child rearing, four boys aged 33, 27, 22 and 16, and one girl aged 30
Religion	International Pentecostal Church	Zion Christian Church	Uniting Reformed Church in Southern Africa (URCSA)
Cultural beliefs	Traditional beliefs and treatment	Traditional and use traditional medicine	Religious beliefs and believe in prayer
Educational level	Nobody in the family passed Grade 1 14 year-old mentally handicapped boy draws a line instead of writing his name	Mother - Grade 8 Father – Grade 12 14 year-old boy – Grade 1 - mentally handicapped; 12 year-old boy - Grade 6 7 year-old girl - Grade 1	Mother - Primary school teacher Father - Grade 12 33 year-old boy - Grade 12 30 year-old girl - Grade 12 27 year-old boy - Grade 12 22 year-old boy – Grade 12 16 year-old boy - Grade 1 - mentally handicapped

6.5 CREATING AWARENESS OF NEEDS

The model of empowerment of families with mentally handicapped children is a two-way, sharing process, in which the mental health professionals work together with the families to identify the family's basic health needs (Gaines, Jenkins & Ashe 2005:522). Methods of assessment included case studies, family interviews, family and child assessment (Ekdawi & Conning 1994:39). The families provided information about their knowledge and skills, beliefs, norms, values, family support groups, and influential persons. The families started realising that they had a crisis and needed help. Available and generated data was gathered, including problems and capabilities encompassing physical, social, psychological and cultural dimensions of Neuman's systems model (George 2002:340).

6.5.1 Case study 1

The Ngoasheng family is a single-parent family staying in Mabokelele-Moletši. The mother is unmarried and is at a child-bearing and child-rearing age. There are four children: a 34-year-old girl, who is married, and three boys aged 14 (mentally handicapped), 8 and 4. The family appears to be communicating openly and to be very close to one another. The mother makes decisions in the family. The family has access to health as they stay 1 kilometre from Moletši Clinic and 30 kilometres from hospital.

- **Religious, educational and cultural status**

The family belongs to the International Pentecostal Church, a very active church that supports children, especially families with mentally handicapped children. No one in the family had passed Grade 1.

The 14-year-old mentally handicapped boy draws a line instead of writing his name. The family is a traditional family and believes in traditional medicine and practices.

- **Social status**

The family is poor, and lives in a three-roomed, unhygienic, substandard house made of mud bricks, which is dimly lit and has small windows. The furnishings are poor, the house is poorly ventilated, and there are no heating, toilet or laundry facilities. In addition, there is poor sewerage and refuse disposal. The family has no proper food, no money to transport the mentally handicapped child to activities, and none of the family is actively employed. The *induna* supports them emotionally through home visits.

- **Social support**

The family receives support from the International Pentecostal Church and from Moletši Inter-denominational Women's League in the form of prayers, food and educational excursions. The mentally handicapped boy, Solomon, receives financial support from the government in the form of a small monthly disability grant. Some neighbours, community-based organisations and Moletši Centre for Mentally Handicapped Children offer support in the form of clothing.

- **Neighbourhood**

The family lives next to noisy neighbours. Two houses in the street sell liquor (a *shebeen*) and groceries (a *spaza* shop). The two places are always noisy as people are constantly coming and going at all hours and over weekends. The children on the street tease and hurt Solomon. The parents in the neighbourhood accept the family and support them emotionally, spiritually and physically. The neighbours' houses are standard and comfortable.

- **Challenges to the family**

The family did not know the definition of mental handicap and had no knowledge of the services available, the rights of mentally handicapped children, the preparation, cooking and serving of meals, and the care, treatment and rehabilitation of a mentally handicapped child. The family had poor housing, poor toilet facilities and inadequate financial support

- **The mentally handicapped child**

Solomon was born normally at Polokwane Hospital and weighed 3 kilograms. However, he achieved the usual milestones slowly. For example, he used chairs and tables to stand, and only walked at two and a half years old. He could not feed himself like other children of his age.

- **Schooling**

Solomon showed poor academic development and performance at school, starting from Grade 1. His teachers classified him as a slow learner and he could not write his name and surname but only draw a line. He used to play while the other children were writing. He had problems adjusting at school and was fond of destroying school property. He was referred to Grace and Hope School for the Mentally Handicapped, but there was no vacancy. He was eventually referred to Moletši Centre for the Mentally Handicapped, which is a voluntary centre.

- **Recreation and church**

The boy's only recreation is at church. In the International Pentecostal Church the children sing and dance in choirs with other children from other churches in the neighbourhood.

- **Speech problems**

From infancy Solomon had difficulty with speech and could not formulate a sentence. He still does not talk clearly.

- **Poor muscle tone**

Due to poor muscle tone in his back Solomon cannot stand for a long time when playing. He usually sits down to rest.

- **Challenges to the mentally handicapped child**

Solomon suffers from Down Syndrome and has poor muscle tone, concentration span, academic development and performance, self-help skills in feeding, and speech development. He also has adjustment problems like temper tantrums and destructiveness; lacks proper clothing and toilet training, and has suffered abuse from other children.

6.5.2 Case study 2

The Sebatjane family is a nuclear family residing in Mankatedi section in central Moletši, in the area where the chief of Moletsi has built his house. The village is in the area of the chief's kraal and next to the traditional offices. The parents are in their child-rearing stage and have two boys and one girl, aged 14, 12 and 7. The family stays 6 kilometres from the clinic and 30 kilometres from the hospital.

- **Religious, educational and cultural status**

The family belongs to the Zion Christian Church. The father passed Grade 12 and the mother passed Grade 8. The family has three children: a 14-year-old boy, who is mentally handicapped, and attended school in Grade 1, a 12-year-old boy in Grade 6, and a 7-year-old girl in Grade 1. The family belongs to the traditional group and resort to traditional medicine.

- **Social status**

The Sebatjane family lead an average life as they have a nine-roomed house and can afford basic needs for the family. Both parents are employed and have bought a Toyota Hilux van and a Volkswagen sedan.

- **Social support network**

The family receives social support from Moletši and Semenya Clinics as well as from WF Knobel Hospital.

The family's strongest support comes from the Zionist Christian Church as the church is a source of entertainment through songs and dances of "*mokhukhu*" (traditional and national song in the Zion Christian Church, sung and danced by male members only) and visit and support the family socially in times of sorrow, such as illness and death.

- **Neighbourhood**

The family neighbourhood is very stressful, consisting of families who are not gainfully employed and have low educational standards. The families are religious and supportive in caring for the mentally handicapped child against home accidents. The family's immediate neighbour is an International Assemblies Church priest and gives the family religious support from immediate neighbours.

- **Challenges to the family**

The family had no knowledge of the definition of mental handicap, the causes and manifestations, the services available, the rights of mentally handicapped children, or the care, treatment and rehabilitation of mentally handicapped children. Although both parents are employed, the family also has financial problems and need financial support. The family does not have a well built toilet.

- **The mentally handicapped child**

The mentally handicapped boy was born by vertex delivery at Polokwane Hospital with the umbilical cord around the neck. During his childhood he had delayed milestones. He learned to sit at six months, crawled at eighteen months, walked sluggishly at two years, and only walked without support at 3. He could not achieve self-management skills, like toilet training, and could not feed himself.

- **Schooling**

The parents took him to the normal government school where he started Grade 1. He made very little progress at school, and could not grasp what the teacher tried to teach him.

The principal informed the parents that the child was unable to cope with the schoolwork and advised them to take him to the Grace and Hope School for Mentally Handicapped Children in Seshego township.

- **Recreation and use of leisure time**

The child was talkative and used his leisure time to listen to music and the radio at home. He also watched television. On Sunday afternoons he went to the Zionist Christian Church, where he danced “*mokhukhu*”, a dance practised with older boys, which he seemed to enjoy.

- **Challenges to the mentally handicapped child**

The child was diagnosed with Hydrocephalus and Epilepsy and was not effectively treated, had poor academic performance and poor self-help skills.

6.5.3 Case study 3

The Mohafe family is a nuclear family living in Mabokelele in Kentucky section. The father works in Johannesburg and comes home every month-end. The family has five children, four boys and one girl. The boys are 33, 27, 22 and 16 years old and the girl is 30. The family lives seven kilometres from the clinic and 30 kilometres from the hospital

- **Religious, educational and cultural status**

The Mohafe family is affiliated to the Uniting Reformed Church of Southern Africa (URCSA) and the mother and father are members of the church council. The family members follow religious beliefs and believe in prayer. They used religious beliefs and prayers for treating their mentally handicapped child. The father passed Grade 12, studied Mechanical Engineering and now works in Johannesburg. The mother passed

Grade 12, took a Diploma in Education and now works as a teacher at the nearby primary school.

The 33-year-old boy passed Grade 12 and is employed as an electrician; the 30-year-old girl passed Grade 12 and works at a restaurant; the 27-year-old boy passed Grade 12 and is a teacher; the 22-year-old boy is attending the University of Technology, and the 16-year-old mentally handicapped boy attends the Grace and Hope School for Mentally Handicapped Children at Seshego.

- **Social status**

The family belongs to the middle class in the community of Kentucky section and has a nine-roomed house. The father works in Johannesburg as an artisan (mechanic). The family can afford to pay for basic needs like food, clothes and transportation to take their child to health care services.

- **Social support network**

The family receives support from their relatives, especially the grandmother. The grandmother assists in taking the mentally handicapped boy to school. Two neighbours are good supporters of the family. The Apostolic Church, which is next to their house, supports the family with prayer.

- **Neighbourhood**

The family stays in a noisy neighbourhood, where several people talk negatively about and have a negative attitude towards the family. The neighbours cannot understand the Mofate child's behaviour and think that the family is bewitched.

- **Challenges to the family**

The family does not know the definition of mental handicap; the rights of the mentally handicapped; services available; care of, treatment and rehabilitation of mentally handicapped children, and preparing, cooking and serving balanced meals. Their toilet was built outside the house and was not clean.

- **The mentally handicapped child**

The Mohafe child was born at Moletši Clinic. The delivery was normal vertex delivery. The nurse at the clinic examined the baby after washing, and came back to the mother and told her that she had given birth to a mongol. A mongol is an old term that was used instead of trisomy 21 or Down Syndrome. Mrs Mohafe was shocked at the news as she thought a mongol was an animal. The mother searched for the cause but was faced with disappointment (see annexure E). The child had slow milestones as he was slow in sitting down, crawling and walked without support at three and half years. His speech was delayed and presently his speech is not clear but has improved. He can wash himself, feed himself and use the toilet effectively.

- **Schooling**

The Mohafe child started school in the normal school. He made slow progress until the class teacher called the mother to explain that he could not write and could not formulate words well. The teacher advised Mrs Mohafe to take the child to the school for the mentally handicapped.

- **Recreation and use of leisure time**

The mother agreed with the father to take the child to the Apostolic Church as the church had strong prayers and entertainment in the form of songs and dances by adults. Singing and dancing were the only sources of entertainment.

- **Challenges of the mentally handicapped child**

The child was diagnosed with Down Syndrome, was abused and ridiculed by the neighbours, and his academic performance was poor.

Table 6.2 summarises the three case studies.

Table 6.2 Participants' case studies

Demographical data	Case study 1	Case study 2	Case study 3
Where residing	Moletši - Old Mabokelele	Moletši - Moshate-ga Selepe	Moletši - Mabokelele Kentucky section
Type, stage and composition of family	Single parent, mother unmarried, child bearing and rearing; one 34 year-old girl, 3 boys aged 14, 8 and 4	Nuclear family, mother and father alive, child rearing, two boys and one girl, aged 14, 12 and 7	Nuclear family, mother, father, child rearing, four boys aged 33, 27, 22 and 16 years of age and one girl aged 30 years of age
Religion	International Pentecostal Church	Zion Christian Church	Uniting Reformed Church in Southern Africa
Social status	Poor, poor housing, no food, no money, no transport and unemployed	Middle class, good housing, can afford basic needs, both parents working	Middle class, good housing, can afford basic needs and both parents working
Cultural beliefs	Traditional beliefs and treatment	Traditional and use traditional medicine	Religious beliefs and belief in prayer
Access to health care	1 kilometre from clinic and 30 kilometres from hospital	6 kilometres from clinic and 30 kilometres from hospital	6 kilometres from clinic and 30 kilometres from hospital
Level of education	No one in the family passed Grade 1	Mother - Grade 8 Father --Grade 12 14 year-old boy - Grade 1 - mentally handicapped 12 year-old boy - Grade 6 7 year-old girl - Grade 1	Mother - Grade 12 and Diploma - primary school teacher Father - Grade 12 -Mechanic 33 year-old boy - Grade 12 30 year-old girl - Grade 12 27 year-old boy - Grade 12 22 year-old boy - Grade 12 16 year-old boy - Grade 1 - mentally handicapped
Social support network	International Pentecostal church; Moletši Inter-denominational Church; some neighbours; community-based workers, and Moletši Centre	Zion Christian Church; aunt, and Moletši Clinic nurses	Apostolic Church; relatives; some neighbours; social workers, and community-based workers
Neighbourhood	Noisy people; children tease and taunt the mentally handicapped child; parents supportive	Unemployment rate high; educated; supportive, religious people, including a priest living opposite family	Noisy people; traditional people, and not supportive

Table 6.3 summarises the information about the mentally handicapped children.

Table 6.3 Participants' mentally handicapped children

Children	Case study 1	Case study 2	Case study 3
Place and type of delivery	Polokwane Hospital; normal vertex delivery	Polokwane Hospital; born with cord around the neck	Moletši Clinic; normal vertex delivery
Milestones	Slow milestones, used chairs and tables to stand, and walked at 3 years	Delayed milestones, sat at 6 months, crawled at 18 months, walked sluggishly at 2 years, and walked well at 3 years	Slow in sitting, crawling and walked at 3½ years; speech delayed
Schooling	Slow learner, cannot write name but draws a line	Slow, advised to go to school for mentally handicapped	Slow progress at school and advised to go to school for mentally handicapped
Recreation and leisure time	Gets recreation from church; listens to music; dances and sings with other children	Listens to music and radio; watches television during leisure time. Sings and dances 'mokhukhu' in Zion Christian Church	Sings with the Apostolic Church children
Self-management skills	Cannot feed himself	Cannot use the toilet and feed himself	Can wash and feed himself, and use the toilet

6.5.4 Themes and categories identified during assessment of family needs

The following themes emerged from the data analysis: lack of knowledge and information on mental handicap; failure to protect the child physically, from human abuse and from infection; lack of emotional, academic, and financial support, poor self-management skills, rejection by health professionals and neighbours, and lack of socialisation skills. Lack of knowledge had five categories, namely, lack of knowledge of the concept "mental handicap"; medications, storage and follow-up; conditions associated with mental handicap; existing health services, and ignorance about the rights of the mentally handicapped (see table 6.4).

Table 6.4 Themes and categories in creation of awareness of needs

Themes	Categories
1 Lack of knowledge and information on mental handicap by families	<ul style="list-style-type: none"> • Definition of concept of “mental handicap” • Medications, storage and follow-up after discharge • Conditions associated with mental handicap, and existing health services • Rights of the mentally handicapped
2 Failure to protect children physically, from abuse and infection	<ul style="list-style-type: none"> • Proper clothing • Failure to prepare, cook and serve meals
3 Poor support	<ul style="list-style-type: none"> • Financial support • Academic support • Emotional support
4 Poor self-management, motor development and speech development	<ul style="list-style-type: none"> • Self-help skills: feeding, toilet training and dressing • Fine and gross motor skills development • Speech development
5 Rejection by health professionals and neighbours	<ul style="list-style-type: none"> • Doctors • Social workers • Neighbours
6 Lack of socialisation skills	<ul style="list-style-type: none"> • Basic socialisation skills; inability to use leisure time and recreation

6.5.4.1 Lack of knowledge and information on mental handicap

The researcher discussed the care, treatment and daily rehabilitation of their children with the families. The family members did not appear to know the definition and meaning of “mental handicap”, its causes, what needed to be done to assist the mentally handicapped children, medications that should be taken, health services for the mentally handicapped, and conditions associated with mental handicap.

- **Definition of the concept “mental handicap”**

All three families did not have knowledge and information on mental handicap, causes, manifestations, and care, treatment and rehabilitation of mentally handicapped children. All three families presented with lack of knowledge, ignorance, and cultural beliefs (Townsend 2003:122).

The participants expressed the causes and treatment of mental handicap as follows:

This child is a present from God.

Her mother saw a cripple when she was pregnant.

We took the child to the traditional healer, with no improvement, thereafter the child was taken to the Apostolic and Zion Christian Church for strong prayers and for religious prescriptions (“ditaelo”). They also sang and danced for the child.

Steenkamp and Steenkamp (1994:13) and Blacher, Shapiro, Lopez, Diaz and Fusco (1997:5) emphasise that families only recognise the strange behaviour that the children display during early childhood. All the participants did not know that anyone could inform them about and teach them about the concept of mental handicap, causes of mental handicap, clinical manifestations, and the care, treatment and rehabilitation of their mentally handicapped children.

To empower the families of mentally handicapped children nurses should educate them on the causes; how children with mental handicap present; how to care for, treat and rehabilitate the child, with the aid of handouts, leaflets, posters, flip charts, films, videos, radio and television. Methods of teaching include lectures, drama, demonstrations, peer-group teaching and counselling by other family members with mentally handicapped children. Todd (1994:2) and Dunn (1995:37) encourage the utilisation of drama and videos in enlightening families of mentally handicapped children.

Burnard (1992:49) and Blacher (1998:87) point out the need for counselling and support for families to accept and love their mentally handicapped children. The families and neighbours were taught about mental handicap, its causes, how to recognise it, and how to support the families with mentally handicapped children. This enabled them to understand and support the families (Blacher 1998:87; Burnard 1992:49). Families of mentally handicapped children should be referred to social workers to motivate for social grants.

- **Medication, storage and follow-up after discharge**

When discharging patients from psychiatric hospitals, the patients and relatives are given discharge letters, taught that they should come to the hospital or clinic monthly for check-ups, collection of medication and health education.

The researcher found that the families were unaware of medication and follow-up after discharge. The families did not know the names of the medications or methods of safe-keeping and storage, about follow-up visits, and the health services that they should consult. According to two of the participants:

I stopped the treatment and never went back to the hospital and clinic and I had no reason for not going there. I just did not go since I did not believe in the hospital treatment, I strongly believed in the traditional medicine.

I keep the medicine safe in the display cabinet.

Concerning the safe-keeping of medication, it is important to keep the medication fresh and effective. Medication should not be put in the sun or any other place that is not cool. Medication should be kept in a cool place and out of reach of children as the children may take it and become poisoned or overdosed (Buntix 1993:11; Uys 1992:60).

- **Conditions associated with mental handicap and existing mental health services**

The families did not know about the conditions associated with mental handicap, such as Down Syndrome, hydrocephalus and epilepsy. Other conditions include autism, hyperactivity, microcephalus, temper tantrums, adjustment problems, speech problems and muscle weakness (Busman 1993:80; Steenkamp & Steenkamp 1994:30). According to the participants:

My child was taken to the traditional healer for the big head and after consultation with the traditional healer, the head became bigger and bigger, and I then took the child to the hospital where they said that my child had a condition named hydrocephalus.

This child was never taken to the clinic whenever those visitors who work with the nurses come to the clinic to check the mentally handicapped children.

The visitors who work with nurses referred to were physiotherapists, occupational therapists and other paramedical personnel. The Moletši Clinic invited families with mentally handicapped children to come to the clinic to be taught about the conditions associated with mental handicap and health services available for mentally handicapped children, such as the Centre for Mentally Handicapped Children, day care centres, social service programmes, and support groups and self-help groups in the community (Steenkamp & Steenkamp 1994:56).

Resources for empowerment of the families with mentally handicapped children include the professional nurses at the clinic, who teach families about the causes and recognition of mental handicap, how to treat it and how mentally handicapped children can be rehabilitated. The occupational therapist assists families to teach their children how to socialise with others, occupational skills, how to manage themselves, and how to use their leisure time. The physiotherapist assists families to exercise the floppy back muscles to become strong. Social workers at the clinic help families who have no food to apply for food parcels from Moletši Clinic. The social workers refer families to the support groups in the community such as families with mentally handicapped children and families with Down Syndrome children. Crawford (1995:3) and Davis (1992:60) emphasise and encourage family support in the form of parent groups and community involvement in helping families to care for, treat and rehabilitate the mentally handicapped children. Families should be referred for medical and psychiatric problems.

The researcher and the psychiatric nurse referred the families of the mentally handicapped children to church organisations, like the Women's League, to come and pray for the children, and assist them with food and clothes.

- **Rights of the mentally handicapped**

Mentally handicapped children have the right to protection and should not be abused (Cartwright 1992:3; DOH 1997:3). The families with mentally handicapped children in the Moletši district do not know about the rights of their children. The children are

harassed, ridiculed and beaten by other children at home and at school, and beaten by relatives and neighbours. Protection from infection is another important element ignored by most families in Moletši district. The researcher found the toilet facilities poor and unhygienic. According to the participants:

What can I say if my child gets beaten by his brother? It is a form of punishment, the child is very silly. Peer group members playing in the street also beat him; he will wake up and fight for himself one day.

I am very busy with the child. I do not have time to sweep and clean the house and surroundings.

The children and visitors go to the bushes for the toilet. I do not have money to build a toilet. It is very expensive.

I have built the house with another man in the community. We are able to live even if it is small. It is better than a tin house.

Rawlins, Williams and Beck (1993:679), Chinkanda (1988:133), and Clarke and McGraw (1996:59) stress that families do not have the right to beat, harass or abuse mentally handicapped children. They can be prosecuted like any other member of the community. Furthermore, should mentally handicapped children be abused they still have the right to be protected, should feel safe. Families of mentally handicapped children should be given time to share their thoughts and taught survival skills; esteem of mentally handicapped children should be supported, and families should be referred to Parents Anonymous (Byrne & Sebastian 1994:3-6; James 2006:101).

In this study, the researcher applied for Reconstruction and Development Programme (RDP) housing from the local councillor of Ward 18 under Polokwane municipality as the family and especially the mentally handicapped child needed safety, security and protection.

In applying the empowerment model, the researcher educated the families on the rights of the mentally handicapped children to be listened to, respected, educated, protected and cared for.

Mentally handicapped children have the right to respect and dignity, not to be discriminated, the right to information, and the right to participate in treatment decisions and confidentiality (Fraser & MacGillivray 1992:75; Steenkamp & Steenkamp 1994:55; Thompson & Herman 1995:4).

The families of mentally handicapped children were invited to a session of presentations on “human rights” organised by the Department of Human Rights for the central Moletši community. The audience was allowed to ask questions on special human rights like the aged, adolescents, families of mentally handicapped and the physically handicapped. The families of mentally handicapped were allowed to ventilate their problems and ask questions, and were given a presentation on the rights of the disabled and booklets on mentally disabled children.

6.5.4.2 Failure to protect the children physically, from human abuse and infection

Protection is a fundamental right of children, including the mentally handicapped children. Mentally handicapped children have the legal right to be protected from harm, whether physical, social, psychological or emotional. People who harass, abuse, or cause any type of harm to mentally handicapped children are guilty of an offence and can be prosecuted by law (DOH 1997:2).

- **Lack of proper clothing**

Two of the families were poor and did not have enough clothes for their mentally handicapped children. The clothes they had were torn and dirty. Clothing is one of the rights of mentally handicapped children (Dexter & Walsh 1997:48). According to a participant:

The child has no clothes for winter. He got some clothes from a welfare organisation last year and they are still big for him.

The researcher invited members of the Moletši branch of the National Council of African Women (NCAW), an organisation that supports the needy, to visit the family, and they donated jerseys, trousers, and winter and summer clothing. In addition, they taught the

mother and the other children the difference between summer and winter clothing. The women, who are not actively employed, promised to visit the family weekly.

- **Failure to prepare, cook and serve meals**

Mentally handicapped children have a right to physical wellbeing, including a well-balanced diet. This is the first physiological need in Maslow's hierarchy of basic needs (Taylor 1990:141). Not one of the three families had an adequate knowledge of preparing, cooking and serving meals. The families were educated about and members of the church were invited to come and assist the families in preparing, cooking and serving meals. The researcher and nurses also motivated neighbours and other families to assist the families (Harrold & Lutzker 1992:50).

Community volunteers and community workers from the clinic were requested to visit and assist the families. This was done in collaboration with nurses from the clinic during home visits. The researcher requested the social worker to apply for food parcels available for the needy families and add them to the waiting list for food.

Moletši Inter-denominational Women's League, an organisation in town that supports mentally handicapped children, started another feeding scheme, which further assisted the families. The Anglican Diocesan Women's Union in Polokwane sent food parcels to the mentally handicapped children in Moletši district.

Food is essential for the health of families and mentally handicapped children. Moreover, people's culture should also be taken into consideration. Culture dictates the type of food and how often food should be served. For example, the addition of avocado in traditional Japanese food adds vitamin C (Kettler & Zucker 2005:15; Rawlins et al 1993:127).

6.5.4.3 Poor financial, academic and emotional support

Generally there is a lack of support for families of mentally handicapped children from relatives, friends, neighbours, colleagues and support services in the community, including other parents with mentally handicapped children. Much of this is due to the stigma of mental handicap.

There is also still little support from doctors, physiotherapists, occupational therapists and other health professionals. Kgole (2000:46) found that the church offered 70% of support. Balkizas and O'Have (1994:30) and Dyson (1997:6) found that the church provided the strongest support for mentally handicapped children in the community. In their study of stress and coping abilities of parents with mentally handicapped children, Burack and Zigler (1998:513) found that groups outside the community supported the parents of mentally handicapped children emotionally and formed family support groups.

In 2006 a workshop was arranged at Moletši Centre for the parents of mentally handicapped children. Lectures and demonstrations were given on how to care for, treat and rehabilitate mentally handicapped children. The families, relatives, friends, neighbours and interested people were invited to the workshop. Youth organisations who work as volunteers in the Moletši Clinic and projects that support mentally handicapped children were also invited to take part in the workshop.

- **Poor financial support**

The first and the second families had problems with applications for social financial security funds (*motente*). This prevented them from purchasing clothing, food and other basic needs for the mentally handicapped children. According to the first and second family participants:

I was suffering and asked for financial security 'motente' until I got tired. The gentlemen told me that financial security is only given to children who have physical disability, like cripples.

I am still waiting for the government to give us "motente".

Dryden (1998:56), Fletcher (2003:11) and Flynn, Wood and Scott (1992:233) stress that mentally handicapped children have the right to financial security and this right should be respected and cherished.

- **Poor academic support**

In Moletši district there is poor academic support for families of mentally handicapped children as there is only one voluntary centre for mentally handicapped children in Moletši.

The families were not taught how to capacitate their children with academic skills. According to one participant:

At the school the mistress said that my child cannot even write his name, but just draws a straight line. This is the fifth year and I wonder who is going to help this child of mine.

Voluntary Moletši Centre teachers are taught to be patient and try to teach mentally handicapped children to write their names. Mentally handicapped children learn by repetition and reinforcement when they do something well (Lego 1996:59; Lievellyn 1995:7; Monyela 1999:63; Ngqoboka 1997:40).

- **Poor emotional support**

The families of mentally handicapped children undergo a series of reactions before they can accept that there is a mentally handicapped child in their family. Reactions include emotional shock, numbness, denial, blaming, guilt feelings and depression (O'Brien 1994:15). Grieving takes time, depending on strengths and weaknesses. One of the participants said:

I did not know what I had done wrong to deserve this punishment of having a mentally handicapped child. Nobody seems to be sensitive to the problems that my family experience.

The families complained that nobody seemed to care or be sensitive to the emotional problems of the families of mentally handicapped children. Boyd (1998:865), Wilson and Kneisl (1992:59), Busman (1993:27) and Williams (1996:98) emphasise the formation of support groups in the form of parent groups, mutual support groups where families come together and discuss the same problems and advise one another on how to solve

individual problems of their mentally handicapped children. Mental health care workers should accept, empathise, listen attentively, and be non-judgmental when supporting the families of mentally handicapped children emotionally. One of the participants reported being rejected by a doctor as follows:

Mummy, I am very busy and will not be able to examine your child. I am going somewhere, I cannot help. I am sending you to the sister in the clinic to help you.

Nurse, Rohde and Farmer (1990:7) refer to this doctor's attitude as an "unhelpful encounter" between the doctors and parents. Many parents are dissatisfied with the amount of information, the language and the lack of interest shown by doctors (Nurse et al 1990:9)

6.5.4.4 Poor self-management skills, motor development and speech development

Self-management skills refer to the ability to care for one's personal hygiene like washing and grooming; ability to feed oneself; the use of the toilet effectively; the ability to socialise; the use of leisure time, and occupational functioning.

- **Poor self-help skills: feeding, toilet training and dressing**

Mentally handicapped children are taught to feed themselves, wash themselves and groom themselves, do their own washing and use the toilet effectively. During the interview and family assessment of the second case study, the mother gave the child food and the researcher observed that the mentally handicapped child messed food on his body and on the floor. The mother complained:

Our child is not able to feed himself and use the toilet alone, he still needs assistance.

The family members were taught to teach their mentally handicapped children how to feed themselves. They started by feeding the child, then the child started using his hands, with the help of family members.

Later the family members were trained how to teach the child to eat by using a spoon and this was repeated as the mentally handicapped child learns by repetition (Uys & Middleton 2002:430). The mentally handicapped child was taught to wash his hands before and after eating.

When visiting the family of the second case study the researcher remarked on the bad smell in the house. According to the mother:

My child is unable to use the toilet effectively and this worries me when I am at work, because the person who stays with him during the day is not as patient as I am.

Steenkamp and Steenkamp (1994:55) point out that inability to use the toilet is one of the problem areas in self-help skills and the child needs intensive training for some time.

The family members were educated about toilet training and the researcher and the clinic nurse taught them to develop the following attitudes when teaching the mentally handicapped children:

- Patience
- Repeat
- Teach from simple to complex
- Teach from easy to difficult
- Reinforce if the child does the procedure well

This procedure should be repeated until the mentally handicapped child is able to perform the procedure. The clinic nurse, who assisted the researcher, will continue with the child during home visits. Families need to be patient and repeat the procedure as the mentally handicapped have slow grasping power (Lubetsky 1995:2).

According to one participant:

My child is still struggling to dress without support, but this year he seems to be improving, since he started school at the Grace and Hope School for Mentally Handicapped Children.

- **Poor motor development**

Poor motor development refers to development of gross and fine muscles such as the thinner muscles of the fingers and muscles of the toes. Fine muscles are developed by exercises such as picking up beads, tying shoe laces, picking up small stones from a sandpit, drawing, and walking on tip-toe. Gross muscles refer to the broad muscles such as gluteus muscles, tibial muscles, latissimus dorsi muscles and broad abdominal muscles. Gross muscles are developed by exercises such as running, walking, pushing a wheelbarrow, jumping, hopping, skipping, tumbling and gymnastics, games and other back and abdominal exercises (Steenkamp & Steenkamp 1994:31). Development of motor skills assists in the maintenance of balance and posture.

One of the mothers referred to her child's weak back muscles as follows:

*My child gets tired easily and sits down while playing with other children.
His back gets tired easily.*

The mother and the entire family were given health education about Down Syndrome and its related problems. Weakness of the muscles was explained and the family was taught that the back muscles are weak due to laxity of the muscles prevailing in Down Syndrome. The family was taught about stimulation in the form of exercises.

- **Poor speech development**

Speech is an essential component of the mentally handicapped child's survival as the child indicates needs by talking/communicating. Speech is a way of modulating physical and emotional discomfort. The mentally handicapped child in the first case study could respond when his name was called, but could not relate a story, irrespective of how many times he was asked (Uys & Middleton 2002:499).

The child had a problem with his speech, even though the mother took him to the clinic and hospital for treatment. The psychiatrist referred the child to the speech therapist and the speech therapist put the child on long-term treatment. The child has to come for speech therapy every month and the mother is given some exercises for the child to practise at home. According to the mother:

My child is still experiencing problems with his speech, though he has greatly improved.

Antai-Otong (2008:179) suggests continuous perseverance in developing mentally handicapped children's speech as it takes a long time for them to develop their speech, and stresses the principles of repetition and patience when dealing with mentally handicapped children. Antai-Otong (2008:179) also emphasises the use of sign language, simple words, and covering more aspects of daily living. Other aspects to be checked and considered when teaching speech include hearing, vision, and gross and fine motor deficits as they should be functioning well for good speech development.

6.5.4.5 Rejection by other health professionals and neighbours

Health professionals rejected the mother of the third case study when she wanted to know what a mongol is. According to her, the doctor and the social worker had little time to attend families with mentally handicapped children:

My diagnosis of the patient, she is still small. I think you should go home and wait and see.

Mummy, I cannot make out the diagnosis of the child, you better go home to observe your baby.

Chen and Tang (1997:258) found lack of acceptance/rejection of parents of mentally handicapped children by the community at large and health services. According to Steenkamp and Steenkamp (1994:11), medical practitioners often adopt a "wait and see" approach, making vague statements, not telling the truth or leaving the mother until she is prepared for the shock and disappointment.

Mavundla, Toth and Mphelane (2009:6) found that the caregivers in a rural community in South Africa were rejected not only by the community, but by nurses and social workers. The caregivers complained that nurses did not assist them when their relatives with mental illness were admitted to hospital and did not give them any health education. The social workers were of little assistance in supporting them with regard to their mentally ill relatives.

The caregivers complained that they were not given health education on mental illness and this frustrated them as they wanted to support their relatives. The caregivers had only heard on the streets that mental illness could be caused by dagga and environmental problems, but they wanted to know the actual causes of mental illness.

The participants referred to rejection by neighbours. According to one participant:

I felt bad when the community and the neighbours rejected my child, even children in the street did not want to play with my child. Neighbours do not care.

Dunn (1995:34) and Mavundla, Toth & Mphelane (2009:1) emphasises establishing good relationships between clients/ families and their neighbours.

6.5.4.6 Lack of socialisation skills

Socialisation is a basic skill necessary for individuals to interact with the family and become responsible members of their society. Successful socialisation involves a conforming to the rules and regulations of the family and society (Steenkamp & Steenkamp 1994:33). The mentally handicapped children from all three case studies lacked basic socialisation skills and were unable to use their leisure time and recreation.

- **Lack of basic socialisation skills**

During basic socialisation in the family children should be taught how to greet, to say “thank you”, to say “sorry”, to say “goodbye”, and be able to share whatever is being eaten (Steenkamp & Steenkamp 1994:35). The mentally handicapped children in all three case studies were not able to display basic socialisation skills. The mentally handicapped children in case studies 1 and 2 were able to greet and two children demonstrated happiness on their faces.

The researcher and the clinic nurse were assigned the task of teaching basic socialisation skills to the families and children during home visits. The researcher donated a video cassette covering basic socialisation skills that the nurses from the clinic played to the family members and the mentally handicapped children.

The researcher also taught them to use games when teaching basic socialisation skills, as children grasp a skill effectively when playing.

- **Inability to use leisure time and recreation**

Recreational activities, use of leisure time, socialisation of children in basic aspects, outings, visiting of support groups, and occupational skills are generally not done in Moletši district for the mentally handicapped children.

According to the mother of the mentally handicapped child in the first case study:

The only recreation that my child gets, is from the International Pentecostal Church. My child sings and dances with other children in church and the church arranges trips for our children.

Balkizas and O'Hare (1994:35) found that the church is an institution of socialisation in the case of children with mental disability.

In Moletši district a "fun day" was arranged by the nursing students from University of Limpopo, Turfloop Campus. The students hired a "jumping castle" from Polokwane and all the mentally handicapped children who came enjoyed the day together and made friends (May 2002:248). This was one of the ways in which the researcher and the clinic nurse together with the nursing students socialised the mentally handicapped children.

Moletši social workers obtained toys for use with the mentally handicapped children in Moletši, and also gave each child one toy to take home. They grouped the children together in the church, played music cassettes and socialised with them.

6.5.4.7 Summary of challenges identified from creation of awareness of needs

The researcher summarised the challenges and needs identified in the case studies (Spradley 1991:333) (see table 6.5).

Table 6.5 Summary of participants' family-related challenges

Challenges	Case study 1	Case study 2	Case study 3
	<ul style="list-style-type: none"> • Poor housing • Poor toilet facilities • Lack of knowledge of preparation, cooking and serving of meals • Lack of financial support • Lack of knowledge of the definition of mental handicap, services available, rights of mentally handicapped, care, treatment and rehabilitation of mentally handicapped children 	<ul style="list-style-type: none"> • Lack of knowledge of the definition of mental handicap, services available, rights of mentally handicapped, care, treatment and rehabilitation of mentally handicapped children • Lack of financial support • Poor toilet facility 	<ul style="list-style-type: none"> • Lack of support from neighbours • Lack of financial support • Poor toilet facility • Lack of knowledge of the definition of mental handicap, services available, rights of mentally handicapped, care, treatment and rehabilitation of mentally handicapped children • Poor knowledge of preparation, cooking and serving of meals

Table 6.6 presents the child-related challenges identified in the study.

Table 6.6 Summary of child-related challenges

Challenges	Case study 1	Case study 2	Case study 3
	<ul style="list-style-type: none"> • Diagnosed Down Syndrome • Poor muscle tone in the back • Poor concentration span • Poor academic performance • Poor self-help skills • Poor speech development • Adjustment problems • Temper tantrums • Poor clothing • Child abused by neighbourhood children 	<ul style="list-style-type: none"> • Diagnosed Epilepsy and Hydrocephalus • Poor self-help skills • Poor academic development 	<ul style="list-style-type: none"> • Diagnosed Down Syndrome • Child abused and ridiculed by neighbours • Poor academic development

6.6 PLAN OF ACTION FOR FAMILIES WITH MENTALLY HANDICAPPED CHILDREN

Mental health care professionals, the researcher and the families of mentally handicapped children worked together to find ways of solving their problems and needs and planned how and who should tackle the needs identified. Short- and long-term goals were formulated according to the needs and plans made for the expertise and specific groups required (Stanhope & Lancaster 2000:318).

Maslow’s hierarchy of needs was used as the basis to facilitate planning for needs of mentally handicapped children and their families (see table 6.7).

Table 6.7 Maslow’s hierarchy of needs

Need	Characteristics
Physiologic	Satisfying needs for oxygen, food, water, shelter, sleep, relief of sexual tension
Safety	Avoiding harm and achieving security and physical safety
Love and belonging	Giving and receiving affection developing companionship and gaining acceptance by a group
Esteem and recognition	Achieving recognition by others leading to self-esteem and feelings of prestige, achieving success in work
Self-actualisation	Achieving one’s own unique potential in all dimensions
Aesthetic and cognitive	Achieving an unbiased understanding and appreciation of the beauty and unity of the world and one’s role in it

All three families lacked some basic needs, especially physiological needs, safety, love and belonging and esteem (see table 6.5). Accordingly, the researcher drew up a plan of action for each family with specific objectives.

6.6.1 Case study 1

The objectives of the plan for case study 1 were to

- educate the members of the family on the causes, manifestation, care, treatment and rehabilitation of mentally handicapped children
- assist in improvement of housing
- prevent abuse by children on the street and neighbours
- teach the family how to prepare, cook and serve meals
- support the family academically, financially, and physically
- assist in improvement of speech and refer to expert support
- improve concentration
- help to improve muscle tone
- assist in adjustment problems and concentration
- improve toilet facilities

6.6.2 Case study 2

The objectives of the plan for case study 2 were to

- educate the family members on the causes, manifestation, care, treatment and rehabilitation of mentally handicapped children
- refer the child to the psychiatrist for Epilepsy
- teach the family how to prepare, cook and serve meals
- support the family academically, financially, and physically
- improve socialisation and recreation skills
- improve poor self-help skills
- improve toilet facilities

6.6.3 Case study 3

The objectives of the plan for case study 3 were to

- educate the family members on the causes, manifestation, care, treatment and rehabilitation of mentally handicapped children
- refer the child to the psychiatrist for Down Syndrome
- prevent abuse of the mentally handicapped child by neighbours
- encourage support from neighbours
- improve the toilet facilities

6.7 MOBILISATION OF RESOURCES, SUPPORT AND INFORMATION

In the mobilisation phase the mental health professionals, the researcher and the families of the mentally handicapped children became actively involved in the empowerment process. The families started to participate in problem solving and to access information, resources and support. The families started to realise that they had to take charge of their needs and become responsible and accountable for achieving autonomy and self-efficacy and become experts in the care, treatment and rehabilitation of their children (Ross & Deverell 2004:289).

6.7.1 Case study 1

The researcher and clinic nurses gave health education lectures on mental handicap and Down Syndrome, which is one of the conditions associated with mental handicap, the clinical features, and the care, treatment and rehabilitation of the Down Syndrome child. Family members were shown a film of Down Syndrome at home, and given handouts. The family expressed appreciation for all the information they received from the nurses.

The family were also informed about the ombudsman for Polokwane municipality. The ombudsman was elected at a community meeting attended by stakeholders from the Department of Health and Social Development, representatives of hospitals, clinics and universities, traditional leaders and key figures of every section of the Polokwane municipality. The family was told that the ombudsman was the advocate for the community whose duty is to monitor whether the community members receive expected health care and their rights. The researcher also gave the ombudsman's telephone number and address for consultation, if the need arose.

- **Improvement of housing**

The researcher applied for RDP housing from the local councillor of Ward 18 under Polokwane municipality as the family, especially the mentally handicapped child, is not safe.

- **Prevention of abuse by children on the street**

The researcher and the clinic nurses visited the Ngoasheng family and invited the neighbours and all the children on the street. The psychiatric nurse and the researcher explained about mental handicap and educated their right to dignity and protection, especially from physical harm. The clinic nurse stressed that the children living on Solomon's street should assist in protecting him from abusive children. By playing with other children Solomon would have a chance to overcome his adjustment problems.

- **Teaching family members how to prepare, cook and serve meals**

The family was educated about preparation, cooking and serving of a well-balanced diet. Women of the International Pentecostal Church were invited to come and assist the family. The women prepared, cooked and served meals in the Ngoasheng home and used the family's utensils. The researcher referred the family to Moletši Clinic for free feeding scheme as he had the right to a well balanced diet for physical health. The Anglican Diocesan Women's Union in Polokwane, who support the needy with food, sent food parcels to the mentally handicapped children in Moletši, including Solomon's family. Moletši Inter-denominational Women's League heard about an organisation in town that supports mentally handicapped children and they started another feeding scheme and Solomon's family was assisted.

- **Improving academic performance**

Voluntary Moletši centre teachers were taught to be patient and try to teach Solomon to write his name and simple words. Volunteers at the centre are encouraged to be patient, kind and loving, and repeat what they teach as mentally handicapped children learn by repetition and reinforcement for doing something well. They use different teaching aids and Solomon is assisted to write in class and build words with letters of the alphabet.

- **Financial support**

The Ngoasheng family members were taken to the *induna* for a letter confirming Solomon's need of financial support. The hospital psychiatrist confirmed Solomon's condition in writing and the need for financial assistance. The social worker described Solomon's condition and that he is deprived socially for the rest of his life. The family took the letters and Solomon to the Social Support Department of the nearest hospital and was told by the officer in the Department to wait for feedback in three months.

- **Assisting in improvement of speech**

Solomon was taken to Moletši Clinic monthly as the speech therapist visits the clinic the last Friday of each month.

Solomon was trained in vowels, pronunciation and the formulation of words and given exercises to practise words used at home. He was taught to speak and open his mouth properly and speak everyday language used at home, such as talking about home utensils, and saying words like “mama” and “papa”. The speech therapist gave Solomon exercises that would improve his concentration at the same time, such as giving short tasks of short duration that the child could finish in a short space of time.

- **Improvement of muscle tone**

The family was referred to the psychiatrist for poor muscle tone for review. The psychiatrist referred Solomon to the physiotherapist, who assisted the family to exercise and strengthen his floppy back muscles to become strong. The family was also given exercises to practise with Solomon at home.

- **Assisting in self-help skill of feeding**

This responsibility was given to the mother and other family members. The family was taught to encourage the boy to eat by singing encouraging songs; showing him how to take a spoon and eat as if they were playing, and praising him when he finished eating. This is repeated several times every day until he is competent.

- **Socialisation and recreation**

Solomon was grouped with the other children at the church with music cassettes playing and Solomon socialised with the children. In Solomon’s church the children are taken on an excursion every fourth Sunday or an occasion is arranged in church in the afternoon for the children. At the International Pentecostal Church, where Solomon’s family worships, socialisation of children is one of their priorities. Solomon’s family was taught that Solomon needs to rest for at least one and a half hours during the day.

On the “fun day” the nursing students hired a “jumping castle” from Polokwane and all the mentally handicapped children enjoyed the day together and made friends (May 2002:248). This was one of the ways in which the researcher and the psychiatric nurse together with the nursing students socialised the mentally handicapped children.

The researcher and the psychiatric nurse referred and showed the family the support groups in the community like families with mentally handicapped children of their type, such as families with Down Syndrome in their homes.

Concerning clothing, the National Council of African Women, who support the needy, was invited to visit the family, and they donated clothing and taught the mother and other small children the difference between summer and winter clothing.

6.7.2 Case study 2

The researcher and clinic nurses gave health education lectures on mental handicap and Epilepsy and Hydrocephalus, which are some of the conditions associated with mental handicap, the clinical features, and the care, treatment and rehabilitation of the Epileptic and Hydrocephalus child. Family members were shown a film of Epilepsy and Hydrocephalus at home and given handouts. The family showed appreciation for all the information.

The family attended the workshop for the parents of mentally handicapped children at the Moletši Centre, which included lectures and demonstrations of how to care for, treat and rehabilitate their mentally handicapped children. Families, relatives, friends, neighbours and interested people were invited to the workshop.

The family was educated about preparing, cooking and serving a well-balanced diet. Women from the Zion Christian Church were invited to come and assist the family. The women prepared, cooked and served meals in the family home and used the family's utensils.

- **Improving academic performance and financial problem**

Voluntary Moletši Centre teachers were taught to be patient and try to teach the mentally handicapped child to write his name. Volunteers at the centre were encouraged to be patient, kind and loving, and repeat what they teach because mentally handicapped children learn by repetition and reinforcement for doing something well.

An application of financial assistance was made to the Department of Social Development at Seshego township.

- **Improving socialisation and recreation**

The mentally handicapped boy was poorly socialised at home. The researcher and the clinic nurse encouraged family members to take him along when they go to church so that he could participate in '*mokhukhu*' dancing on Sundays after church.

For socialisation, Moletši social workers obtained different toys for the mentally handicapped children, and the boy was also given one to take home.

On the "fun day" the nursing students hired a "jumping castle" from Polokwane and all the mentally handicapped children who attended enjoyed the day together and made friends (May 2002:248). This was one of the ways in which the researcher and the psychiatric nurse together with the nursing students socialised the mentally handicapped children. The researcher and the clinic nurse referred and showed the family the support groups in the community like families with children with Epilepsy and Hydrocephalus. The boy also took part in family excursions, songs in church and music competitions in church to improve socialisation and concentration.

- **Preparation, cooking and serving of meals**

Neighbours and other families whose women are not working were grouped to assist the families with preparing, cooking and serving meals. The family was grouped together with other families for the demonstrations.

Community volunteers like community workers from the clinic were requested to visit the family and also assist in the preparation, cooking and serving of meals. This was done in collaboration with nurses from the clinic during home visits.

The family was also assisted by the Moletši Inter-denominational Women's League feeding scheme.

6.7.3 Case study 3

The Mohafe family was encouraged and their mentally handicapped child was referred to the psychiatrist for Down Syndrome for examination, treatment and rehabilitation.

- **Preparing, cooking and serving meals**

The family was educated about preparing, cooking and serving a well-balanced diet. Members of the Uniting Reformed Church of Southern Africa were invited to come and assist the family

- **Improving academic performance**

Voluntary Moletši Centre teachers, where the children go for extra classes, were taught to be patient and try to teach the mentally handicapped child to write his name. Volunteers at the centre were encouraged to be patient, kind and loving, and repeat what they teach as mentally handicapped children learn by repetition and reinforcement for doing something well.

- **Encourage support from neighbours**

The neighbours were taught about mental handicap, its manifestation, problems associated with the condition, and the care, treatment and rehabilitation of the mentally handicapped children. The researcher and the clinic nurse gave the neighbours a lecture on the importance of support for the families of mentally handicapped children and avoidance of abuse of the mentally handicapped child.

The family attended the workshop at Moletši Centre where they were given a series of lectures and demonstrations on how to care for, treat and rehabilitate their mentally handicapped child. Families, relatives, friends, neighbours and interested people were also invited to the workshop.

The family and other families with mentally handicapped children were invited to a session organised by the Department of Human Rights when a group of women presented "human rights day" talks for the entire central Moletši community.

The audience was allowed to ask questions on special human rights like the aged, adolescents, family of mentally handicapped and the physically handicapped. The families were given a platform to ventilate their problems and ask questions related to their children and were discouraged from abusing the mentally handicapped children.

- **Improving toilet facilities**

The family was encouraged to build a new and bigger toilet that allowed ventilation and had a chimney for removing contaminated air.

Table 6.8 summarises the mobilisation of resources for the three families.

Table 6.8 Mobilisation of resources

Case study 1	Case study 2	Case study 3
<ul style="list-style-type: none"> • Referred to doctor for Down Syndrome-related problems like poor muscles in the back • Socialisation of the child through fun days • Family assisted by organisations such as Anglican Diocesan Women’s Union, Social Services, Moletši Inter-denominational Women’s League, National Council of African Women, and volunteers for meals, socialisation, recreation, health education and assistance • RDP house applied for. • Educated on preparing, cooking and serving meals • Taught importance of toilet and clean house environment • Applied for financial assistance • Educated on care, treatment and rehabilitation of mentally handicapped children 	<ul style="list-style-type: none"> • Referred to psychiatrist for Epilepsy and Hydrocephalus. Socialisation of the child through fun days • Family assisted by organisations such as Anglican Diocesan Women’s Union, Social Services, Moletši Inter-denominational Women’s League, National Council of African women and volunteers for meals, socialisation, recreation, health education and assistance • Educated on preparation, cooking and serving of meals • Taught the importance of toilet and clean house environment • Applied for financial assistance • Educated on care, treatment and rehabilitation of mentally handicapped children 	<ul style="list-style-type: none"> • Referred to psychiatrist for Down Syndrome • Educated on preparing, cooking and serving meals • Taught on importance of toilet and clean house environment • Applied for financial assistance • Educated on care, treatment and rehabilitation of mentally handicapped children • Socialisation of the child through fun days • Family assisted by organisations such as Anglican Diocesan Women’s Union, Social Services, Moletši Inter-denominational Women’s League, National Council of African Women, and volunteers for meals, socialisation, recreation, health education and assistance

6.8 MONITORING AND EVALUATION

Monitoring and evaluation should start during the planning stage to determine whether the goals go hand in hand with the problems identified, and whether implementation takes place according to the set objectives throughout the empowerment process (Stanhope & Lancaster 2000:313).

The researcher, the mental health professional and the clinic nurse who assisted the researcher in the implementation of the model evaluated the empowerment process to establish whether the empowerment process was successful or not. Colleagues who were observers evaluated the impact of the empowerment model in the care, treatment and rehabilitation of the families of the mentally handicapped children. The families of the mentally handicapped children were involved in monitoring and evaluation as the model for empowering families involves power sharing, and is a two-way process in which both the families and the mental health professionals share.

6.8.1 Case study 1

- **Monitoring of request for food from clinic**

The researcher and the other mental health professionals met with the family to ascertain whether food was obtained from the clinic. The family reported that the social worker had informed them in writing that they were number 30 on the waiting list for the food parcels that are given to the needy families.

- **Feedback on rights of mentally handicapped child**

The clinic staff, staff in the nearby clinics, the researcher and mental health professionals discussed the rights of the mentally handicapped children. It was discovered that the family members understood the rights of their mentally handicapped child, and knew that their child had the right to be protected, to a name and surname, happiness, education, respect, dignity, to be loved and cherished, and the right to live like any other child.

- **Feedback on housing**

The family was informed that feedback was still awaited from the councillor of ward 18 of Polokwane municipality, who had indicated that the family had been moved from number 250 to 110 on the list. With the next batch of houses, the family might be included.

- **Feedback on academic performance**

The family reported that they were invited to the Moletši parents group on mental handicap where they discussed their children's problems including their failure to progress at school. The family found that the other families had the same problems and they consoled and supported one another. The family gave feedback on their child's improved academic performance and explained to the other parents how they were assisted.

- **Monitoring of speech problem**

Home visiting was done and it was found that there was improvement in the boy's speech. He was able to pronounce several words, had mastered the speech exercises given to him, could pronounce everyday objects better, but still needed more exercises.

- **Feedback on preparing, cooking and serving meals**

The researcher and the clinic nurse visited the family at home and observed improvement in the preparation, cooking and serving of meals. The mother wanted to be alone when she prepared the meals. The meals were prepared in a clean environment, utensils were clean, and the meals were well cooked and served attractively. The family thanked the researcher and the clinic nurse and the voluntary organisations for their assistance.

- **Monitoring of care, treatment and rehabilitation**

The family members and the child were observed in care for the mentally handicapped child to find out whether improvement is marked or not. The family was able to clean their mentally handicapped child with little support from organisations and neighbours. The mentally handicapped child and the family were found to be clean. The family took the boy for treatment regularly and the family assisted each other to rehabilitate him. The researcher and the clinic nurse were pleased with the improvement in the family.

6.8.2 Case study 2

The researcher and the clinic nurse visited the family to observe how many times the child had had fits in a month. The family reported that the boy had only had one fit in the month since being referred to the psychiatrist in the nearby hospital.

The researcher and the clinic nurse found that the family members understood the rights of their mentally handicapped child, and could tell that he had the right to be protected, to a name and surname, happiness, education, respect and dignity, to be loved and cherished and the right to live like any other child.

The family also reported that they had been invited to the Moletši parents group on mental handicap and had found that the other families had the same problems and they consoled and supported one another. The family was referred to Grace and Hope School for Mentally Handicapped Children. After a month the clinic nurse and the researcher went to evaluate the progress at his home and found the boy able to write his name, an achievement that made the family happy.

The researcher and the clinic nurse visited the family and observed an improvement in the preparation, cooking and serving of meals.

The family members and the mentally handicapped boy were observed to find out whether improvement was marked or not. The family was able to clean the mentally handicapped child with little support from organisations and neighbours. The family and the boy were found to be clean. The researcher and the clinic nurse were pleased with the improvement in the family. Regarding the application for financial assistance, it was found that the boy was on the waiting list.

6.8.3 Case study 3

In evaluating the family it was found that the family members understood the rights of their mentally handicapped child, and knew that he had the right to be protected, a name and surname, happiness, education, respect and dignity, to be loved and cherished, and to live like any other child. The family understood that abuse of mentally handicapped children should to be reported to the police and is an offence.

The family also reported that they were invited to the Moletši parents group and found that the other families had the same problems and they consoled and supported one another. The problem of academic failure was reported to the psychiatrist, who referred the boy to the Grace and Hope School for Mentally Handicapped Children and the boy could write a sentence within a month.

On visiting the family at home the researcher and the clinic nurse observed an improvement in the preparation, cooking and serving of meals. The family thanked the researcher and the clinic nurse and the organisations who had assisted them.

The family had taken the mentally handicapped child to the psychiatrist for examination and the doctor explained that children with Down Syndrome have floppy muscles in the back. The doctor prescribed exercises for the back and referred them to the clinic physiotherapist who visits the clinic once a month.

The researcher visited the family and found that they had built a well-constructed, hygienic toilet. She congratulated the family for that.

Concerning financial assistance it was found that within two months the boy received financial assistance (in the form of a disability grant) after applying to the Department of Social Support.

6.9 SELF-EFFICACY

Collins English Dictionary (1995:224) defines efficacy as “power or capacity to produce the desired effect; ability to achieve results; effectiveness”. Efficacy is competence, capability, effectiveness and success (*Collins English Dictionary* 1995:225). Increment of self-efficacy refers to the development of a sense of personal power or mastery over events in one’s life. At the end of the empowerment process each family was expected to be able to care for, treat and rehabilitate their mentally handicapped children without support.

6.9.1 Case study 1

The family became independent and efficient and only goes to the doctor when they observe positive changes in Solomon.

The family was able to achieve the following objectives:

- Preparation, cooking and serving of meals was managed without support.
- The family members opened up and were observed discussing the concept of mental handicap, the causes such as heredity and non-prescribed drugs, conditions associated with mental handicap like Down Syndrome, the services available for mental handicap, and care, treatment and rehabilitation of mentally handicapped children with other families. The information was accurate.
- The family members were invited to the clinic and could identify the basic rights of mentally handicapped children. They knew the rights of their mentally handicapped child and could teach the other parents about them.
- The family's clothing improved after receiving donations of clothing and kept the clothes clean. The family could be seen differentiating between winter and summer clothing.
- The family could differentiate between the right support and the wrong support or assistance, like when their children are abused.
- The family received financial assistance within three months as the mother was informed that she should come for the child's grant. The money received was for a period of three months. The family could then meet their basic needs.
- **Weaknesses observed**

The boy's speech is not yet perfect, and he still needs follow-up and a lot of practice with the clinic psychiatric nurses.

The boy still has a marked weakness of the back (spinal) muscles and requires continuous exercise and follow-up.

The child's academic problems remain the main issue requiring continuous attention. A slight improvement was observed.

He can only write his name upside down but can speak about other points that were taught to him. He learns better by speaking and not writing.

- **Intervention**

The clinic nurses report that the boy still needs follow-up. He needs to continue speech therapy and spinal muscle exercises. His academic performance also needs to be improved and monitored until he is able to read and write.

6.9.2 Case study 2

The family was able to achieve the following objectives:

- The family could prepare, cook and serve meals for breakfast, lunch and supper. The family members opened up and were observed discussing the concept of mental handicap, the causes such as heredity and non-prescribed drugs, conditions associated with mental handicap like Epilepsy and Hydrocephalus, the services available, and the care, treatment and rehabilitation of mentally handicapped children with other families.
- They knew about the community facilities or resources where they could take the child for assistance, and were able to take the boy to the hospital on their own for epilepsy check-up.
- They could explain how community facilities are utilised, including the social worker and mental health professionals.
- Could differentiate between the right and the wrong support or assistance, like when their children are abused.
- The boy was given financial support after three months.

6.9.3 Case study 3

The family was able to achieve the following objectives:

- The family members opened up and were observed discussing the concept of mental handicap, the causes such as heredity and non-prescribed drugs, conditions associated with mental handicap like Down Syndrome, the services

available for the mentally handicapped, and the care, treatment and rehabilitation of mentally handicapped children.

- The family members were invited to the clinic and could identify the basic rights of mentally handicapped children. They knew the rights of their mentally handicapped child and could teach the other parents about them. The boy's abuse by neighbours stopped.
- They could indicate the community facilities or resources where they could take their child for assistance.
- They were able to explain how the community facilities are utilised, including the social worker and mental health professionals.
- Could differentiate between the right and the wrong support or assistance, like when their children are abused.

The case studies were conducted over a period of three months. Each family with a mentally handicapped child met the inclusion criteria of the study (see chapter 2). The researcher transcribed the data collected verbatim and used Tesch's model for data analysis (Creswell 1994:155).

Table 6.9 summarises the self-efficacy of the three families.

Table 6.9 Self-efficacy

	Case study 1	Case study 2	Case study 3
Self-efficacy	<ul style="list-style-type: none"> • Knowledge acquired on definition, causes, recognition, care, treatment and rehabilitation of mental handicap. Knowledge of services available for Down Syndrome child, like parents groups. Knowledge of right and wrong advice, and the rights of mentally handicapped children. Got financial assistance and could differentiate between winter and summer clothing. 	<ul style="list-style-type: none"> • Clothing improved, knowledge acquired on definition, causes, recognition, care, treatment and rehabilitation of mental handicap and epilepsy. knowledge of right and wrong advice, and the rights of mentally handicapped children. Got financial assistance. 	<ul style="list-style-type: none"> • Knowledge acquired on definition, causes, recognition, care, treatment and rehabilitation of mental handicap. Knowledge of services available for Down Syndrome, Knowledge of parents groups. knowledge of right and wrong advice, and the rights of mentally handicapped children.

6.10 CONCLUSION

This chapter discussed the findings of the evaluation of the implementation of the model for empowerment of families with mentally handicapped children. The themes and categories that emerged from the data were described. Chapter 7 discusses the conclusions reached from the findings, the limitations of the study, and makes recommendations for practice and further research.

CHAPTER 7

Conclusions, limitations and recommendations

7.1 INTRODUCTION

Chapter 6 discussed the evaluation and findings of the implementation of the model for empowerment of families with mentally handicapped children, using literature control to validate the study. The model was evaluated by means of case studies, semi-structured interviews and assessment guides. Six themes emerged from the data, namely lack of knowledge and information on mental handicap; failure to protect the child physically, from human abuse and from infection; poor emotional, academic, and financial support; poor self-management skills; rejection by health professionals and neighbours, and lack of different socialisation skills. Lack of knowledge was found in five categories namely on the concept of mental handicap; medications, storage and follow-up; conditions associated with mental handicap; existing health services, and the rights of mentally handicapped children.

This chapter discusses the conclusions drawn and limitations of the study and makes recommendations for practice and further research.

7.2 CONCLUSIONS

This study was a continuation of an exploratory study conducted by the researcher which revealed that families with mentally handicapped children were not properly supported in their endeavour to care for, treat and rehabilitate their mentally handicapped children. A theory-generative, qualitative, descriptive and contextual design was used to achieve the objective of the initial study. The researcher then used the findings to develop and describe a model to support families to care for, treat and rehabilitate their mentally handicapped children. The researcher used Chinn and Kramer's (1995:20) design in developing the theory and model, beginning with the identification of the main concept of the model, namely "empowerment". The concept of empowerment was analysed to identify its attributes.

The defining attributes were then synthesised to form the definition of empowerment used in the model developed in this study. Therefore, the concept of empowerment became central to supporting families with mentally handicapped children in the context of a rural community of Limpopo province in South Africa. It was imperative for the researcher to empower rural families in Moletši village as they lacked the knowledge and skills to care for, treat and rehabilitate their mentally handicapped children.

The theory-generative research design played a major role in helping the researcher construct an intervention (model) to support families in an effort to care for, treat and rehabilitate their children. It also gave the researcher a step-by-step process to follow in the development of a theory. Theory testing is coupled with theory development and in this study the researcher developed practice guidelines to evaluate the implementation of the model. The implementation of the guidelines to operationalise the model further enabled the researcher to evaluate its impact in empowering families with mentally handicapped children.

During the implementation of the model in the practice of community psychiatric nurses, the researcher employed a qualitative research strategy, using case studies, interviews and assessment guides (Keen & Packwood 2008:2). Three families who volunteered to participate in the study were carefully studied whilst implementing the stages of the empowerment model, namely creation of awareness of needs; formulation of plan; mobilisation of resources; monitoring, and evaluation to reach self-efficacy. The model proved capable of offering support to families with mentally handicapped children. Furthermore, the researcher found that rural families with mentally handicapped children have many challenges and lack the knowledge to help them render holistic care to their mentally handicapped children.

The family members of the mentally handicapped children valued the researcher and the psychiatric nurse's support and interest in their problems. They also valued the fact that the researcher wanted to hear from them what their shortcomings were, as well as the sharing relationship and active participation that prevailed in order to care for, treat and rehabilitate their mentally handicapped children. Mobilisation of resources, information, and support for the families with mentally handicapped children led to independence, self-directedness and self-efficacy.

The theory-generative research process followed in the study proved to be complicated and abstract. This sharpened the researcher's critical thinking abilities.

7.3 LIMITATIONS

The study was restricted to the clinical area of Moletši Clinic and five families with mentally handicapped children and who attend the clinic were chosen for a case study. Only families who lived with their mentally handicapped children and whose children attended Moletši Clinic were included in the sample because these families had insight into their children's needs. Two families later defaulted. Consequently, only one single and two nuclear families of mentally handicapped children were included in the sample. This excluded the views and experiences of the broader spectrum of extended relatives.

The findings of the study, therefore, cannot be generalised to the whole province or to other areas of the country. Nevertheless, the model could be used elsewhere.

7.4 RECOMMENDATIONS

Based on the findings of the study, the researcher makes the following recommendations for psychiatric nursing practice, nursing education, and nursing management/administration, and further research.

7.4.1 Nursing practice

The model of empowerment of families with mentally handicapped children should be implemented in psychiatric wards, occupational health settings, health centres and psychiatric community clinics to encourage psychiatric nurses and psychiatric nursing students to work together with the families of mentally handicapped children. They should identify the needs of the children, plan how the needs could be met, mobilise resources to meet the needs, and monitor and evaluate whether the actions/nursing care, treatment and rehabilitation rendered is successful or not. If not successful, the needs of families with mentally handicapped children should be re-assessed and the process started again.

The model for empowerment of families of mentally handicapped children should be taught to the community where mentally handicapped children live, in the forms of workshops, health education days, fun days, and community mental handicap awareness days in order to remove the stigma of mental handicap. The community would eventually internalise the concept of mental handicap and be motivated to form family support groups for caring for, treating and rehabilitating mentally handicapped children.

The implementation of the model for empowerment of families with mentally handicapped children should be integrated into primary health care (PHC) services to improve the mental health care of children. Through the family empowerment model PHC nurses, as the first contact health professional for health care, would train home-based carers to have knowledge and skills at their level to assist in assessing mentally handicapped children from birth up to school-going age. The care, treatment, and rehabilitation would therefore be planned according to the identified needs, resources mobilised, information given, and support rendered, monitored and evaluated for self-efficacy achieved.

7.4.2 Nursing education

The nursing education directorate should promote the model by means of conferences, in-service education, presentation at symposia, refresher courses, and short courses for registered nurses who work in the nursing units, particularly those caring for the mentally handicapped children, and psychiatric nursing services.

Psychiatric nursing tutors at colleges should undergo training sessions on the model so that they can teach the psychiatric nursing students the scientific approach of caring for and empowering families with mentally handicapped children. Tutors should also apply the model when they do accompaniment of psychiatric nursing students in the clinics and community setting and teach them to care for, treat and rehabilitate families with mentally handicapped children successfully.

Planners of psychiatric nursing education programmes should also be capacitated in this model for empowerment of families with mentally handicapped children so that psychiatric nursing education programmes should be included in the psychiatric nursing

education curriculum for the comprehensive four-year course and the Bachelor's degree for basic nursing students.

It is recommended that community-based education (CBE) and problem-based education (PBE) be strengthened in basic psychiatric nursing curricula to enable psychiatric nursing students to identify the needs or create awareness of needs of families, plan for their care, mobilise resources, give them information and support them, and evaluate the care, treatment and rehabilitation offered to the mentally handicapped children. The efforts would improve the implementation of CBE and OBE (Maree & Fraser 2008:144).

It is recommended that community psychiatric nursing students utilise case studies from the model during execution of family studies and home visits for greater understanding and in-depth study of the families. In addition, they should explore family needs in order to equip them with relevant information and knowledge of resources and support.

7.4.3 Nursing administration

The model of empowerment of families with mentally handicapped children should be presented as part of the in-service education programmes to psychiatric nursing department staff, including community psychiatric services. The model should also be utilised when planning for community psychiatric services.

It is further recommended that the empowerment model be implemented at all levels, including national level, to facilitate empowerment of families with mentally handicapped children in all the provinces.

7.4.4 Nursing research

It is recommended that further research be conducted on the following topics:

- The attitude of the Moletši community towards mental handicap to enable mental health workers to determine the community perception of mental handicap and provide relevant assistance and health education to the community.

- Mental health professionals' attitude towards and knowledge of the care, treatment and rehabilitation of mentally handicapped children.
- The role of medical practitioners, nurses, social workers and other health care professionals in supporting families of mentally handicapped children.
- The implementation of the model with urban families with mentally handicapped children.
- The challenges of rural and urban families with mentally handicapped children, and the type of empowerment strategies required to remedy the situation.

7.5 CONCLUSION

This chapter concluded the study, presented the researcher's conclusions, discussed the limitations, and made recommendations for nursing practice, education and administration, and for further research.

ANNEXURE A

Request for permission to conduct the study

Permission obtained from the Department of Health and Social Development to conduct the study

Permission obtained from Unisa, Research and Ethics Committee (Clearance Certificate) to conduct the study

ANNEXURE B

Request for consent to conduct the study

ANNEXURE C

Request for assistance in a research

ANNEXURE D

Evaluation tool for psychiatric nurses who took part in empowerment of families with mentally handicapped children and evaluation of the family members after the implementation of the empowerment model

ANNEXURE E

**Family and mental health assessment,
interviews and summaries of case studies**

ANNEXURE A

PO Box 5461
Polokwane North
0750

The Director
Department of Health and Social Welfare
Limpopo Province

Sir/Madam

REQUEST FOR PERMISSION TO CONDUCT THE STUDY

As a post-graduate student at the University of South Africa I have been developing a model for empowerment of families with mentally handicapped children in the Moletši district(Limpopo province) as part of the requirement for acquiring Doctor of Philosophy in Nursing (D LITT et PHIL). To attain this goal I need to identify families that will be part of this research. Families will be requested to provide information to the researcher during interviews to ascertain the effectiveness of this model. The study will be conducted under the supervision and guidance of Prof M Mavundla of the Department of Health Studies, UNISA.

The participants from these families will be given informed consent and they have the right to withdraw their participation at any time during the research project.

The model will be used by health professionals in Moletši district province, South Africa and worldwide.

Your positive response will be highly appreciated.

Yours faithfully

JERMINA CHUENE KGOLE

ANNEXURE B

PO Box 5461
Polokwane North
0750

Sir/Madam

REQUEST FOR CONSENT TO CONDUCT THE STUDY

As a post-graduate student at the University of South Africa I have been developing a model for empowerment of families with mentally handicapped children in the Moletši district (Limpopo province) as part of the requirement for acquiring Doctor of Philosophy in Nursing (D LITT et PHIL). To attain the goal I request you to provide me with information to ascertain the effectiveness of the model. The research will be conducted under the supervision and guidance of Prof M Mavundla of the Department of Health Studies, at the University of South Africa.

Should you be in agreement with the request, I would like to request from you, to take part in interviews and discussions of empowerment with regard to your mentally handicapped child.

Confidentiality and anonymity will be strictly maintained. You have the right to withdraw your participation at any time during the research project.

Your positive participation will be highly appreciated.

Yours faithfully

JERMINA CHUENE KGOLE

ANNEXURE C

PO Box 5461
Polokwane North
0750
02 February 2007

Dear Research Assistant

REQUEST FOR ASSISTANCE IN A RESEARCH STUDY

As a post-graduate student at the University of South Africa I have been developing a model for the empowerment of families with mentally handicapped children in the Moletši district (Limpopo province) as part of the requirement for acquiring a Doctor of Philosophy in Nursing (D LITT et PHIL). To attain the goal I request you to assist me with the identification of a family who will participate in the research study. You will assist me in obtaining the information to ascertain the effectiveness of the model. The research will be conducted under the supervision and guidance of Prof M Mavundla of the Department of Health Studies, at the University of South Africa.

Should you be in agreement with the request, I would like to request from you, to take part in interviews on family empowerment with regard to their mentally handicapped child. The interviews will take approximately 45 to 60 minutes duration which will be audio taped for verification of findings by an independent coder who is an expert in qualitative research. Confidentiality will be ensured by erasure of audio taped material on completion of transcription of the tapes, and anonymity will be strictly maintained by omitting the use of names.

Your positive participation will be highly appreciated.

Yours faithfully

JERMINA CHUENE KGOLE

CELL: 0822005268
TEL: 0152290273 (HOME)
0152682841 (WORK)
E-mail: kgolej@ul.ac.za

Signature of participants

----- /----- /-----
Date

Professor TR Mavundla

----- /----- /-----
Date

ANNEXURE D

**EVALUATION TOOL FOR PSYCHIATRIC NURSES WHO TOOK PART IN
EMPOWERMENT OF FAMILIES OF MENTALLY HANDICAPPED CHILDREN**

How did you find the model? Did you find the model clear?

How many times did you see and discussed with the family?

Describe the position of the family during the first visit

Describe the position of the family during the second visit

Discuss your findings/observations you recognised during the last visit

Was there any improvement in the care, treatment and rehabilitation of the child?

Were the family members confident in caring for their mentally handicapped child?

Have the family member reached autonomy and self-efficacy? What are the indicators?

SIGNATURE:-----

DATE:-----

EVALUATION OF THE FAMILY MEMBERS AFTER THE IMPLEMENTATION OF THE EMPOWERMENT MODEL

Did the mental health professionals at the clinic and the researcher explain the purpose of the mode/discussion/identify the needs of your mentally handicapped child with you

YES/NO

Did the mental health professionals establish a relationship of trust, sharing, understanding, honesty, openness and acceptance with the family members?

YES/NO

Did the mental health professionals identify your physical, social, psychological, cultural, religious and academic needs of your mentally handicapped child?

YES/NO

Did the mental health professionals involve in the plan of action and were the outcome of the plan identified?

YES/NO

Was the plan based on physical, social, psychological, cultural, religious and academic needs of the mentally handicapped children?

YES/NO

Were you and other family members, including the mentally handicapped child referred to physical, social, psychological, cultural, religious and academic resources?

YES/NO

Were the all family members equipped with information on the concept mental handicap, causes, clinical manifestations, care, treatment and rehabilitation of the mentally handicapped children?

YES/NO

Were the family members capacitated on leadership, assertive, decision making, communication and decision making skills?

YES/NO

Were neighbours, friends, relatives, church members and other community members encouraged to support/assist you? YES/NO

Were your mentally handicapped child referred to family training resources and ombudsman YES/NO

Were the family members involved in awareness campaigns on mental handicap? YES/NO

Were the family members capacitated on how to teach their mentally handicapped children the following skills:

Self-management YES/NO

Socialisation YES/NO

Occupational functioning YES/NO

Use of leisure time YES/NO

Were the family members referred to family therapy for solution of problems? YES/NO

Were the family members capacitated on the right of the mentally handicapped children? YES/NO

Has your child improved from the pre-morbid status? YES/NO

Can you care, treat and train your child independently and efficiently? YES/NO

Have all family members improved in the care, treatment and rehabilitation of your child? YES/NO

SIGNATURE:-----

DATE:-----

ANNEXURE D

FIELDWORK FOR EMPOWERMENT OF FAMILIES WITH MENTALLY HANDICAPPED CHILDREN

NB: Situational analysis done

I did situational analysis in the clinic to assess if they have psychiatric nurses, unfortunately in some clinics that I wanted to group, there is shortage of staff and it became impossible to group five psychiatric nurses at the same time, but at least I could try two psychiatric nurses in some areas where clinics are not far from one another

ORIENTATION

- Make an appointment (date and time) with the psychiatric nurse who is going to assist in the study, as to when we can meet.
- Give the psychiatric nurse the letter of request to participate in the research study to read and if she agrees psychiatric nurse should sign to prove that she or he agreed to participate.
- Assure her of the confidentiality that will be maintained.
- Give the psychiatric nurse at the clinic the clearance letter from the university and the letter of permission from the department of health and social development to prove that permission has been granted.
- Orientate the clinic nurse who is chosen to assist with the application of the model, give her a clear copy of the model (coloured), explain the model in details, give the goal of the model.
- Go through all the phase of the model(teach the nurse the model) to make sure that she understand the model, that is, awareness of the needs, plan for the needs, mobilization of resources, monitoring and evaluation and efficacy
- Ask the psychiatric nurse to respond to the model and to comment and make some additions where necessary
- Check the schedule of the clinic, for example, intake days to avoid overcrowding, adjustment of the programme may become necessary
- Check the availability of time, for an example I will take 3 hours to explain the model to the sister who is going to take part in the study
- I will check if it becomes necessary to prepare the equipment, for an example, I will be having a tape recorder, pen pencil, note book for recording the interviews

- I will have somebody to accompany me to take notes who will act as a scribe

CASE STUDY –start with a pilot study

- The family members of the mentally handicapped children should go through orientation, given letters clearance letters from the university and department of health and national development and they should be given their letters to ask for permission to participate in the research.
- Family members to be given the model, explanation given to them (the description), the outcome of the model and show them how it is going to assist them in the care, treatment and rehabilitation of their children.
- Explain your expectations, that their favourable concentration is important and that they should participate throughout the phases of the model.
- The letter to ask for permission from participants should be given to the family, families should go through it, ask questions and sign to prove that they agree to take part in the field work.
- Ask family to respond and sign if they are satisfied.
- Arrange for token economy to encourage the families and the psychiatric nurse
- The psychiatric nurse should help the researcher to get as much information from the families.
- Keep the audiotape in a safe place throughout the research study.
- Case study design consists of the following steps:
 - Determine the outcome of the purpose of the case study
 - Identify the unit of analysis, which is the family
 - Determine how data sources will be selected
 - Specify the data collection plans and methods
 - Collect, analyse and interpret data
 - Write a report of findings
 - Suggest directions for further research, on the basis of these findings (Kate & Lacey 2006:143)

- The case study consists of three phases, namely:
 - assembling raw case data
 - constructing case record
 - writing of a case study narrative

- The psychiatric nurse at the clinic will continue with formative work and the researcher will do summative evaluation at the end of the research before analysis of information.

- Analyse data by using Tesch method of analysis and compile results/recording.

- Evaluate the effectiveness of the model/ that is, the researcher, the psychiatric nurse, and the family of mentally handicapped children.

ANNEXURE E

ASSESSMENT TOOL FOR THE MENTALLY HANDICAPPED CHILD

Please participate in the following assessment guide/structured interview and give the entire, honest information as asked. This information is needed to determine the needs that your mentally handicapped child has in order for the mental health professionals to empower you, the entire family accordingly, that is, to care, treat and rehabilitate the mentally handicapped children. The assessment guide will give the answers that the researcher is looking for in order to empower you to care, treat and rehabilitate your mentally handicapped child.

1. IDENTIFICATION

Surname *Ngoasheng*

Names of the patient *S*

Sex *Male*

Age *14 years of age*

Language *Northern Sotho*

Religion *International Apostolic church*

Nationality *Black*

Registration number

Diagnosis

Mental handicap (DOWN SYNDROME diagnosed by psychiatrist at Polokwane hospital)

Date of admission

Was never admitted in hospital. He last slept at the hospital after birth

2. THE BIRTH HISTORY

Labour

Normal labour in Polokwane hospital

Delivery

Normal delivery in Polokwane hospital

Forceps

Nil – normal vertex delivery

Caesarean section

N/A

Birth weight

Three(3) kg

3. EARLY DEVELOPMENT LIKE

Feeding

Normal but used to vomit after taking meals. he still vomits sometimes

Sleeping

Always restless during the night

Crying

Was always crying and restless

Restlessness/ irritability

Restlessness was the order of the day, especially when asleep and the baby was always irritable

Role of the parent

The parent was baby-sitting the baby as he was restless and irritable and always crying

Level of mental handicap

The baby was classified by the psychiatrist as severe mental handicap in his early months of life because the child could not manage the self-help skills well

4. MILESTONES

Motor activity like

Muscle tone was weak sluggish, but restless all the times

Sitting

Never sat down like other children, was falling at all times, actually he was unable to sit down

Crawling

Never crawled normally, he used to make backward movements

Standing

Was never able to stand still, but learnt to stand with objects like beds, walls and chairs at the age of two (2) years and half

Walking

Walked by means of chairs at the age of three years

Relationship with other family members

The mother was very overprotective and was always having her baby in her arms and the child seemed to know family members because he always laughed with them

5. LANGUAGE

Babbling

Babbled a lot during childhood and had problems in talking

Constructing sentences

Had it difficult to construct a sentence, and in fact, was never able to write sentences.

Comprehending

The child was very slow to comprehend. Could understand too little information

6. BLADDER / BOWEL CONTROL

Day

During the day the child seemed to have frequency of micturition, but improved as he grew older

Night

Bladder control was very poor and the child used to have bed wetting but has now overgrown it

7. PHYSICAL HEALTH

Illness

None specific was reported by the family except the problem of the back muscles. The mother mentioned that the back muscles are weak and S gets tired easily.

Operation

Never had any operation as a child

Injury

Was injured on the shoulder by the other boys in the street who seemed to be abusive. S was taken to Moletši clinic, where he was cleaned, dressed and given medication.

Hospitalisation

Was never hospitalized since he left the hospital after he was delivered

8. SEPARATION DURING CHILDHOOD

Age of child

At five (5) years the mother had to work and cooked at school to earn some living from Monday to Friday every week. The child was staying with his sister, who also had a small baby, before she became married.

Length of separation

Separation was only for six (6) hours a day.

Nature of alternative care

The sister was caring for the child well before she stayed with the in-laws though the mother said S was problematic, crying very hard

Reaction of the child

She was always angry if the breast was not there

9. SCHOOL HISTORY

Schools attended by child and reasons for leaving the school

The mother said that S started attending school in a normal school. He had no progress, could not write, he was always playing when the other children were writing, always fugitive, making noise and showing some temper tantrums. He was referred to Grace and Hope school for the mentally handicapped and he could not get any space. He was taken to Moletši centre for the mentally handicapped children, which is a voluntary centre.

Scholastic ability

S was very poor at school He could only draw a line, instead of writing his name

Adjustment

Very poor adjustment to school environment. Adjusted after a long time, but later started dancing and singing.

Conduct

Poor conduct towards the school. Fond of damaging school property.

Reports from school

Reports from school were very poor. He could not write his name, but just wrote a line. S is still drawing a line instead of writing his name at Moletši centre for the mentally handicapped children. He does homework better with. plastic work. He likes making articles with plastic.

10. BEHAVIOURAL PROBLEMS

Temper tantrums

S has a lot of temper tantrums. If his mother can discipline him he goes outside the yard and cry at the back of the yard for a long time.

Personality as a child

He was always happy but does not want to be shouted at, he can become aggressive

11. LATER CHILDHOOD

Social relationship

S's social relationship is fair, though he likes playing all the time and also troublesome because he is fond of disturbing other children. He is always happy and dancing.

Physical and emotional problems

Weakness of the back is a problem as he gets tired very easily. He also has temper tantrums, especially when disciplined at home . He goes to the back of the yard.

Psychosexual history

Can relate and play well with the opposite sex but cries easily

12. ACTIVITIES OF DAILY LIVING

Self-management

S cannot eat very well, may vomit sometimes, but can use the toilet with supervision. He can wash himself but not very well.

Socialisation skills

Socialisation is easy to teach but S does not concentrate . All the visitors love him. Visitors believe that he is the best patient to deal with because he is always happy and easy to deal with.

Occupational functioning

She concentrates a little bit with plastic work when he makes mats but always leave them half-way

Use of leisure time

Always happy and every time is leisure to him All the visitors are seen by him first and he jumps to greet first

Involvement of the family in activities

The family is highly involved because the mother believes the child will become a teacher one day. The sisters and brother play with the child at all times.

13. PHYSICAL EXAMINATION

Physical dimension: Personal appearance tidy/untidy others

S is always untidy because he is figitive and restless and play with dirt a lot

Eating habits: appetite/vomiting others

Appetite good, does not eat well and but vomits sometimes

Sleeping pattern: nightmare/ insomnia others

Insomnia and restlessness especially at night

Epileptic seizures

None observed

Gross motor: behavoiura/shippling/normal/rigid and others

Can walk but gets tired easily and sleeps due to weak muscles at the back.

Fine motor: controlled/stroke/tremors/figiting others

There are times when tremors are observed, especially when restless, cannot control his motor muscles and is very figitive

Speech quality: normal/talking/others

Was never clear from childhood and even now the child has speech problems

Emotion: normal/elevated/depressed others

Emotions are always high especially when disciplined, he walks always not speaking to anybody

Consciousness: alert/drowsy/stuperous others

Alert for a short period and then becomes drowsy and weak easily

Attention: good/fair/poor others

Very poor attention span does not concentrate when he is taught a skill

14. GENERAL COMMENTS

Generally the child has a very poor attention span He has problems with concentration he is not yet *able to write his name. He just draws a line.* He gets tired easily and sits down. *The child will be taken back to the doctor to suggest some therapies and for lack of concentration. Otherwise he is very good in drawing and painting pictures, but cannot use plastic for other articles.*

Assessed by -----

Signature-----

Rank -----

Date: *2008.02.20*-----

ANNEXURE E

FAMILY ASSESSMENT TOOL 1

FAMILY HEALTH ASSESSMENT TOOL MODIFIED FROM SPRADLEY (1997:449).

Please participate in the following assessment guide/structured interview and give the entire, honest information as asked. This information is needed to determine the needs that you have in order for the mental health professionals to empower you, the entire family accordingly, that is, to care, treat and rehabilitate the mentally handicapped children. The assessment guide will give the answers that the researcher is looking for in order to empower you to care, treat and rehabilitate your mentally handicapped child and eventually gain independence and self-efficacy.

1. IDENTIFYING DATA

Family name

Ngoasheng family

Address and phone

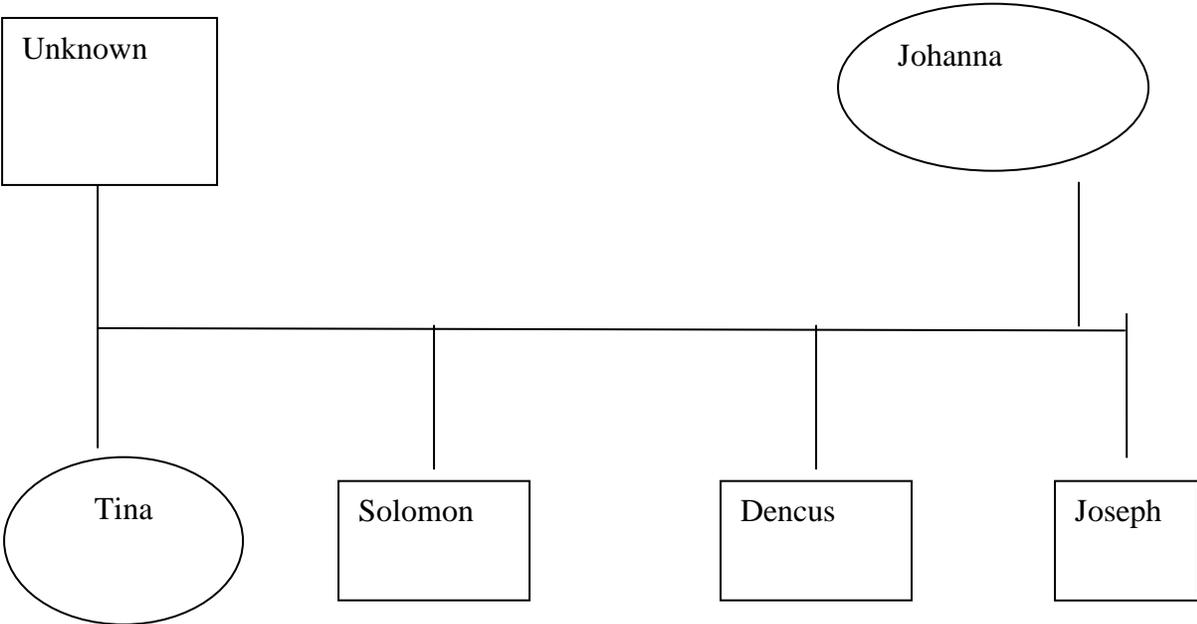
Mabokelele Village

Private Bag 14

P.O Koloti

0709

Family composition (genogram)



Type of family form

S's family is a single parent family, his mother was never married

Cultural background

The family of S is Northern Sotho culture, they originally come from ga-Mothiba. At ga-Mothiba Ngoasheng family was living a traditional life and survived on traditional medicine for medication.

Religious identification

The religion that Ngoasheng family belong to is International Pentacostal Church of Christ (IPCC) church and they call themselves "Bana ba ntate"

Social class status

From the researcher and the psychiatric nurse from the clinic point of view they observed Ngoasheng family to belongs to the lowest class in the village, they live below the poverty datum line and struggle to acquire the simplest form of food.

2. FAMILY RECREATIONAL AND OR LEISURE TIME ACTIVITIES

The family's recreational activities consists of music and dances they engage in at the International Pentacostal Church on Saturday night during the service. The family spends their leisure time either sleeping at home, singing with the other brothers and sisters, and visiting their relatives who stay at ga-Mothiba.

3. DEVELOPMENTAL STAGE OF HISTORY OF THE FAMILY

Family present developmental stage

The family is in a child-bearing and child-rearing stage and the children are still very young and need to stay with somebody older whilst their mother is out, looking for work.

Family history

J was born at ga-Mothiba of three brothers and she was the third born child. Her mother died in 1985 and her father in 1988.

J's family said that they originated from ga-Mothiba and migrated to Moletši 25 years ago. *S's mother was never married, but there was a man who promised to marry her but failed because the parents to the man who fathered J's children rejected her. Ngoasheng family then migrated to Moletši to stay with another man, who also rejected her.*

Environmental data

- *The researcher and the psychiatric nurse from the clinic observed the house to be a three-roomed, unhygienic, dimly-lit very small house built by J, Solomon's mother. One room is very small and the bed cannot fit, the other room is dark and small. Staying with the children in such a small house is not healthy. They need a bigger space. There are no facilities for*

Toilet

laundry

garbage disposal

proper ventilation

lighting

furnishings and

heating.

- *The house is situated in a noisy area and the home environment is not very clean. Solomon's street has many troublesome children that make a lot of noise because Solomon's family seem to be interesting to them.*

Characteristics of neighbourhood and larger community

S's neighbours are having standard house and furnishings, their dwellings are comfortable. The street consists of older people than S's mother and few of them are said to be very supportive. The supportive neighbours usually offer food to S's family if their mother is not around. The entire

community knows Solomon's mother very well and they involve S and his family members in community activities like community parties. The crime rate is high in the neighbourhood and children are not safe in S's street. The clinic is available in the neighbourhood and it is accessible. A primary school, International Pentacostal church and Moletši centre for the mentally handicapped children are situated about 1kilometre away.

Demographic of characteristics from the community availability and accessibility of health and other basic services and facilities

Family geographic mobility

J's family has lived in Moletši area for 25 years. The family moved from ga-Mothiba and migrated to build in Moletši area.

Family's association and transaction with the community

Family social support network

The support system that the Ngoasheng people has is the church people because they visit the family, give them food when needed, take S out for an excursion or entertainment. Another support that the family gets is financial security through the social worker. They also get support from their induna who usually checks them to find out what their problems are.

Family coping pattern

From the researcher and the psychiatric nurse's points of view, the family has very poor coping patterns because when they meet the stressor they cry and the whole community will know the stressors and assist them. There was a day when one of S's sister was very ill and the mother was not around and the children had no money, but one community member volunteered to take the child to the hospital for free.

Family health behaviour

Ngoasheng family is a very religious family and they believe in getting help from their church. When one family member is sick the first consultant is the priest, the mothers union and they will pray for them and advice them to go to the hospital or clinic, where the family will get professional help with the care, treatment and rehabilitation of their mentally handicapped children.

Family cognitive development/knowledge

Knowledge of mental handicap.

Ngoasheng family members said they have a slight knowledge about mental handicap, the causes thereof, how it manifests itself, the care, treatment and rehabilitation of the mentally handicapped children.

The family does not have knowledge of the training of mentally handicapped children and the health services available for the mentally handicapped children.

Family structure

Family composition

The family consists of six members. Solomon Ngoasheng was born from a single parent family. The mother, who seems to have mental problems is the one who takes care of the family. She was never married, but has a boyfriend who has mental problems, just like Solomon. The researcher found the mother with six children, a girl of 34 years, two boys of eight and four years of age and a grand child of four years. The 34year old girl is married and the mother is not happy about the marriage because the mother says they fight several times because the lady is not clean and cannot cook well.

Access to health services

The family has the nearest clinic, which is about five kilometers from where the family stays. The clinic is easily accessible should they have health problems. The doctor comes bimonthly to the clinic for problematic and referred patients. The physiotherapist and occupational therapy come monthly for referred patients. The hospital is about 30 kilometers from where the patient stays, where they go for medical services.

Communication pattern

On observation the family members seem to be communicating openly and they are very close to one another and the mother says she loves all her children, especially the mentally handicapped boy. In the evenings the family members share all the problems they encountered in the community during the day (Spradley 1997:338).

Functional or dysfunctional-

The family is observed to be dysfunctional because in a functional family all members do all their expected roles without fail. In Ngoasheng's family there is mental handicap, the mother is not working and she seems to have one form of mental illness, so the mother does not mentally handicapped child absolute attention. The sister who is married does not seem to be doing her duty of supporting her family members.

Power struggle

Decision making process

Ngoasheng family is a single parent's family and their mother, J is the one who makes decision for almost everything in the family, be it household matters, childrearing, problems of health care and even in case of a crisis. The children are still very small and the eldest girl is not staying with them, so she just tells the children whatever should be done. Otherwise the people who may try to make decisions for the family is the members of the International Pentacostal church only.

Role power

Informal role structure

The mother is responsible is responsible for rearing, protecting, caring, treating and rehabilitating the mentally handicapped child

Family values

The family values the church very much because the children act like their mother, they also like going to church. The family also value education and health of the children, because she always take them to the clinic when they have minor ailments.

Affective function

There is a close relationship between mother and children. They are so close that they are always together, laughing and singing together.

Socialisation function

The mother says she is responsible for socializing the children to live well together. She taught the children how to greet, how to say "thank you" when they are given something.

Health care function

Ngoasheng family is responsible for taking children to the clinic and hospital in case they become sick. They also go to the clinic to seek for help with regard to the care, treatment and rehabilitation of their mentally handicapped child. The family view illness as an enemy that can steal one member of their family. The family, especially the mother wish her family to be healthy at all times. Health means that the child does not cough, has no high temperature, eyes are normal and the child does not suffer from stomachache.

Self-care requisites of family members

The family does not have enough food in the house. The mother said that S is getting a disability grant and two other children are getting children’s grants but the money is too little to support all the four members of the family.

They do not have toilet facilities, no facility for garbage disposal, no proper ventilation due to the small house, but have enough water and the family has enough time for rest and sleep during the day.

Family stresses and problems

Family stresses include the lack of enough food, small house, abuse by some children in the community.

Family resources

Family resources include International Pentacostal church members, who are very supportive to the family, Moletši clinic, some neighbours, other churches, Moletši inter-denomination women’s league and the community as a whole. .

Assessment done by-----
Time-----
Date-----
Signature-----

ANNEXURE E

INTERVIEW 1

Speaker	Communicated experiences	Non-verbal
Interviewer:	Good morning Miss Ngoasheng and how do you do this morning?	
Interviewee:	Good morning madam, I am fine and I am happy that you came to see me.	
Interviewer	Miss Ngoasheng, will you please relate all types of empowerment/ assistance/ support that you received since the birth of your mentally handicapped from birth up to date.....Ok... be free to relate all you experiences, so that we can both identify the loopholes and plan something	
Interviewee:	Ok... since the child was born, I suffered a lot mummy and there was nobody at Ga-Mothiba who cared for me, even the father of the very mentally handicapped child. This child was born very well, his muscles were not very strong and they were floppy. After delivery I told the nurse this child of mine is not like other children. I went home not being satisfied with child.	
Interviewer:	Hm...What did you do with the child?	Started crying bitterly saying "I am very unlucky, and I touched her back to comfort her
Interviewee	The child remained weak at six month, she did not sit like other children, in fact the child was slow, sitted late, cold not crawl, stand late and he walked supporting himself for more than two and half years to three years, and I took my child to the hospital, where he was seen by the psychiatrist and he diagnosed the child to be mentally, handicapped with features of Down syndrome, he said. I did not know what Down syndrome meant, I thought my child was dying. I asked the doctor what the term meant and he answered that the child is not normal and	The mother was very restless, went up and down the ward.

Speaker	Communicated experiences	Non-verbal
	<p>you need to come back for an explanation from the sisters.. I was worried because the child was restless at night and vomited after taking his meals, but the doctor was busy and did not have time for me.</p>	
Interviewer:	<p>Hm...I am very sorry about that...very sorry mummy</p>	
Interviewee:	<p>Nurse, this child gave me a lot of problems. He started attending school in the government school with no progress, could not write, he was always playing when other children were writing, always fugitive, very noisy and showing temper tantrums. I took him to the clinic, where the sister referred him to Grace and Hope school for the mentally handicapped children and he did not get any space.</p>	
Interviewer:	<p>Tell me more about the weakness of the child</p>	
Interviewee:	<p>The muscles of the back remained very weak and floppy, even now he rest after every hour, but the doctor said nothing can be done for my child, I must get used to the child.</p>	
Interviewer:	<p>Is the child getting any training in different skills like socialization, recreation, self-help skills and occupational skills?</p>	
Interviewee:	<p>Nothing at all. I wish to get all the training for my child.</p>	
Interviewer:	<p>Tell me more about the empowerment you received</p>	<p>She talked continuously as if she has pressure of talk.</p>
Interviewee	<p>I received nothing, my child cannot talk well even now, I need information on the causes of this disease so that it cannot happen to my grand children. Please nurse...help me, we do not have money to eat delicious food like other families. I need people to whom I can talk freely, who have the same problems, may be they can understand me better. Nurse, I</p>	

Speaker	Communicated experiences	Non-verbal
Interviewer:	<p>need a lot of things, look at my toilet, it is not up to standard, we live in a very small house. Oh! I wish I had a lot of money. Tell me everything that you know that can help us to make our mentally handicapped child independent.</p> <p>Thank you for now mummy you seem to have a lot of problems we will meet next week to discuss all the relevant information that you need and even start applying for R.D.P house. Goodbye for now.</p>	

ANNEXURE E

MOHAFE CASE STUDY REPORT

1. INTRODUCTION

Datta, Lois-ellin (1990:1) states that case study approach has gained a highly popular status in social work areas all over the country. It is highly utilized I evaluation research in particular, during the recent years. Case study is used extensively in evaluation research. In this study of empowerment of families with mentally handicapped the case study method will be used to evaluate whether the family empowerment model is effective in caring, treating and rehabilitating the mentally handicapped children.

2. PRE-MORBID FUNCTIONING OF THE CLINIC ON EMPOWERMENT

The professional nurses, including the psychiatric nurse, at the clinic were asked about ways in which they empowered the families with mentally handicapped children. The staff at the clinic said that they were short-staffed, catered for over eighteen villages, do not have transport to do follow-ups of their families. The clinic nurses said the families only bring their mentally handicapped children for minor ailments and at that time they get time to educate the families about their mentally handicapped children and refer children with problems to the psychiatrist in hospital, especially the children who suffer from Epilepsy.

The families were asked about the ways they used to care, treat and rehabilitate their mentally handicapped children at home so that at the end of application of the model the care, treatment and rehabilitation before empowerment and after empowerment could be compared.

3. SELECTION OF CLINICAL SETTING

The researcher selected Moletši clinic and selected Mohafe family as the fourth case study. The clinic deals with nursing practice takes place where the theoretic relationships can be observed by implementation of the theory. Moletši clinic is where Reuben got some of his immunizations up to 2 years and went for some the minor ailments.

4. IDENTIFICATION OF THE UNIT OF ANALYSIS

The unit of analysis was the Mohafe family, where Reuben Mohafe's mother delivered/ gave birth.

5. DETERMINING OUTCOMES

The purpose of the application of the model was determined and applied to the family of mentally handicapped child to find out its effectiveness (Chinn and Kramer 1995:102), to find out if after application of the model of empowerment the family became independent in the care, treatment and rehabilitation of their mentally handicapped children.

The purpose of the case study was to establish or to identify the needs, problems, weaknesses and shortcomings in Reuben's family together with the entire family, plan to meet those needs identified, mobilize resources together, put them into action together with the family and do combined evaluation to find out if the needs were met and the family are able to care, treat and rehabilitate their mentally handicapped children and have become independent and achieved self-efficacy.

Specific outcomes of the case study were to:

- Identify the needs, problems, weaknesses and shortcomings
- Formulate plan of action to meet the needs
- Mobilise and gain access to resources, support and information to meet the needs
- Evaluate and monitor the effectiveness of the plan/if needs are met
- Determine if the model was effective and self-efficacy is met, and if the process was not effective the researcher, psychiatric nurse at the clinic should restart the process again.

The plan included the people that will be involved, how they will be involved why they will be involved, when, where and to whom they would be involved in the empowerment process.

Establishment of relationship

Building of the relationship was bit difficult due to the shyness of the mother, but the researcher tried her best and gave some food parcels as incentive and the entire family started to accept the researcher. The other thing that made the mother to open up was the presence of the clinic psychiatric nurse, who had established relationship in the clinic as the mother went to the clinic for

minor ailments. The researcher started to greet the mother together with the children, who gave a positive response. The family was not very jolly all the time, so, building a relationship was very difficult, until incentives were given and the clinic psychiatric nurse visited him regularly. The researcher was simple, used simple Northern Sotho language that could be easily understood and this language was preferred by members of the family. The researcher became approachable and respected the family by calling their real names and rapport was established. The researcher was open, the relationship became a sharing relationship, so that the family could be able to be aware of their needs and the researcher would also be able to identify the needs for the family with mentally handicapped children. The relationship of the model is a power-sharing relationship, so the researcher, together with the psychiatric nurse at the clinic displayed a relationship of sharing, mutual sharing and respected the family of mentally handicapped children.

The objective of the meeting was explained to the family members, that, I was going to needs with them being actively involved in identifying their needs. The researcher accepted the family and encouraged them to express their views with regard to their needs because they are the ones that need assistance or help.

The environment that the researcher created was enabling, was listening carefully, showed sympathy from his face and was communicating very well with the family of the mentally handicapped children. The family of the mentally handicapped child was encouraged to be free and participate in the identification of problems.

6. PREPARATION AND TRAINING FOR THE CASE STUDY

Yin (2003:57) stressed that good preparation of case study should start with the desired skills such as good listening, adaptiveness and flexibility, grasping of the issues being studied and lack of bias.

The family

The researcher and the psychiatric nurse at the clinic had already established the best possible interpersonal relationship with the family members in order to neutralize the mistrust that might have prevailed. Letters of permission from the Department of Health and Social development and the clearance letter from the University of South Africa Ethics committee were shown to the participant as a proof that I have the permission to conduct research. A letter for requisition of permission to take part in the research study was given to the family and they were told who the researcher was, where the researcher came from, which study she was following, the purpose of

the study, that the confidentiality of the interaction would be kept anonymous and confidential, that they were not chosen for harassment but because a small portion of the population is needed for this research, and that the researcher wished to apply the model to find out if it can be effective to the care, treatment and rehabilitation of their mentally handicapped children. The family was informed about the audiotape that would be used during the discussion. The family members were put at ease to enable them to express their honest and deep-seated anxieties (Mouton and Marais 1995:93). Their expectations were explained to them, that they need to be interviewed in a case study to start the process of empowerment model for families of mentally handicapped children. The family members were encouraged to talk and ask some aspects that were not clear to them. The family members read the letter and signed as proof that they agree to take part in the application of the empowerment model

Appointments were scheduled as to when interview can be started and subsequent appointments were scheduled in order to go through the process of the model. They were promised incentives in the form of food packages as a token of appreciation.

The psychiatric nurses at the clinic

The researcher went to Moletši clinic to make an appointment with the psychiatric nurse. The researcher and the psychiatric nurse agreed on the date and time for the orientation and training to apply the model of empowerment model. The psychiatric nurse agreed to meet on Friday afternoon when there are few patients at the clinic and the clinic was not busy.

Letters of permission from the Department of Health and Social development and clearance letter from the University of South Africa Ethics committee were given to the psychiatric nurse at clinic in order to prove that I have the permission to conduct research.

A letter for requisition to assist in the research study was given to the psychiatric nurse, which request the psychiatric nurse to be involved in the awareness of the needs, formulation of plan, mobilisation of resources, monitoring and evaluation to find out if the model is effective and yielded independence and self-efficacy. The psychiatric nurse at the clinic was given a copy of the model that was enlarged, clear and coloured to make it easy to understand. The psychiatric nurse was taught about the model, the purpose, the context, the phases, the structure and that it was going to be applied to the families of mentally handicapped children to find out its effectiveness to bring independence and self-efficacy to the families of mentally handicapped. The psychiatric nurse at the clinic was also told about the audiotape that would be utilized for recording and be transcribed.

The psychiatric nurse at the clinic was allowed to make any additions and suggestions for the model. The psychiatric nurse was a given token in the form of tea and sometimes cool drinks as a token of appreciation.

Family composition

The family consists of seven members. Reuben was born from a nuclear family, that is, the mother, father who is working in Johannesburg, the mother who is a mistress at home and five children, four boys, aged 30, 27, 22 and 16 years, and one girl, who is 33 years of age. The first boy and a girl are gainfully employed as labourers. The mentally handicapped child, Reuben is the last born

Access to health services

The family have the nearest clinic, which is about six kilometers from where the family stays. The clinic is easily accessible should they have health problems. The doctor comes bimonthly to the clinic for problematic and referred patients. The physiotherapist and occupational therapy come monthly for referred patients. The hospital is about 30 kilometers from where the patient stays, where they go for medical services.

7. CHALLENGES/PROBLEMS IDENTIFIED FROM FAMILY IF MENTALLY HANDICAPPED CHILD- SOLOMON NGOASHENG

Accommodation

Mohafe family are living in a big face bricked house. The house has a seven rooms, well furnished, well ventilated, good lighting but the only have a problem with sewerage disposal and do not have proper toilet facilities.

Diet

The food is sufficient for the family because they always buy enough food for the family and the father brings enough grocery from Johannesburg. The total monthly income for the family amounts to R21 000,00 plus the social security of R940,

Food is in abundance in that family but not well prepared, for an example, vegetables need to be included in their menus, and the food that they eat is not well balanced. The family seems not to

have knowledge of preparation and cooking of meals. The mother is a mistress, it will not be difficult to guide and educate on preparation, cooking and serving of meals.

Abuse

The mentally handicapped child gets beaten by small boys in the street while and ridiculed. Moletši community has that problem of ridiculing other children if they discover the child has a questionable behaviour. The child became the centre of attraction for the children in the street. This problem worries the mother very much because the child keeps quite sometimes with wounds all over the body. The child has the right for protection, it is the right of mentally handicapped children

Support

The family need to know other families with the same condition in order to discuss common problems of their children and assist one another with the type of care, treatment and rehabilitation that should be given to their mentally handicapped children. They need friends who have the same children in their families, that, is, they need mutual support/ parents groups. The mother, being the chief carer of the mentally handicapped child wanted to know some parents with mentally handicapped children, telephone numbers and their addresses.

Academic development

Reuben, like other children was taken by the family to the normal school, but was removed because he was discovered to have sub-average intelligence and had problems in understanding the content that is to children of his age group. The mother was advised by the visiting school nurses to take the child to Moletši clinic and the child was then referred to Grace and Hope school for the mentally handicapped children after thorough examination by the social worker at the clinic but the child could not get any space and was put on the waiting list. He was taken to Grace and Hope two years later. It is hoped that at the school for mentally handicapped children he will grow academically (Patton 1990:388).

Limping

The mother she observed that the child limping since he learned how to walk. The left leg seems to be shorter than the right leg. The limping was not worrying the mother, The mother took it to be normal because the child was not feeling any pain.

Lack of knowledge on mental handicap

Both the mother, father and the siblings as well as the sisters to the mother who are good and helpful supporters, seemed to lack knowledge about mental handicap, causes, clinical manifestations, care, treatment and rehabilitation of mental handicap. This was evident when the mother was shocked when the sister at the clinic said that the child was a mongol and by the fact that the mother searched for the cause of the illness from different health professionals, churches and traditional healers.

Lack of financial security

The child has the right to financial security in the form of monthly grant for purchasing the basic needs of the mentally handicapped child. This money would assist in buying of food, clothes, paying for transport to the school for mentally handicapped child and paying for whatever fee at the school for mentally handicapped children.

Lack of proper sewerage disposal

The family does not have proper toilet facilities and this is very crucial for the health of the family to prevent infections

8. FORMULATION OF PLAN OF ACTION

The psychiatric nurse at the clinic, the researcher and Ruben's family wrote down all the problems and joined hands to formulate the plan of action. The plan should include the what, who, why, the where, the when and the whom. In this research study the plan should be formulated by the family of the mentally handicapped children, the researcher and the psychiatric nurse at the clinic. According to the model it should be a power-sharing process.

The plan should entail the objectives, the mental health professionals and the family members, methods of monitoring and evaluation of the empowerment process. The plan should depend on the needs that were identified by the mental health professionals and the family members. The plan needs to be flexible if any thing can be discovered later during the case study. Like the assessment the plan should be based on the physical, social, psychological, academic, religious and cultural needs of the family of mentally handicapped children.

In this case study objectives of the plan should include the following objectives:

- To educate the family members on the origin, the causes, clinical manifestations, care, treatment and rehabilitation of the mentally handicapped children.
- To educate the family members about the rights of the mentally handicapped children according to Integrated Disability strategy.
- To involve the family of mentally handicapped in the socialization of their children
- To demonstrate to the family members on the preparation, cooking and serving of meals.
- To advise the family on the existing health services for the mentally handicapped children like the medical health services where their mentally handicapped child may be taken for the limping leg and support groups available..
- To motivate for the child, Reuben to get financial security (motente) in Northern Sotho.
- To protect the child against any type of abuse, it is the legal right of the mentally handicapped child.
- To encourage safe sewerage disposal

9. MOBILISATION AND GAINING ACCESS TO RESOURCES, SUPPORT AND INFORMATION

Information

Mental health professionals arranged health education days in collaboration with University of Limpopo nursing students on mental handicap. The nursing students staged health education days in the form of “fun day”. The students presented a drama to the community of which Reuben and his family were present. The family in the drama was very rich did not accept that their child is mentally handicapped. They abused the child until a neighbour reported the family to the nurse at the clinic. The clinic nurse visited the family and the nurse wanted to know why the child was abused and started to educate the family on the causes, how the child with mental handicap would present, the treatment and how the child could be rehabilitated. The psychiatric nurse at the clinic gave handouts, leaflets and referred the child to the social worker to motivate for social grant and eventually to the psychiatrist for medical treatment because the child had limping. The family accepted the child and loved him.

The mental health professionals educated the families of mentally handicapped children, using different teaching aids like posters, flip charts, films, radios and television, which was the most

popular teaching aids to make the subject clear to the families. Methods of teaching included lectures, demonstration, peer group teaching and counseling by other family members who have mentally handicapped children.

The family was capacitated about preparation, cooking and serving of a well balanced diet. Some interested members of the church were invited to come and assist the families and involved the children in recreational activities at the church, like singing and dancing.

The family and the neighbours were educated about mental handicap, its causes, how to recognize it and how to support the families with mentally handicapped children so that they can understand Reuben's family and be able to support them. Teach them to prepare teaching materials like printed materials, demonstration, peer presentations, field trips, computer-assisted learning, posters, booklets and peer counseling

The family were educated on the rights of the mentally handicapped children so that they should know what is right for their mentally handicapped children. The rights of the mentally handicapped children are human rights. They have the rights to be listened to, respected, educated, protected and cared for. Mentally handicapped children have the right to respect and dignity, not to be discriminated, the right to information, to participate in treatment decisions and confidentiality

Environmental hygiene was stressed, especially on the proper toilet facilities and the family was referred to the health inspector to assist them as to the type of toilet that should be built.

Resources

The families with mentally handicapped children were invited to the clinic with Reuben's family to be taught about the health services available for the mentally handicapped children and on other important services.

The families of mentally handicapped children were invited to the Department of Health and Social development by the MEC for health to attend a ceremony where the community was introduced to the Capricorn district OMBUDSMAN for psychiatric patients. It was explained to the community that Mr Mmakgolane was chosen as the Ombudsman, who would assist in the protection of the mentally ill individuals as well as the mentally handicapped children. All the complaints should be directed to him and would report them to the relevant office.

Resources for empowerment of the families of mentally handicapped included the mental health professionals at the clinic, who taught the family on causes, recognition of mental handicap, how to treat it and how the mentally handicapped children could be rehabilitated. The occupational therapist empowered the families to teach their children how to socialize with others, the occupational skills, how to manage themselves and how to use their free time. The physiotherapist assisted the families to exercise the limping leg to become strong. Social workers in the clinic took part in the empowerment of families by applying for food parcels for the families that are suffering to eat and for financial security.

On the “fun day” the nursing students hired a “jumping castle” from Polokwane town and all mentally handicapped children who were there jumped and enjoyed the day together and made friends (May 2002:248). This was one of the ways in which the researcher and the psychiatric together with the nursing socialized the mentally handicapped children. Refer and show the family the support groups in the community like families with mentally handicapped children of their type like families with Down syndrome in their families. On this day families were not falling under any support group were motivated to form parents groups

Family was referred to the psychiatrist for limping for review and perhaps doctor may order some supporting aids for the children.

Refer the family of the mentally handicapped child, Reuben to the organisations in the church to church, like the women’s league to come and pray and this will be the form of religious support.

Support

Neighbours and other families whose women are not working were grouped to assist the families with preparation, cooking and serving of meals. Reuben’ family was briefed about the help that would be given to them.

Community volunteers like community workers from the clinic were requested to visit the family and also assist in the preparation, cooking and serving of meals. This was done in collaboration with nurses from the clinic during home visits. The researcher with the psychiatric nurse from the clinic wrote a letter to the social worker to request for

A gentleman from DICAG, who visits Moletši centre twice a year arranged a workshop for the parents of mentally handicapped children and gave a series of lectures and demonstration on how

to care, treat and rehabilitate their mentally handicapped children. The families and their supporters, being relatives, friends, neighbours and interested people were also invited to the workshop. The nearby projects that support the mentally handicapped children were also invited to take part in the workshop like youth organization who work as volunteers in the Moletši clinic.

Reuben's family and other families with mentally handicapped children were invited to a session that was organized by the Department of Human rights when a group of ladies presented "human rights day" for the entire central Moletši community. The audience was allowed to ask questions on special human rights like the aged, adolescents, family of mentally handicapped and the physically handicapped. The families of mentally handicapped were given a platform to ventilate their problems and asked questions.

Moletši Inter-denomination women's league heard about the organisation from town that support their mentally handicapped children and they started another feeding scheme and Solomon's family was assisted to the full. The children got food parcel in March and the next badge will be sent in June 2008.

For socialization Moletši social workers sent different toys to all the children who are mentally handicapped in Moletši, and Reuben also got one to play at home. Reuben was grouped with the other children in church where the radio was playing cassettes and they together and Reuben socialized with them. In Reuben's church the children have trips every fourth Sunday to go out for a tour or an occasion is arranged in church in the afternoon for the children. At Dutch Reformed church, where Reuben's family attends their church service socialization of children is one of their priorities. Reuben's family were taught that Reuben, like other mentally handicapped children needs to rest for at least one and half hour during the day.

9. MONITORING AND EVALUATION

The people who need to evaluate the empowerment process to establish whether the empowerment process was successful or not include the researcher, other mental professionals, and the mental health professional who works at the clinic, the one who was taking part in the implementation of the model. The other colleagues who were observers need to evaluate the impact of the empowerment model in the care, treatment and rehabilitation of the families of the mentally handicapped children. The families of the mentally handicapped children should also evaluate the empowerment process.

Meeting

A *meeting* was held where the above mental health professionals sat together with the family of the mentally handicapped children, looked at the model and examined the objectives, (both short and long-term) of the empowerment model and determined as to whether the objectives were met or not. The objectives of the empowerment process were effective because

Discussion

The *discussion* was held between the staff that are working in that clinic, staff in the nearby clinics, the researcher, mental health professionals and people who are experts in evaluation to discuss the findings, as to whether is effective or not, that is, the family find themselves competent in the protection of their child from the abusing community members on their own.

Home visit

Solomon's family was *visited* by psychiatric nurse from the clinic and the researcher at *home* and improvement was observed in the preparation, cooking and serving of meals. Solomon's mother was not very free to be with the mental health professionals because she wanted to be alone when she prepared her meals.

Observation

The family members of the mentally handicapped children and the very children were *observed* to find out if improvement is marked or not. Indeed, there was improvement The family members were able to teach their children self-management skills for the child's own safety, It was also observed as to whether the toilet facility has been improved and they were still preparing to build it, bricks were already bought.

Interview

The families of mentally handicapped children were *interviewed* to find out whether there was any improvement and the answer was positive and the mental health professionals also observed improvement in the preparation, cooking and serving of meals The meals were prepared in a clean environment, utensils were very clean, meals were well cooked and served attractively.

During the interview it became clear that Reuben was going to get financial security/grant (motente) in the next two months.

10. AUTONOMY AND EFFICACY

It is expected that at the end of the empowerment process the family should be competent in caring, treating and rehabilitating their mentally handicapped children.

According to LSMHP (2001:5) empowered families possess the following:

- Know the rights of their mentally handicapped children
- Have the knowledge of community facilities or resources for their children
- Are able to explain how each community facilities are utilized
- Can differentiate between the right support or help from the wrong support and or assistance
- Are able to support other families who have the mentally handicapped children as they share the same problems with their children.
- Possess t6he understanding that a mentally handicapped child deserves the same dignity as all other children

ANNEXURE E

SEBATJANE REPORT

1. INTRODUCTION

Datta, Lois-ellin (1990:1) states that case study approach has gained a highly popular status in social work areas all over the country. It is highly utilized I evaluation research in particular, during the recent years. Case study is used extensively in evaluation research. In this study of empowerment of families with mentally handicapped the case study method will be used to evaluate whether the family empowerment model is effective in caring, treating and rehabilitating the mentally handicapped children.

2. PRE-MORBID FUNCTIONING OF THE CLINIC ON EMPOWERMENT

The professional nurses, including the psychiatric nurse, at the clinic were asked about ways in which they empowered the families with mentally handicapped children. The staff at the clinic said that they are short-staffed, caters for over eighteen villages, do not have transport to do follow-ups of their families. The clinic nurses said the families only bring their mentally handicapped children for minor ailments and at that time they get time to educate the families about their mentally handicapped children and refer children with problems to the psychiatrist in hospital, especially the children who suffer from Epilepsy.

The families were asked about the ways they used to care, treat and rehabilitate their mentally handicapped children at home so that at the end of application of the model the care, treatment and rehabilitation before empowerment and after empowerment could be compared.

3. SELECTION OF CLINICAL SETTING

The researcher selected Moletši clinic and selected Sebatjane family as the fourth case study. The clinic deals with nursing practice, where the theoretic relationships can be observed by implementation of the theory. Moletši clinic is where Reuben got some of his immunizations up to 2 years and went for some the minor ailments.

4. IDENTIFICATION OF THE UNIT OF ANALYSIS

The unit of analysis was the Sebatjane family, where the mother delivered/ gave birth gave birth to the mentally handicapped child, named Boy.

5. DETERMINING OUTCOMES

The purpose of the application of the model was determined and applied to the family of mentally handicapped child to find out its effectiveness (Chinn and Kramer 11995:102), to find out if after application of the model of empowerment the family became independent in the care, treatment and rehabilitation of their mentally handicapped children.

The purpose of the case study was to establish or to identify the needs, problems, weaknesses and shortcomings in Boy;s family together with the entire family, plan to meet those needs identified, mobilize resources together, put them into action together with the family and do combined evaluation to find out if the needs were met and the family was able to care, treat and rehabilitate their mentally handicapped children and have become independent and achieved self-efficacy.

Specific outcomes of the case study were to:

- Identify the needs, problems, weaknesses and shortcomings
- Formulate plan of action to meet the needs
- Mobilise and gain access to resources, support and information to meet the needs
- Evaluate and monitor the effectiveness of the plan/if needs are met
- Determine if the model was effective and self-efficacy is met, and if the process was not effective the researcher, psychiatric nurse at the clinic should restart the process again.

The plan included the people that will be involved, how they will be involved why they will be involved, when, where and to whom they would be involved in the empowerment process.

Establishment of relationship

Building of the relationship was bit difficult due to the shyness of the mother, but the researcher tried her best and gave some food parcels as incentive and the entire family started to accept the researcher. The other thing that made the mother to open up was the presence of the clinic psychiatric nurse, who had already established relationship in the clinic as the mother went to the

clinic for minor ailments. The researcher started to greet the mother together with the children, who gave a positive response. The family was not very jolly all the time, so, building a relationship was very difficult, until incentives were given and the clinic psychiatric nurse visited him regularly. The researcher was simple, used simple Northern Sotho language that could be easily understood and this language was preferred by members of the family. The researcher became approachable and respected the family by calling their real names and rapport was established. The researcher was open, the relationship became a sharing relationship, so that the family could be able to be aware of their needs and the researcher would also be able to identify the needs for the family with mentally handicapped children. The relationship of the model is a power-sharing relationship, so the researcher, together with the psychiatric nurse at the clinic displayed a relationship of mutual sharing and respected the family of mentally handicapped children.

The objective of the meeting was explained to the family members, that, the researcher was going to needs with them, being actively involved in identifying their needs. The researcher accepted the family and encouraged them to express their views with regard to their needs because they are the ones that need assistance or help.

The environment that the researcher created was enabling, was listening carefully, showed sympathy from his face and was communicating very well with the family of the mentally handicapped children. The family of the mentally handicapped child was encouraged to be free and participate in the identification of problems.

6. PREPARATION AND TRAINING FOR THE CASE STUDY

Yin (2003:57) stressed that good preparation of case study should start with the desired skills such as good listening, adaptiveness and flexibility, grasping of the issues being studied and lack of bias.

The family

The researcher and the psychiatric nurse at the clinic had already established the best possible interpersonal relationship with the family members in order to neutralize the mistrust that might have prevailed. Letters of permission from the Department of Health and Social development and the clearance letter from the University of South Africa Ethics committee were shown to the participant as a proof that I have the permission to conduct research. A letter for requisition of permission to take part in the research study was given to the family and they were told who the researcher was, where the researcher came from, which study she was following, the purpose of

the study, that the confidentiality of the interaction would be kept anonymous and confidential, that they were not chosen for harassment but because a small portion of the population is needed for this research, and that the researcher wished to apply the model to find out if it can be effective to the care, treatment and rehabilitation of their mentally handicapped children. The family was informed about the audiotape that would be used during the discussion. The family members were put at ease to enable them to express their honest and deep-seated anxieties (Mouton and Marais 1995:93). Their expectations were explained to them, that they need to be interviewed in a case study to start the process of empowerment model for families of mentally handicapped children. The family members were encouraged to talk and ask some aspects that were not clear to them. The family members read the letter and signed as proof that they agreed to take part in the application of the empowerment model

Appointments were scheduled as to when interview can be started and subsequent appointments were scheduled in order to go through the process of the model. They were promised incentives in the form of food packages as a token of appreciation.

The psychiatric nurses at the clinic

The researcher went to Moletši clinic to make an appointment with the psychiatric nurse. The researcher and the psychiatric nurse agreed on the date and time for the orientation and training to apply the model of empowerment model. The psychiatric nurse agreed to meet on Friday afternoon when there are few patients at the clinic and the clinic was not busy.

Letters of permission from the Department of Health and Social development and clearance letter from the University of South Africa Ethics committee were given to the psychiatric nurse at clinic in order to prove that I have the permission to conduct research.

A letter for requisition to assist in the research study was given to the psychiatric nurse, which request the psychiatric nurse to be involved in the awareness of the needs, formulation of plan, mobilisation of resources, monitoring and evaluation to find out if the model is effective and yielded independence and self-efficacy. The psychiatric nurse at the clinic was given a copy of the model that was enlarged, clear and coloured to make it easy to understand. The psychiatric nurse was taught about the model, the purpose, the context, the phases, the structure and that it was going to be applied to the families of mentally handicapped children to find out its effectiveness to bring independence and self-efficacy to the families of mentally handicapped. The psychiatric nurse at the clinic was also told about the audiotape that would be utilized for recording and be transcribed.

The psychiatric nurse at the clinic was allowed to make any additions and suggestions for the model. The psychiatric nurse was a given token in the form of tea and sometimes cool drinks as a token of appreciation.

Family composition

The family consists of five members. Boy was born from a nuclear family, that is, the mother, father who is working in Johannesburg, the mother who is a labourer, 14, 12 and 10 years.. The mentally handicapped child is the first born in the family.

Access to health services

The family has the nearest clinic, which is about six kilometers from where the family stays. The clinic is easily accessible should they have health problems. The doctor comes bimonthly to the clinic for problematic and referred patients. The physiotherapist and occupational therapy come monthly for referred patients. The hospital is about 30 kilometers from where the patient stays, where they go for medical services.

BACKGROUND INFORMATION

Sebatjane child, Boy was delivered at Polokwane hospital and was born with a cord around the neck. The child was born and diagnosed hydrocephalus by the obstetrician. The mother was discharged from the hospital and was told to come back so that the child could be observed. To the surprise of the family the child had three toes in both feet, but the doctor said that the missing was not a major challenge. The child would be able to survive without all the toes of the feet. The mother never went back because the family believed the child had been bewitched and they took the child for traditional medicine. The child started crawling at thirteen months and started walking after three years. At three years the child was attacked by epilepsy and the family took the child to Moletši clinic and the child was referred to W.F. Knobel hospital, where the doctor ordered treatment. The family was told that the child must live on treatment until the doctor changes the prescription. After the medication was finished, the family said they never took her back but took the child back to the traditional healer and the child did not have any fit for sixteen months. The family thought the child was healed. The child started to have fits continuously and the family took the child to Moletši clinic again and the child was transferred to W.F. Knobel hospital again. The family found another doctor, who checked the old records and talked to the family strongly about

the child's illness and gave them health education on epilepsy and its prognosis. The doctor ordered Tegretol for the child and the child became better.

The family went to Zion Christian church and the family was given religious prescriptions and water that was prayed for and the father of the child was the first to be baptized. They did not go for check-up at the clinic or hospital and child started all over again with epileptic fit and that time the mother said it was worse and this time the family went to Polokwane hospital because they were afraid to go back to Moletši clinic and W.f. Knobel hospital. The child was given treatment and transferred to Ga-Rankuwa hospital for a day for further investigation. The child was referred back to Moletši clinic and was still on Tegretol treatment. The family applied to Grace and Hope school for the mentally handicapped and still waiting for an acceptance but the family said at Grace and Hope it was remarked that he needs to be stable first before admission. The mother feels very guilty because she was not reliable with the treatment of the child.

CHALLENGES OF SEBATJANE'S FAMILY

Lack of knowledge on the treatment of mental handicap

The families went up and down searching for the cause, they went to the clinic and , hospitals several times and when the child was all right the family stopped the treatment several times. The family changed hospitals and clinics and was not adhering to the treatment. The family lacks knowledge of psychotropic drugs, like Tegretol, which is an anticonvulsant drug.

Lack of knowledge on mental handicap and diseases associated with mental handicap.

The family had no knowledge of mental handicap because they believed that the presence of mental handicap in their family was punishment from God and that the child needed to be left alone and just given basic needs. They family did not know that there are diseases that occur at the same time with mental handicap like epilepsy, down syndrome, autism, hyperactivity and many other diseases and they also needed to be attended to.

Lack of self-help skill of dressing

The child is unable to dress himself, but at least can do the self-help skills like eating using the toilet.

Financial support

The child was never given any financial security like all mentally handicapped children

Poor academic development

Sebatjane child had poor academic development, could write his name but was always happy with everybody he comes across.

FORMULATION OF PLAN OF ACTION

The psychiatric nurse at the clinic, the researcher and Ruben's family wrote down all the problems and joined hands to formulate the plan of action. The plan should include the what, who, why, the where, the when and the whom. In this research study the plan should be formulated by the family of the mentally handicapped children, the researcher and the psychiatric nurse at the clinic. According to the model it should be a power-sharing process.

The plan should entail the objectives, the mental health professionals and the family members, methods of monitoring and evaluation of the empowerment process. The plan should depend on the needs that were identified by the mental health professionals and the family members. The plan needs to be flexible if any thing can be discovered later during the case study. Like the assessment the plan should be based on the physical, social, psychological, academic, religious and cultural needs of the family of mentally handicapped children.

OBJECTIVES OF THE PLAN

The objectives of the plan were to:

- Educate the family on the concept mental handicap was, the causes, manifestations. Care, treatment and rehabilitation of the mentally handicapped children
- Teach the family to involve the child religious and social activities
- Teach the family to train the mentally handicapped child the skill of dressing
- Assist the family to apply for financial support for the mentally handicapped children
- Educate the families of the mentally handicapped children on the rights of mentally handicapped persons according to South African Disability Strategy

- Teach the family on anti-convulsive drugs, their pharmacologic action, the side-effects and the complications thereof

MOBIZATION OF RESOURCES

Information

The family was educated about anticonvulsants, how they work and how they prevent the epileptic fits and they need to know that anticonvulsants should be taken for life in order for the child to be stable. The treatment should never be stopped. It is the psychiatrist or doctor who may change the treatment and order another type of anticonvulsants. The family was told that the treatment was going to be taken for the rest of the children's life and the child needs long-life support and needs to go for check-up and go and take monthly treatment. The family was given information that as the child grows, he need not be involved in employment where machinery is used and the continuous supervision.

It became very important that the family should be taught that there are diseases that are associated with mental handicap like Down syndrome and epilepsy that may occur simultaneously with mental handicap and these diseases need to be treated with mental handicap. The family was capacitated on Epilepsy, that it occurs at the same time as mental handicap and the epileptic child should be taken to the psychiatrist, neurologist or to the medical practitioner for medical treatment. The psychiatrist ordered Tegretol for the child and the family members were told that the treatment should be given daily as prescribed and they did so.

The family was educated on the causes, manifestations, care, treatment and rehabilitation of mental handicap. The family also needed to be involved in training of these children like in social skill training, occupational training, training in self-management skills so that they may be independent in future.

A gentleman from DICAG, who visits Moletši centre twice a year arranged a workshop for the parents of mentally handicapped children and gave a series of lectures and demonstration on how to care, treat and rehabilitate their mentally handicapped children. The families and their supporters, being relatives, friends, neighbours and interested people were also invited to the workshop. The nearby projects that support the mentally handicapped children were also invited to take part in the workshop like youth organization who work as volunteers in the Moletši clinic.

Lack of some self-help skills

Self- help skill of dressing is very important. The child needs to be dressed like other people because they are human too. The family members were taught to teach the child how to dress himself, they repeated the skill until the child got a firm grip of the skill. This procedure was repeated several times and is still being done until the child is able to do so.

The child refuses to go to school and poor academic development

Resources

The family of Sebatjane were taught to take the child to the hospital or clinic and was taught to take the child for monthly check-ups and medication.

Support for refusal to go school

The family went to school to find out why the child does not want to go to school all of a sudden. They found out there was a mistress that was very strict and that Sebatjane child was the only one who is school-shy. Due to failure to adjust to the strict mistresses the child became school shy and had psychogenic trauma.

Social worker, younger sisters and the nurse supported the family in the care of the child. The child does not get financial support in the form of the grant. The chief and induna gave Sebatjane family a letter to be taken to the social worker and to the doctor, who wrote motivation letters to social security department in April 2008 and the child will get the first social grant end of July 2008.

The family was referred by Moletši clinic psychiatric nurse to the parents support group of the parents with mental handicap in the Moletši district. The family realized that they are not the only ones who have mentally handicapped children and will learn from the group that their children need their faithful support. The support group deals with all issues around mental handicap, including encouragement of children to go to school.

Support of poor academic development

Sebatjane child, like other children was taken by the family to the normal school, but was removed because he was discovered to have sub-average intelligence and had problems in understanding the content that is to children of his age group. The mother was advised by the visiting school nurses to take the child to Moletši clinic and the child was then referred to Grace and Hope school for the mentally handicapped children after thorough examination by the social worker at the clinic and started schooling at Grace and Hope school for the mentally handicapped children.

Recreation

On the “fun day” the nursing students hired a “jumping castle” from Polokwane town and all mentally handicapped children who were there jumped and enjoyed the day together and made friends (May 2002:248). This was one of the ways in which the researcher and the psychiatric nurse together with the nursing students socialized the mentally handicapped children. They referred and showed the family the support groups in the community like families with mentally handicapped children of their type like families with Down syndrome in their families.

The family also involved the mentally handicapped child in recreation on Sunday when the boys sing and dance their Zion church traditional “mokhukhu”, which is the most fascinating traditional practice. The boys sing, dance and jump and this is a good means of exercise

9. MONITORING AND EVALUATION

The people who need to monitor and evaluate the empowerment process to establish whether the empowerment process was successful or not include the researcher, other mental professionals, the family of mentally handicapped children and the mental health professional who works at the clinic, the one who was taking part in the implementation of the model. The other colleagues who were observers need to evaluate the impact of the empowerment model in the care, treatment and rehabilitation of the families of the mentally handicapped children.

Meeting

A *meeting* was held where the above mental health professionals sat together with the family of the mentally handicapped children, looked at the model and examined the objectives, (both short and

long-term) of the empowerment model and determine as to whether the objectives were met or not. The objectives of the empowerment process was effective because the family of mentally handicapped children could assist their child to perform life skills independently and the family took the tasks as their responsibility.

Discussion

The *discussion* will be held between the staff that are working in that clinic, staff in the nearby clinics, the researcher, mental health professionals and people who are experts in evaluation to discuss the findings, as to whether is effective or not, that is, the families find themselves competent and may take of their on their own and look for some help when needed. The family reported that they understand epilepsy, mental retardation and all issues around mental handicap and training that should be embarked on.

Home visit

Reuben's family was *visited* by psychiatric nurse from the clinic and the researcher at *home* and improvement was observed in the self-help skill of dressing, an improvement was marked.

Observation

The family members of the mentally handicapped children and the very children were *observed* to find out if improvement is marked or not. Indeed, there was improvement The family members were able to teach their children self-help skills like dressing and other self-help skills were reinforced like washing and eating.

Interview

The families of mentally handicapped children were *interviewed* to find out whether there was any improvement and the answer was positive and the mental health professionals also observed improvement in the knowledge of anticonvulsant drugs knowledge of side effects and safe keeping of drugs.

10. AUTONOMY AND EFFICACY

It is expected that at the end of the empowerment process the family should be competent in caring, treating and rehabilitating their mentally handicapped children.

According to LSMHP (2001:5) empowered families possess the following:

- Know the rights of their mentally handicapped children
- Have the knowledge of community facilities or resources for their children
- Are able to explain how each community facilities are utilized like centres for mentally handicapped.
- Can differentiate between the right support or help from the wrong support and or assistance
- Are able to support other families who have the mentally handicapped children as they share the same problems with their children.
- Possess the understanding that a mentally handicapped child deserves the same dignity as all other children and need to be respected.

ANNEXURE E

Solomon report

1. INTRODUCTION

Datta, Lois-ellin (1990:1) states that case study approach has gained a highly popular status in social work areas all over the country. It is highly utilized in evaluation research in particular, during the recent years. Case study is used extensively in evaluation research. Each case study will highlight a new or unique aspect of the nursing care.(Good:1).In this study of empowerment of families with mentally handicapped children the case study method will be used to evaluate whether the family empowerment model is effective in caring, treating and rehabilitating the mentally handicapped children.

2. PRE-MORBID FUNCTIONING OF THE CLINIC ON EMPOWERMENT

The professional nurses, including the psychiatric nurse, at the clinic were asked about ways in which they empowered the families with mentally handicapped children. The staff at the clinic said they they are short-staffed, caters for over eighteen villages, do not have transport to do follow-ups of their families. The clinic nurses said the families only bring their mentally handicapped children for minor ailments and at that time they get time to educate the families about their mentally handicapped children and refer children with problems to the psychiatrist in hospital, especially the children who suffer from Epilepsy.

The families were asked about the ways they used to care, treat and rehabilitate their mentally handicapped children at home so that at the end of application of the model the care, treatment and rehabilitation before empowerment and after empowerment could be compared (Chinn and Kramer 1995:1).

3. SELECTION OF CLINICAL SETTING

The researcher selected Moletši clinic and selected S Ngoasheng s'family as her pilot case study. The clinic deals with nursing practice, where the theoretic relationships can be observed by implementation of the theory. Moletši clinic is where S got all his immunization and go for all the minor ailments.

4. IDENTIFICATION OF THE UNIT OF ANALYSIS

The unit of analysis was the Ngoasheng family, in which where S Ngoasheng was born.

5. DETERMINING OUTCOMES

The purpose of the application of the model was determined and applied to the families of mentally handicapped children to find out its effectiveness (Chinn and Kramer 11995:102), to find out if after application of the model of empowerment the family became independent in the care, treatment and rehabilitation of their mentally handicapped children.

The purpose of the case study was to establish or to identify the needs, problems, weaknesses and shortcomings in S's' family together with the entire family, plan to meet those needs identified, mobilize resources together, put them into action together and do combined evaluation to find out if the needs are met and the family is able to care, treat and rehabilitate their mentally handicapped children and have become independent and achieved self-efficacy.

Specific outcomes were to:

- Identify the needs, problems, weaknesses and shortcomings
- Formulate plan of action to meet the needs
- Mobilise and gain access to resources, support and information to meet the needs
- Evaluate and monitor the effectiveness of the plan/if needs are met
- Determine if the model was effective and self-efficacy is met, and if the process was not effective the researcher, psychiatric nurse at the clinic should restart the process again.

The plan included the people that will be involved, how they will be involved why they will be involved, when, where and to whom they would be involved in the empowerment process.

Establishment of relationship

Building of the relationship will not be new to a patient because it was long started with primary (parents, friends and siblings), secondary (colleagues, friends, and relations) and now the health care providers in the form of mental health care professionals The researcher greeted the mother together with the children, who gave a positive response. The family was very jolly and laughing all the time, so, building a relationship was very easy. The researcher was simple, used simple

Northern Sotho language that could be easily understood and this language was preferred by members of the family. The researcher became approachable and respected the family by calling their real names and rapport was established. The researcher was open, the relationship became a sharing relationship, so that the family could be able to be aware of their needs and the researcher would also be able to identify the needs for the family with mentally handicapped children. The relationship of the model is a power-sharing relationship, so the researcher, together with the psychiatric nurse at the clinic displayed a relationship of mutual sharing and respected the family of mentally handicapped children (Kaplan 2003:27).

The objective of the meeting was explained to the family members, that, I was going to identify the needs with them being actively involved in identifying their needs. The researcher accepted the family and encouraged them to express their views with regard to their needs because they are the ones that need assistance or help.

The environment that the researcher created was enabling and she was listening carefully, showed sympathy from her face and was communicating very well with the family of the mentally handicapped children. The family of the mentally handicapped child was encouraged to be free and participate in the identification of problems.

6. PREPARATION AND TRAINING FOR OF THE CASE STUDY

Yin (2003:57) stressed that good preparation of case study should start with the desired skills such as good listening, adaptiveness and flexibility, grasping of the issues being studied and lack of bias.

The family

The researcher and the psychiatric nurse at the clinic had already established the best possible interpersonal relationship with the family members in order to neutralize the mistrust that might prevail. Letters of permission from the Department of Health and Social development and from the University of South Africa Ethics committee were shown to the participant as a proof that the researcher has the permission to conduct research. A letter for requisition of permission was given to the family, which requested the family to take part in the research study and they were told who the researcher was, where she come from, which study she was following, the purpose of the study, that the confidentiality of the interaction would be kept anonymous and confidential, that they were not chosen for harassment but because a small portion of the population was needed for this research, and that it is wished to apply the model to find out if it can be effective to the care,

treatment and rehabilitation of their mentally handicapped children. The family was informed about the audiotape that would be used during the discussion. The family members were put at ease to enable them to express their honest and deep-seated anxieties (Mouton and Marais 1995:93). Their expectations were explained to them, that they need to be interviewed in a case study to start the process of empowerment model for families of mentally handicapped children. The family members were encouraged to talk and should ask some aspects that were not clear to them. The family members read the letter and signed as proof that they agree to take part in the application of the empowerment model

Appointments were scheduled as to when the process can start and subsequent appointments were scheduled in order to go through the process of the model. They were promised incentives in the form of food packages as a token of appreciation.

The psychiatric nurses at the clinic

The researcher went to the clinic to make an appointment with the psychiatric nurse at Moletši clinic, The researcher and the psychiatric nurse at the clinic agreed on the date and time for the orientation and training to apply the model of empowerment.. The psychiatric nurse agreed to meet Friday afternoon when there were few patients at the clinic.

Letters of permission from the Department of Health and Social development and from the University of South Africa Ethics committee were shown to the psychiatric nurse at clinic in order to prove that the researcher has the permission to conduct research.

A letter for requisition to assist in the research study was given to the psychiatric nurse which requested the psychiatric nurse to be involved in the awareness of the needs, formulation of plan, mobilisation of resources, monitoring and evaluation to find out if the model was effective and yielded independent and self-efficacy. The family was requested to take part in the research study and they were told who the researcher was, where the researcher came from, which research study she is busy with, the purpose of the study and that she will assist in the application of the model

The psychiatric nurse at the clinic was given a copy of the model that was enlarged, clear and coloured to make it easy to understand. The psychiatric nurse was taught about the model, the purpose, the context, the phases, the structure and that it was going to be applied to the families of mentally handicapped children to find out its effectiveness to bring independence and self-efficacy to the families of mentally handicapped children. The psychiatric nurse at the clinic was also told

about the audiotape that would be utilized for recording and be transcribed. The psychiatric nurse at the clinic was allowed to make any additions and suggestion for the model. The psychiatric nurse was given token in the form of tea and drinks as a token of appreciation.

Family background

J's(S's'mother) family originated from ga-Mothiba from the family of three boys and J was the fourth born child. J's mother died in 1985 from complications of blood pressure and her father died in 1988 from heart disease. J's family is in a child-bearing and rearing stage, consists of five members of which one girl died in 2002 and left one little girl who is now seven years of age. S Ngoasheng was born from a single parent family. The mother, who seems to have mental problems is the one who took care of the family. She was never married, but has a boyfriend (S's father) who had mental problems, just like S. The researcher found the mother with five children, a girl of 34 years, who is married, S who is 14 years of age, two boys of eight and four years of age and a grand child of seven years. The 34year old girl is married and the mother is not happy about the marriage because the mother says the girl fights with the husband several times because the lady is not clean and cannot cook well. The family lives below the poverty datum line and have problem with buying of clothing, food, transport to health services and other accessories, housing.

Access to health services

The family has the nearest clinic, which is about one kilometre from where the family stays. The clinic is easily accessible should they have health problems. The doctor comes bimonthly to the clinic for problematic and referred patients. The physiotherapist and occupational therapist come monthly for referred patients and arrange disability grants for the needy patients. The hospital is about 30 kilometers from where the family stays, where they go for medical services. J is the one who decides what to do if one is sick in the family.

Family support systems

The family belongs to the Northern Sotho group and are attending church at International Pentecostal church, which plays a very big role in supporting, socializing, recreating and caring for the religious aspect of the family. Other support systems include some community members, the clinic, the hospital, mental health professionals and different voluntary organizations from the community, including the induna, who is concerned about the family's health.

S's family lives in a noisy area, where the children are noisy, crime rate was high, and beat S whilst playing.

The mentally handicapped child

The child, that is, S was born in 1994 and is now 14 years. He was born of a normal delivery in Polokwane hospital. He was not very active like other children, was weak and his muscle tone was weak. In early childhood he was restless and fidgetive, had low concentration span, was sometimes vomiting after eating, was not sleeping well, had slow milestones, was unable to comprehend the spoken word and the psychiatrist diagnosed the child as severely mentally handicapped with Down syndrome. The child had poor development of self-help skills. During schooling he had language problem, was not comprehending well, could not construct a sentence, had poor scholastic performance and had poor adjustment problems. The child had temper tantrums, though he could socialize easily with others.

7. CHALLENGES/PROBLEMS IDENTIFIED FROM FAMILY IF MENTALLY HANDICAPPED CHILD - SOLOMON NGOASHENG

Poor housing/accommodation

Solomon's family belongs to the low socio-economic status and the family has a very small house, so small that the kitchen only accommodated the stove and one table only. There is one very bedroom and it is very dark and cannot accommodate any bed. The third small room accommodated one single and small table. The house seemed to be built by an unskilled person and it is made out of mud. The family really needs an alternative better accommodation.

Insufficient food/diet

The food is not sufficient for the family because they always eat little food to cover the date of social security to get their monthly stipend. S gets R940,00 per month, starting from April 2008. Other two small children, a boy and a girl gets a combined children' grant of R290,00 per month. Total income R1520,00 starting from April 2008.

Food is not well prepared. The family seemed not to have knowledge of preparation and cooking of meals. The family needs health education on preparation and cooking of meals.

Abuse

The mentally handicapped child gets beaten by small boys in the street while and ridiculed. He was beaten on the shoulder to an extent that he was taken to the clinic, sutured and recovered. The child has the right for protection, it is the right of mentally handicapped children

Poor support

The family needs to know other families with the same condition in order to discuss common problems of their children and assist one another with the type of care, treatment and rehabilitation that should be given to their mentally handicapped children. They need friends who have the same children in their families, that is, they need mutual support/ parents groups

Poor academic development

S was taken by the family to the normal school, but was removed because he understood nothing and was referred to Grace and Hope school for the mentally handicapped children after thorough examination by the psychologist but the he could not get any space. The mother took him to a voluntary centre for the mentally handicapped children, which is registered with department of Social development and Department of social welfare. At the centre for mentally handicapped children he has gross academic problems and cannot even write his own names and draws a line for a period of two years. The family wants to know the type of help that could be given to their son so that he must be able to write letters for them as the entire family could not write letters well. There is need to consult the doctor to find out what else can be done for the mentally handicapped child (Patton 1990:388).

Poor muscle tone

The family said the child cannot stand for a long time. He gets tired and sleep at all times. "His back muscles are very weak," said the mother crying.

Lack of proper clothing

S's clothes were not very clean, compared to the children who play with him in the street and at home and they were not appropriate for the weather. The psychiatric nurse asked to whether the

child had enough clothing and the mother's answer was positive. During the home visits the psychiatric nurse asked the mother to show her S's clothing, only to find that S has enough clothing for cold and hot weather. It became clear that the mother needs a lot of education with regard to the weather. The clothing of the entire family, including S's clothes were not up to standard, not very clean, but were not torn.

Speech problems

S had problems with speech. One could not make out what he is saying, even now, the child still has a speech problem.

Insomnia

From birth S was said to be a "crying" and restless baby, who has a problem of sleeping, even today he still has a problem of insomnia.

Lack of concentration, vomiting and improper use of toilet remain the problems of S.

8. FORMULATION OF PLAN OF ACTION

The psychiatric nurse at the clinic, the researcher and the family wrote down all the problems and joined hands to formulate the plan of action. The plan should include the what, who, why, the where, the when and the whom. In this research study the plan was formulated by the family of the mentally handicapped children, the researcher and the psychiatric nurse at the clinic. According to the model it should be a power-sharing process.

The plan should entail the objectives, the mental health professionals and the family members, methods of monitoring and evaluation of the empowerment process. The plan should depend on the needs that were identified by the mental health professionals and the family members. The plan needs to be flexible if anything can be discovered later during the case study. Like the assessment the plan should be based on the physical, social, psychological, academic, religious and cultural needs of the family of mentally handicapped children.

9. MOBILISATION AND GAINING ACCESS TO RESOURCES, SUPPORT AND INFORMATION

Information

Mental health professionals arranged health education days in collaboration with University of Limpopo nursing students on mental handicap. The nursing students staged health education days in the form of “fun day”. The students presented a drama to the community of which S and his family was present. The family in the drama was very rich did not accept that their child is mentally handicapped. They abused the child until a neighbour reported the family to the nurse at the clinic. The clinic nurse visited the family and the nurse wanted to know why the child was abused and the nurse educated the family on the causes, how the child will present, the treatment and how the child could be rehabilitated. The nurse at the clinic gave handouts, leaflets and referred the child to the social worker to motivate for social grant and eventually to the psychiatrist for medical treatment because the child had epilepsy. The family accepted the child and loved him.

The mental health professionals educated the families of mentally handicapped children, using different teaching aids like posters, flip charts, films, radios and television, which was the most popular teaching aids to make the subject clear to the family. Methods of teaching included lectures, demonstration, peer group teaching and counseling by other family members who have mentally handicapped children.

The family was educated about preparation, cooking and serving of a well balanced diet. Some interested members of the church were invited to come and assist the family.

Voluntary Moletši centre teachers were taught to be patient and try to teach the mentally handicapped child to write his name. Volunteers at the center were encouraged to be patient, kind, loving, repeat what they teach because the mentally handicapped children learn by repetition. and reinforcing the mentally handicapped child if he does something good.

Family and the neighbours were taught about mental handicap, its causes, how to recognize it and how to support the families with mentally handicapped children so that they could understand S’s family and be able to support them. Teaching materials like printed materials, demonstration, peer presentations, field trips, computer-assisted learning, posters, booklets and peer counseling were prepared.

The family was educated on the rights of the mentally handicapped children so that they should know what is right for their mentally handicapped children. The rights of the mentally handicapped children are human rights. They have the rights to be listened to, respected, educated, protected and cared for. Mentally handicapped children have the right to respect and dignity, not to be discriminated, the right to information, to participate in treatment decisions, confidentiality

Resources

The researcher applied for Reconstruction and development housing from the local councilor of Ward 18 under Polokwane municipality because the family and especially the mentally handicapped child is not safe but he has the right for protection

The researcher referred the family to Moletši clinic for free feeding scheme for the needy families. S, like other mentally handicapped children has the right to a well balanced diet for physical health.

The families with mentally handicapped children were invited to the clinic with Solomon's family to be taught about the health services available for the mentally handicapped children.

Resources for empowerment of the families of mentally handicapped included the mental health professionals at the clinic, who taught the family on causes, recognition of mental handicap, how to treat it and how the mentally handicapped children could be rehabilitated. The occupational therapist empowered the families to teach their children how to socialize with others, the occupational skills, how to manage themselves and how to use their free time. The physiotherapist assisted the families to exercise the floppy back to become strong. Social workers in the clinic took part in the empowerment of families by applying for food parcels for the families that are suffering to eat.

On the "fun day" the nursing students hired a "jumping castle" from Polokwane town and all mentally handicapped children who were there jumped and enjoyed the day together and made friends (May 2002:248). This was one of the ways in which the researcher and the psychiatric nurse together with the nursing students socialized the mentally handicapped children. They referred and showed the family the support groups in the community like families with mentally handicapped children of their type like families with Down syndrome in their families.

The family was referred to the psychiatrist for poor muscle tone for review and perhaps the doctor may order some supporting aids for the children.

The researcher and the psychiatric nurse referred the family of the mentally handicapped children, including S to the organisations in the church to church, like the women's league to come and pray for the child and assisted in giving clothes and food to the family of the mentally handicapped child

Support

Neighbours and other families whose women are not working were grouped to assist the families with preparation, cooking and serving of meals. Solomon's family was briefed about the help that would be given to them.

Community volunteers like community workers from the clinic were requested to visit the family and also assist in the preparation, cooking and serving of meals. This was done in collaboration with nurses from the clinic during home visits. The researcher with the psychiatric nurse from the clinic wrote a letter to the social worker to request for food parcels that are available for the needy families and Solomon's family was put on the waiting list for food preparations.

A gentleman from DICAG, who visits Moletši centre twice a year arranged a workshop for the parents of mentally handicapped children and gave a series of lectures and demonstration on how to care, treat and rehabilitate their mentally handicapped children. The families and their supporters, being relatives, friends, neighbours and interested people were also invited to the workshop. The nearby projects that support the mentally handicapped children were also invited to take part in the workshop like youth organization who work as volunteers in the Moletši clinic.

Solomon's family and other families with mentally handicapped children were invited to a session that was organized by the Department of Human rights when a group of ladies presented "human rights day" for the entire central Moletši community. The audience was allowed to ask questions on special human rights like the aged, adolescents, family of mentally handicapped and the physically handicapped. The families of mentally handicapped were given a platform to ventilate their problems and ask questions.

Concerning clothing National council of African women, that support the needy was invited to visit the family, and they donated clothing in the form of jumpers, jerseys, pairs of trousers and summer clothing and taught the mother and other small children the difference between summer and winter clothing. The National council for African women promised to visit the family weekly, especially the woman that are on pension and are not actively employed.

The other group that supported the family was Anglican Diocese women's union in Polokwane that support the needy on the basic need of food. The union sent food parcels to the mentally handicapped children in Moletši, including Solomon's family

Moletši Inter-denomination women's league heard about the organisation from town that support their mentally handicapped children and they started another feeding scheme and Solomon's family was assisted to the full. The children got food parcel in March and the next badge will be sent in June 2008.

For socialization Moletši social workers sent different toys to all the children who are mentally handicapped in Moletši, and Solomon also got one to play at home. Solomon was grouped with the other children in church where the radio was playing cassettes and they together and Solomon socialized with them. In Solomon's church the children have trips every fourth Sunday to go out for at tour or an occasion is arranged in church in the afternoon for the children. At Modise church, where Solomon's family attends their church service socialization of children is one their priorities. Solomon's family was taught that Solomon needs to rest for at least one and half hour during the day.

9. MONITORING AND EVALUATION

The people who need to evaluate the empowerment process to establish whether the empowerment process was successful or not include the researcher, other mental professionals, and the mental health professional who works at the clinic, the one who was taking part in the implementation of the model. The other colleagues who were observers need to evaluate the impact of the empowerment model in the care, treatment and rehabilitation of the families of the mentally handicapped children.

Meeting

A *meeting* was held where the above mental health professionals sat together with the family of the mentally handicapped, looked at the model and examined the objectives, (both short and long-term) of the empowerment model and determine as to whether the objectives were met or not. During the meeting with the family, they reported that they were got a letter from the social worker informing them that they are on the waiting list for the food parcels that are given to the needy families.

Discussions

The *discussion* will be held between the staff that are working in that clinic, staff in the nearby clinics, the researcher, mental health professionals and people who expert in evaluation to discuss the findings and make necessary recommendations. From the discussions it was discovered that the family members understand the rights of their mentally handicapped child, they could tell that their child has the right to be protected, the to a name and surname, happiness, to education, respect, dignity, to be loved, cherished and the right to live like any other child.

Concerning *housing* feedback the family was informed that feedback was still awaited from the ward coucillor of ward 18 of Polokwane municipality.

The family also reported that they were invited to Moletši parents group on mental handicap where they discussed problems of their children on like failure to progress at school and the family she found that the other families have the same problems and they consoled and supported one another.

Home visit

Solomon's family was *visited* by psychiatric nurse from the clinic and the researcher at *home* and improvement was observed in the preparation, cooking and serving of meals. Solomon's mother was not very free to be with the mental health professionals because she wanted to be alone when she prepared her meals. The family thanked the researcher and the psychiatric nurse from the clinic and the other voluntary organizations like church organizations that assisted.

Observation

The family members of the mentally handicapped children and the very children were *observed* to find out if improvement is marked or not. The family was able to clean their mentally handicapped child with little support from the nearby organizations and the neighbours. The mentally handicapped and the family as a whole were found to be very clean. The researcher and the psychiatric nurse from the clinic were happy to observe the improvement in Solomon's family.

Interview

The families of mentally handicapped children were *interviewed* to find out whether there was any improvement and the answer was positive and the mental health professionals also observed improvement in the preparation, cooking and serving of meals. The meals were prepared in a clean environment, utensils were very clean, meals were well cooked and served attractively. The family told the health researcher and the psychiatric nurse at the clinic that they have taken their mentally handicapped child to the psychiatrist for examination of the back and the doctor explained that a Down syndrome has floppy muscles at the back and advised them on exercise of the back and referred them to the clinic physiotherapist who visits the clinic once a month.

10. AUTONOMY AND EFFICACY

At the end of the empowerment process the family had tremendously improved in caring, treating and rehabilitating their mentally handicapped children.

The family has made an improvement and achieved some of the skills like ;

- Preparation, cooking and serving of meals
- The family opened up and could talk to the other families about mental handicap and discussed common problems.
- Knew the rights of their mentally handicapped children and could teach the other people about them, that they are not allowed to abuse their mentally handicapped children, otherwise they would be arrested.
- The clothing of the family improved after being donated with clothing and the families kept the clothes clean.
- Had the knowledge of community facilities or resources where they could take their children for assistance.
- Were able to explain how each community facilities are utilized, the social worker and other mental health professionals

- Could differentiate between the right support or help from the wrong support and or assistance, like when their children are abused.
- Were able to support other families who have the mentally handicapped children as they share the same problems with their children and formed close relationships with them and their children.
- Families can now tell somebody about the care and rehabilitation of the mentally handicapped child and they possess the understanding that a mentally handicapped child deserves the same dignity as all other children and need protection.

FIELD NOTES

Field notes are referred to as the description of what has been observed during data collection and they are descriptive in nature. Field notes should be noted if the researcher thinks they have value to the research. They should have a date, where the observation took place, who was present, what the physical setting was, what social interaction was happening.

During the first visit J was very tense because she sat on the chair, shivering, I could see her lips shivering, was chasing the children out of her small house, took a broom, put it next to her, put it down twice and settled when I sat down on the mat that was on the floor and greeted the entire family. She was very restless and crying bitterly at first and the eye contact was poor but S came running to greet me and J removed S forcefully. I greeted and took S by hand and then J stopped crying and became better.

**EMPOWERMENT OF FAMILIES OF MENTALLY HANDICAPPED CHILDREN
COMPONENTS**

ASPECTS	THE NEEDS	MEETING NEEDS
PHYSICAL	<ul style="list-style-type: none"> ▪ Lack of food ▪ Poor preparation, cooking and serving of meals ▪ Lack of proper clothing ▪ Poor support ▪ Poor housing ▪ Poor speech development ▪ Poor muscle tone ▪ Vomit sometimes ▪ Poor toilet Training ▪ Abuse by other children 	<p>Anglican Diocese, Moletši inter-denomination women's league, community volunteers, National council of African Women assisted in the preparation, cooking and serving of meals, donated clothing to S's family and the social worker promised to give food to the family</p> <p>Application made to ward 18 councillor for R.D.P.</p> <p>Referral to the speech therapist</p> <p>Referral to the psychiatrist</p> <p>Training by mental health professionals and volunteers</p> <p>Education to the community about human rights</p>
PSYCHOLOGICAL	<ul style="list-style-type: none"> ▪ High expectations from mother about the child ▪ Insomnia ▪ Restlessness ▪ Adjustment problems ▪ Lack of concentration 	<p>Explain to the mother that due to the low intelligent quotient, the child will not become a teacher</p> <p>Refer the child to the psychologist and psychiatrist</p> <p>S should join the other children and play and be involved in recreational activities</p> <p>Give the child simple, non-competitive tasks of a short duration</p>
SOCIAL	<ul style="list-style-type: none"> ▪ Isolated ▪ Poverty ▪ Mother unemployment ▪ Little support from the community 	<p>Involve with other parents and their activities</p> <p>Ask for assistance from social worker and volunteers</p> <p>Encourage neighbours to support J, especially home-based carers</p>

ASPECTS	THE NEEDS	MEETING NEEDS
RELIGIOUS		
ACADEMIC	<ul style="list-style-type: none"> <li data-bbox="581 218 948 306">▪ Family lack information about mental handicap issues <li data-bbox="581 369 948 424">▪ Child has poor academic performance 	<p data-bbox="972 218 1455 338">Education on causes, signs and symptoms care, treatment and rehabilitation of the mentally handicapped children</p> <p data-bbox="972 369 1455 424">Continue training for life, be patient, repeat and reinforce if improved</p>

**UNIVERSITY OF SOUTH AFRICA
Health Studies Research & Ethics Committee
(HSREC)
College of Human Sciences**

CLEARANCE CERTIFICATE

Date of meeting: **12 July 2007** Project No: **5015057**

Project Title: **An empowerment model for the families of mental
handicapped children**

Researcher: **JC Kgole**

Supervisor/Promoter: **Prof TR Mavundla**

Joint Supervisor/Joint Promoter:

Department: **Health Studies**

Degree: **D Litt et Phil**

DECISION OF COMMITTEE

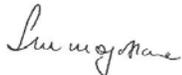
Approved

Conditionally Approved

24 July 2007
Date:



**Prof L de Villiers
RESEARCH COORDINATOR: DEPARTMENT OF HEALTH STUDIES**



**Prof SM Mogotlane
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

