

**EMOTIONAL ADJUSTMENTS MADE BY PARENTS OF
PHYSICALLY DISABLED CHILDREN FOLLOWING THEIR
DISCHARGE FROM INSTITUTIONAL CARE:
A CASE STUDY OF CHESHIRE HOMES, LUSAKA ZAMBIA**

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DEDICATION

To Cathlyn and Lawrence my parents who though they have passed on to world's unknown, continue to be an ever present source of inspiration.

DECLARATION

I Paula Pule Kapungulya do declare that this thesis is my own work and that it has not been previously submitted for a degree at this University or any other University.

SIGNED Paula Pule Kapungulya DATE 06-11-00

APPROVAL

This thesis by Paula Pule kapungulya is approved as fulfilling part of the requirements for the award of the degree of Master of Education by the University of Zambia.

SIGNED.....INTERNAL EXAMINER .....DATE 06-11-00

SIGNED.....INTERNAL EXAMINER.....DATE.....

SIGNED.....EXTERNAL EXAMINER.....DATE.....

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ABSTRACT

Scholars such as Hornby (1994), have proposed that the parents of disabled children go through a series of emotional adjustments which lead to the final state of acceptance of the child's condition. Based on Hornby's adaptation model, this study set out to establish the emotional adjustments made by parents of children with physical disabilities following discharge from institutionalised care.

Data was collected from a sample of twenty parents and fifteen staff of Cheshire home in Kabulonga. The parents were drawn from the sum of Lusaka based parents whose children had been discharged from Cheshire Home within the last five years.

Data was collected using three methods namely; self administered questionnaires, semi structured interviews and focus group discussions.

Results of the study revealed that the parents' emotional adjustments were highly individualised. The pattern of emotional adjustments made by the parents understudy was spiral rather than the linear continuum suggested by Hornby and other scholars. A notable factor was that there seemed to be no absolute end-point of the motional adjustments experienced by the parents.

The study also revealed that there is a relationship between the parents' emotional adjustments and most of the socio-economic factors studied. Further, that the child's

movement between the institution and the parental home was characterised by emotional experiences associated with related practical problems faced by the parents. This was especially so during the period following the child's return from the institution.

Chapter One

1.0 INTRODUCTION

1.1 OVERVIEW

The rise in the population of children with disabilities seems to have brought about a growing awareness and concern for their welfare and service provision. There has been little mention made about the extension of support service provision to the parents of children with disabilities. A case in point is the preparation of parents for their parenting role after their children have left the expert hands of child care institutions.

This study was carried out in order to conduct an in-depth assessment of the emotional adjustments made by parents of physically disabled children upon discharge to their parental homes. The researcher's interest in the subject was aroused by the observation that whilst attempts have been made to cushion the stressful impact of disability on the affected children, there are virtually no notable support services available for the parents and other primary care givers in Zambia. This study's ultimate goal was to make recommendations for the promotion of psycho-social support for parents of children admitted to Cheshire home. This, it was hoped, would assist the parents and other primary care-givers to accept their children's conditions with greater ease.

1.2 BACKGROUND TO THE PROBLEM.

1.2.1 Global picture

The Global incidence of disabled persons is estimated to be 10% of the total world population, of these 2% are Children (UNICEF 1980, UN 1982). Rehabilitation International (1981) also echoes this. Tefferra (1997) estimates the current global population of disabled persons to be 500 million. Of these, 75% live in the developing world. The UN (1993) further projects that by the year 2 000, there will be at least 600 million people with disabilities living in the world. In addition, Teferra (1997) observes that this population is growing with a resultant increase in the number of persons with disabilities particularly in the developing world.

1.2.2 Incidence of Disabilities in Developing Countries

The incidence and prevalence of disabilities seems to be higher than that of the industrialised world. As many as 80% of all persons with disabilities live in isolated rural areas in developing countries. In some of these countries 20% of the total population are disabled persons. The UN (1982) states that if families and relatives are included, 50% of this stated population could be adversely affected by disabilities. Projections show that by the year 2000, one third of the world's population will be children below the age of 15, living in developing countries. Of this number, 150 million are disabled children. UNICEF (1989) points out that these children will remain beyond reach of help unless governments and people work together now to change the situation.

1.2.3 The Zambian Picture

In Zambia, it is estimated that the population will hit the 11.8 million mark in the year 2,000. Of this population 1,938,008 will be in the 7-13 year age range and possibly attending primary school "Focus On Learning, (1992)". This policy document stipulates that out of this school population, between 160,000 and 250,000; 7-13 year olds will be disabled children. Currently however, the country's residential and integrated schools are catering for only two thousand (2000) children.

1.2.4 Response to Childhood Disability

In response to the problem of disability, the Western philosophy of normalisation and integration began in the late 1960s in Scandinavia with particular reference to mentally retarded people. Over the past two and half decades, approaches to people with disabilities have undergone an evolutionary process. Thornburn and Marfo (1994) state that increased scientific understanding and the adoption of principles of human rights have helped to change practices. These practices have changed from those of regarding people with disabilities as non-human out-casts of society to people with positive attributes, with contributions to make, and who have rights like any one else.

The Japanese Journal of Brain Development editorial of 1996 highlights countries like Japan where for instance, as the number of heavily and diversely disabled children has been increasing, schooling for physically handicapped children and their medical care have been intensified. Following the trend of normalisation, the Government of Japan has defended the rights of children to education. As such, they have ensured that school medical services are available for that country's disabled children.

Globally, the inception of the International Year of the Child stimulated a lot of projects for disabled children. In addition, the International Year for the Disabled Persons focused attention on three main goals for improving the quality of life for disabled people. These goals were (1) full participation and equality, (2) social integration and (3) solidarity. These three goals have been adopted, elaborated and presented in the World Programme of Action Concerning Disabled Persons of 1983. This has now become the blue-print for development of action programmes for groups and nations around the world (Thornburn & Marfo, 1998).

However, despite all this being in place, studies have shown that the problem disabled persons face in meeting the stated goals is one of attitude rather than technology. There is evidence that in developing countries, attitudes and practices towards disabled persons still reflect superstition. In a study conducted in Jamaica, Leawitt (1988) found that many people especially in the poorer classes still have superstitious beliefs about disabilities. On the other hand, the study revealed that many people also have strong beliefs in the power of God to change or affect the development of the disabled child. The study further noted that though the beliefs were not harmful, they do however delay the seeking of advise or discourage the implementation of an intervention of rehabilitation programmes.

Since the International Year for Disabled Persons, much emphasis has been given to the awareness and sensitisation of people and communities to the needs of disabled persons. However, due to the economic constraints of the eighties, the advances that were beginning in the early part of the decade have not proceeded at the same pace as was hoped.

1.2.5 Position of the child with disability

Disabled children in the developing countries are extremely vulnerable. They need as much help in order to lead as normal a life as possible. According to Thomas (1978), provision of services for the disabled is not of prime importance in developing countries. Thomas states that in these countries, the question of priorities can become a stumbling block in developing services for disabled children. He further explains that many policy-makers agree that the scarce resources should be directed more towards those efforts that serve the majority of people. Thomas's statements were a clear reflection of what was obtaining in Zambia during this period. Government had recognised the painful reality that the few special education classes and social welfare services available were only a drop in the ocean compared to what was needed. This could mainly be attributed to the fact that the resources available in form of help for the disabled children were limited.

The figures of disabled children quoted by "focus on learning (1992)" above do not include the emotionally disturbed children. Neither do they take account of those who are exceptionally gifted or talented and require more challenging education. This oversight in Zambia's key policy document may be seen as an indicator of the level of importance or none at all, attached to the plight of disabled learners.

Currently, the educational needs of children with severe disabilities are being catered for through special education schools and special education units attached to ordinary schools. In 1995, there were 31 special education institutions: 28 at primary, one at secondary, and two at tertiary levels. There were also 80 special education units: 51 at primary and 29 at secondary school levels (MOE, 1996). Since Government took over the running of special education institutions in 1971, there has been little progress made. This has been mainly due to the financial constraints faced by the state. The state has, in the recent past, experienced a downward trend in economic development. This trend has inevitably affected the delivery of special education in the country because special needs education is financed by the central government. The funding is often inadequate and Grants are only given to residential schools that

provide an exclusive type of education. In addition to this, the nation is far from realising education for all by the year 2000.

1.2.6 Role of NGOs and Co-operating Partners

Kalabula (1998), notes that some sympathetic and friendly foreign nations such as Sweden, Norway, Denmark and Finland have played a major role in funding special needs education. In addition to these, some NGOs and charitable organisations have risen to the challenge of providing care for these vulnerable children. The Society for Cheshire Homes in Zambia is among the organisations that provide services for the physically disabled children. They, however, have limited capacity of operation and thus discharge the children to their parental homes after treatment. The Cheshire Homes provide institution-based type of intervention. As the trend in the provision of special educational needs has shifted towards integration of children into their communities and regular schools, one needs to ask what the implications could be on the parents' emotional and physical ability to cope.

1.2.7 Theoretical Framework

The study employs Hornby's (1994) adaptation model. This model is based on the grieving process and has been modified to discuss the continuum of emotional adaptations that parents of disabled children go through in order to come to terms with their child's condition. Hornby outlines the stages as Shock, Denial, Anger, Sadness, Detachment, Reorganisation and Adaptation. The principal focus of this study was to establish the effect that various factors have on the parents' transition along the continuum described by Hornby.

1.3 STATEMENT OF THE PROBLEM

The current trend in special education provision lays emphasis on integration of children with disabilities into the mainstream. This entails that children will not only be integrated into regular schools, but, that they will also have to blend in with the larger mainstream society. Parents play an important role in ensuring that their children with disabilities fit comfortably into society's mainstream.

In carrying out this role, parents are likely to encounter various practical as well as socio-emotional problems. In view of this assumption; this research set out to investigate what emotional adjustments the parents of these disabled children make during the parenting of their children, following their discharge from Cheshire Home.

1.4 PURPOSE OF THE STUDY

The study established the emotional adjustment that parents of disabled children make after their children are discharged from Cheshire Homes in Lusaka District. The major task of the study was to identify variations with which parents adjust emotionally and factors that affect their varied emotional responses.

1.5 OBJECTIVES OF THE STUDY

1.5.1 Main Objective

The main objective of the study was to establish emotional adjustments made by parents of physically disabled children, after their discharge from Cheshire Homes.

1.5.2 Specific Objectives

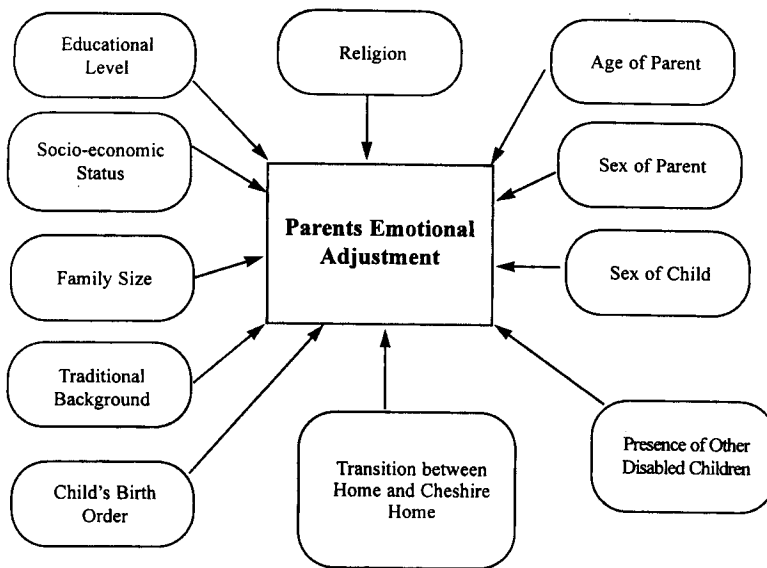
- 1.5.2.1 (i) To establish the emotional adjustments made by individual parents
- 1.5.2.2 (ii) To establish a possible relationship between the following background factors (see problem analysis chart) and parents' emotional adjustment: type of family; sex of parents; sex of the child; educational level of the parent; socio-economic status; religion of parent; traditional background of parent; birth order of the child and number of disabled children
- 1.5.2.3 (iii) To establish the effect that the child's transition between home and Cheshire home has on the parent.
- 1.5.2.4 (iv) To establish any effects that previous professional counselling has had on parent's emotional adjustment.

1.6 RESEARCH QUESTIONS

The study attempted to answer the following questions in order to meet the stated objectives.

- 1.6.1 How do different individual parents react to their child's disability?
- 1.6.2 What effect does the child's transition between home and Cheshire home have on the parents' emotional adjustment?
- 1.6.3 What effect does the presence of other disabled children in the family have on the parent's emotional adjustment to disability?
- 1.6.4 Does previous professional counselling have effect on the parent's emotional adjustment?

1.7 PROBLEM ANALYSIS CHART



1.8 SIGNIFICANCE OF THE STUDY

Statistical projections show that the levels of disabled children are on the increase. But observations show that in Zambia, there is no corresponding rise in the number of services available for both children and their parents. The few services available are over stretched. They only cater for a minimal number of children. Kabulonga Cheshire Home for example, does not offer professional counselling services. In addition the institution faces constraints in meeting even the basic needs of the children under its care. Because of the problems stipulated above, the establishment of the emotional adjustment made by parents of children who are fortunate enough to receive treatment is vital. In addition, relevant literature reveals that the area of parental emotional response to childhood disability is not widely researched in Zambia. This is particularly true of research based on the grieving process theory.

It was hoped that the findings of this study would be utilised to introduce the aspect of psychosocial support for parents of the disabled children admitted to the institution. In this vein, the study encourages the parents to give their views on possible interventions in the promotion of psychosocial support.

Theoretically, it was hoped that though the findings could not be generalised beyond the Cheshire Home, they would help to fill in the gaps identified during literature review and make a reasonable contribution to the existing body of knowledge.

1.9 OPERATIONAL DEFINITION OF KEY TERMS

1.9.1 Parents emotional Adjustment

Refers to the emotional experiences that the parent has undergone in response to the child's disability; based on the seven stages of Hornby's adaptation model.

1.9.2 Discharged Physically disabled children

Refers to children with reduction or loss of function in their skeletal, neuro-muscular system who have undergone treatment at Cheshire homes in Lusaka and have since been sent to their parental homes.

1.9.3 Socio- Economic Status

Refers to two aspects namely:

- (a) The parents' employment status, which is broadly divided in two categories namely: employed, and non employed
- (b) The monthly income earned by working parents.

1.9.4 Family Size

Refers to the total number of biological children and spouse. The registered/recognised permanent dependants living within the household shall be taken into account.

1.9.5 Educational level

Refers to the highest academic achievement of the parent.

1.9.6 Religion of Parent

Refers to the attitude and feelings of the parent towards the disabled child in view of his/her belief in transcendent controlling power.

1.9.7 Age of Parent

Refers to the age at the parent's last birthday.

1.9.8 Sex of Parent

Is used to distinguish between the male and female parent.

1.9.9 Sex of the Child

Is used to distinguish between the male and female child.

1.9.10 Professional Counselling

Refers to the one to one discussions held with a trained psychosocial counsellor tailored to assist the parent to come to terms with the child's disabling condition.

1.9.11 Presence of other disabled children

Refers to the presence of a disabled sibling living with or away from the family.

1.9.12 Birth Order

Refers to the position of the child in the family in relation to the siblings.

Chapter Two

2.0 LITERATURE REVIEW

This chapter consists of a general review of some of the existing literature on emotional experiences of parents of children with disabilities. In addition, a general critique of some of the major studies based on the methodological approaches which may have influenced the outcomes of certain results presented by the writers referred to so far has been included. Literature on parental problems reveals that there are two main approaches to the study of this area. The first approach involves the study of facts about family difficulties. This approach concerns practical factors and is the hallmark of British research. The second one, which Thomas (1978) says seems to be typical of American work, tends to emphasise on the emotional reaction of parents and siblings to disability. It must however, be pointed out that some studies involve both approaches.

Dyson (1991) examines the association between child with handicaps and parental stress, as well as family functioning with emphasis on establishing various factors that relate to parental stress, resulting from the presence of a disabled child in the family. In addition, Dyson analyses the effect of the presence of a disabled child on family functioning. The study reveals that although the families of disabled children appeared to have a high degree of stress, they differed only minimally from 'normal' families in their functioning. Dyson (1991) employed a quantitative method and, therefore, may not have been able to get to the depth of the problems parents face. Emotional problems are highly subjective and cannot be adequately assessed by quantitative method. Kazuo (1994), conducted a similar study but unlike Dyson, their research method included both qualitative and quantitative approaches. Because of this approach, they obtained more descriptive information by use of open ended questions. The respondents were encouraged to talk about issues concerning their coping and that of the child. In the quantitative data collection Kazuo requested the parents to fill in questionnaires similar to the one used by Dyson.

Dyson (1991)'s selection of the study sample also shows methodological weakness. The nature and degree of disability of the children for example, was not taken into account. Dyson's sample included children with different types of disabilities of varying severity. Other studies have revealed that different disabilities of varying severity may trigger off varied responses. One such scholar is Kamfe (1989) who suggests that several variables influence the family's adaptation to the birth of a disabled child, including the child's specific disability. Dyson (1991) also overlooked the child's birth order and family size. Dyson's omission of the family size, may be attributed to the fact that she applied a methodology best suited to the western setting where extended family system is not practised. It can be assumed that the larger the family size the greater the levels of stress experienced. However, it should be noted that in a larger family, members may be able to assist with care of the disabled sibling which could help to reduce the parental stress. In addition, Dyson does not take into account the age of the parent. This researcher's view is that age and experience of the parent may influence stress levels. It is more than likely for instance, that a young mother having a disabled first child, is likely to experience more emotional disturbances, than an older and more experienced woman whose disabled child ranks low on the birth order. Finally, Dyson does not take into account the presence of other siblings with disabilities in the family, and whether or not this added to the stress reported to have been experienced by the parent. Although there are identified gaps in Dyson's work, her research has several merits that deserve acknowledgement. Dyson, for example dealt with control variables such as socio-economic status.

This study is of the opinion that socio-economic status may have a bearing on the emotional stress experienced by the parent. The coping pattern employed by a wealthy parent who is self sufficient, may be different from that of a poor parent. The latter is likely to experience a greater impact of the burden of having to meet the additional needs of the disabled child. This would inevitably add to the adverse emotional experiences that the poor parent goes through.

Scholars on disability have studied similarities and differences of parental stress between mothers and fathers of children with disabilities, and have shown that there

are sex differences in emotional reactions to disability. One such scholar is Krauss (1993) whose study results revealed that fathers reported more stress related to their child's temperament and their relationship to the child. Krauss also found that mothers on the other hand, reported more stress from the personal consequences of parenting. Although Krauss establishes that both parents experience some degree of stress, the study does not give reasons for the variation. Probably the use of qualitative approach could have revealed more on this aspect. Kraus's findings differ slightly from Gerety (1991)'s study which explains that in western culture, men are socialised to conceal their feelings of grief from others, including those closest to them.

Makasa (1988) examined some practical and psychological problems faced by parents of mentally handicapped children in Zambia. Makasa's assessment of the psychological effects that the disabled child has on the family revealed that most parents showed perfectly normal responses to the presence of the disabled child. By 'normal', Makasa meant that although some parents felt disappointed that they had a disabled child, the majority achieved a satisfactory adjustment to their psychological and emotional problems. Makasa further alludes to the fact that these responses may have been as a result of culture, severity and onset of the problem. Makasa does not give empirical evidence to support his findings and as such, the magnitude of the problem has not been measured.

Besides measuring the stress experienced by parents of disabled children, literature reveals that various other approaches have been taken in investigating parental emotional problems. One such approach is the use of theoretical models. Bowlby (1973); Gerety (1991); Mereness and Taylor (1978); Pasquali *et al* (1985); all acknowledge grieving as a psychological response to suffering that follows the actual or perceived loss of an object that is of value. Bowlby (1973) as cited by Pasquali *et al* (1985) has established that grieving is set in motion by a loss or separation that leads to feelings of emancipation from the lost object. He further explains that the individual experiences an array of feelings ranging from numbness and anger to healing and resolution. Lindeman (1944) conducted extensive studies which resulted in his detailed description of the grieving process. The characteristics that Lindeman

describes are echoed by Gerety (1991), Pasquali et al, (1985) Mereness and Taylor (1978). Lindeman from extensive studies describes the grieving process in detail. However, unlike Lindeman, Mereness and Taylor only describe four stages. They omit the feelings of hostility that Lindeman includes in his description.

Whilst agreeing that grief and mourning do not progress in a linear fashion, Gerety (1991) explains that they are generally described as occurring in a sequence of phases, clusters of reactions or stages that change over time. In addition, Gerety introduces the concept that adaptive denial. Denial occurs to protect the individual from overwhelming stress of loss. Pre existing factors such as the person's personality, are also said to affect the ultimate outcome of mourning.

However, although some scholars such as Lindeman have supported the grieving process as a natural reaction to loss, it has been noted that no comprehensive theory exists that explains the classification and management of normal grief. Reports show that researchers and clinicians who have continued to study grief since Lindeman, stress that, various factors affect the process of grief. These include previous experience, age, and support system of the person facing the loss, ethnic and religious backgrounds; physical and mental health and whether the loss is sudden or anticipated, influence grief responses, the process of mourning and the length of time it takes to complete grief work.

2.1 APPLICATION OF THE GRIEVING PROCESS THEORY TO DISABILITY

Hornby (1994) adopted the grieving process in order to describe the Adaptation Model related to disability. He states that although several models have been proposed to explain the process which people experience in adapting to a family member with a disability, the most widely used model involves a continuum of reactions. These begin with diagnosis of the disability through which parents pass in order to come to terms with the disabling condition. Although Hornby describes the stages in unison with the grieving process, Hornby does not allude to the fact that there are variables that do affect parental adaptation to the presence of a disabled child

in the home. Some scholars such as Shea and Bauer (1994), however, state that although adaptation of families to members with disabilities has been perceived as a progression through a series of psychological stages, it is not a self-limiting process. They cite Krothe and Otteri (1985) as supporting the view that parents experience a chronic sorrow, grief that persists throughout the life of the parent and child. In the same vein, Gascoigne (1996), gives an example of a research carried out by SCOPE which examined the experiences of a number of parents whose children were diagnosed with disabilities very early in life. The research drew two important conclusions; that even if a child has been diagnosed with disability very early in life, it does not mean that the emotions experienced by the parents can fade away. Although the study included parents of adult people with disabilities, their memories of the moment their children's conditions were disclosed were still very real and detailed. The same applies to the emotions experienced. The second conclusion was that although parents reported having experienced the stages of adaptation, they did not necessarily do so in the sequence that was described by Hornby.

Sawrey (1972) states that while there are different patterns of reaction to evidences of the inadequacy of one's offspring, these are not peculiar to parents of children with disability but are also experienced by parents of non disabled children from time to time. Blacher (1984) cited by Shea and Bauer, concludes that the stages are as a result of clinical judgement, based on interviews with parents of children with disabilities, rather than analysis of the objective data. Blacher's view is supported by Allen and Afleck (1985)'s report which found no evidence to support the stage-like arrangement or grouping of parent's emotional reaction. During their literature review. They conclude that application of the stage theory is problematic as it presupposes a final stage; closure with adjustment to or acceptance of the situation. Kratochiveil and Deverebeex (1988) suggest that despite their seemingly overall adjustment to the child's disability, parents do experience "down periods." There are occasions when the initial reactions may be re-experienced. This view seem to be in line with the views cited by Hornby (1981) which state that, although parents of children with disabilities to some extent resolve their feelings of loss, they do experience chronic sorrow.

A reaction to this criticism is that, emotions are subjective and that some amount of subjectivity is necessary during the investigation of parents' emotions. The combination of qualitative and quantitative methods of research seems to be the best approach in order to attain a clear and holistic picture of the parental emotional adjustment.

2.2 SUMMARY

The study identified several gaps in methods employed by the researchers whose works have been reviewed. These have been discussed in this section of the chapter with special reference to this study.

2.2.1 Although Dyson (1991) and Kamfe (1989) suggest that several variables influence the parents' emotional responses to disability, they do not take into account the individual parent's age and birth order of the child. It is, in this researcher's view, that age and experience of the parent may influence their stress levels. If a young inexperienced mother for instance, has a disabled first child, she is likely to experience more emotional disturbances than an older and more experienced woman whose child ranks low in the birth order. This study examines the influence of the parent's age as well as the child's birth order on the parents emotional adjustment.

2.2.2 The family size is a factor that has been overlooked by the reviewed studies. This study takes into account the family size and its possible effect on the parent's emotional adjustment.

2.2.3 Review of literature shows that there are sex differences in emotional reactions to disability. This study found it imperative to establish whether or not the Zambian male parent understudy experiences emotional changes on the same level as the female parent.

2.2.4 Dyson (1991), and Makasa (1988), utilised single research methods. This could have resulted in these researchers' not having an in-depth perceptions of the emotional problems faced by the parents under study. Although this research took a qualitative stance, quantitative data was utilised for the purpose of triangulation.

The issues arising from the literature review, and the fact that no conclusion has been reached on the applicability of the adaptation process to the study of emotional adjustment of parents with disabled children makes it an area open to further research.

Chapter Three

3.0 METHODOLOGY

3.1 INTRODUCTION

This research adopted a case study design. Its focus was to establish the emotional adjustments made by parents of children with physical disabilities after their discharge from institutionalized care. Both quantitative and qualitative methods were used to investigate the emotional adjustments the parents under this study had undergone. Owing to the subjective nature of emotions, the research study took a predominantly qualitative stance. However, for reasons of validity, reliability and the production of a holistic view of the parents' experiences, the researcher found it necessary to triangulate methods used in the overall study design. Qualitative data was used for qualification of the recorded emotional adjustments. This was mainly helpful in the area of validation of findings.

Qualitative data on the other hand facilitated the interpretation and detailed discussion of the quantitative data. It helped to fill in the gaps where quantitative data was not able to fully address the research questions. In addition, the subjective nature of emotions made it imperative that the more value-laden qualitative data be utilised to explain issues in great depth.

3.2 DEVELOPMENT OF RESEARCH INSTRUMENTS

A review of literature on emotional adjustment of parents of children with disabilities formed the basis for the development of data collection instruments used in this study. Greater emphasis was placed on the adaptation process model described by Hornby (1994). This adaptation process model (also called the stage model), is the theoretical model upon which the research study is based. It is one of the most widely used models in the study of emotional adjustment and involves a continuum of stages of reaction. The stages outlined by Hornby are; shock; denial; anger; sadness; attachment; reorganization and adaptation.

In designing the instruments, the study, sought to identify possible relationships between the various factors outlined in the objectives, and the adjustment made by the parent in comparison with the stages outlined by Hornby's model. Three data collection instruments were designed.

3.2.1 Staff Questionnaire

Self-administered questionnaires were developed for the members of staff. They consisted of 22 questions. These were a mixture of open ended and closed-ended questions. The researcher designed the questionnaires to enable her access rich details of the problem under investigation. From the staff's questionnaire, information on professional qualifications, years of service and experience as well as previous training in psycho-social counselling was sought. Questions on the main duties and professional qualifications held by the staff to a large extent, were considered indicative of the capability of the staff to offer psycho-social support to the parents whose children were admitted to the Home.

3.2.2 Parent Interview Schedule

The parent interview schedule was semi-structured and consisted of 29 questions. Information sought in the questionnaire about parents included demographic data such as age, sex, religion as well as education. Information was also sought on Social Economic Status (SES), which was mainly focused on the current employment status and level of income.

The section on emotional adjustment of the parent interview schedule sought information on emotional reactions of during child transition between the parental home and the institution. In addition, information on previous professional counselling was also sought. The main question in this section was a matrix type question which required the parent to freely give a detailed account of all his or her experiences during the period following the child's discharge. The matrix was structured in form of a checklist that required the

interviewer to tally the various observations made during the parent's narration as indicated below:

- ◆ number of positive symptoms corresponding with stage process.
- ◆ sequence in which the symptoms were experienced.
- ◆ factors or incidences that triggered off the symptoms expressed.
- ◆ duration of the experienced symptom.

Overall, the interview schedule sought in-depth information about the individual parent's emotional experiences in relation to the child's disability.

3.2.3 Focus Group Discussion Guides

Guidelines for the two focus group discussions were prepared for use with the biological parents and the auxiliary staff (house parents) responsible for child-care in the dormitories. The major topics for discussion were based on the adaptation process model. Factors affecting the parent's emotional adjustment from the child's first admission to Cheshire home up to the child's subsequent discharge were sought. The theme for the topics for discussion was basically based on the study objectives.

3.3 PILOT TESTING OF INSTRUMENTS

The questionnaire and interview schedules were pilot-tested in order to identify any ambiguities, inconsistencies and to check for clarity of the data collection instruments. The pilot testing of these two instruments was carried out at the local University Teaching Hospital Day Care Centre for children with learning disabilities. A total of four staff and six parents of the Day Care Centre were included in the pilot sample. The pilot study took a whole day and was conducted by the researcher. Following the pilot testing, corrections were made in the phrasing and sequencing of the questions and all other ambiguities corrected.

3.4 FIELD WORK

The main study was conducted between October, 1999 and January, 2000. It was conducted in two parts. The first part involved data collection at Cheshire Home in

Kabulonga residential area. Data collection involved distribution of staff questionnaires as well as conducting one Focus Group Discussion (FGD) with the auxiliary staff. In addition to data collection, the initial identification of the parent population was carried out during this stage. The second stage consisted mainly of visits to the various parental homes during which the semi-structured interviews and one FGD with the parents were administered.

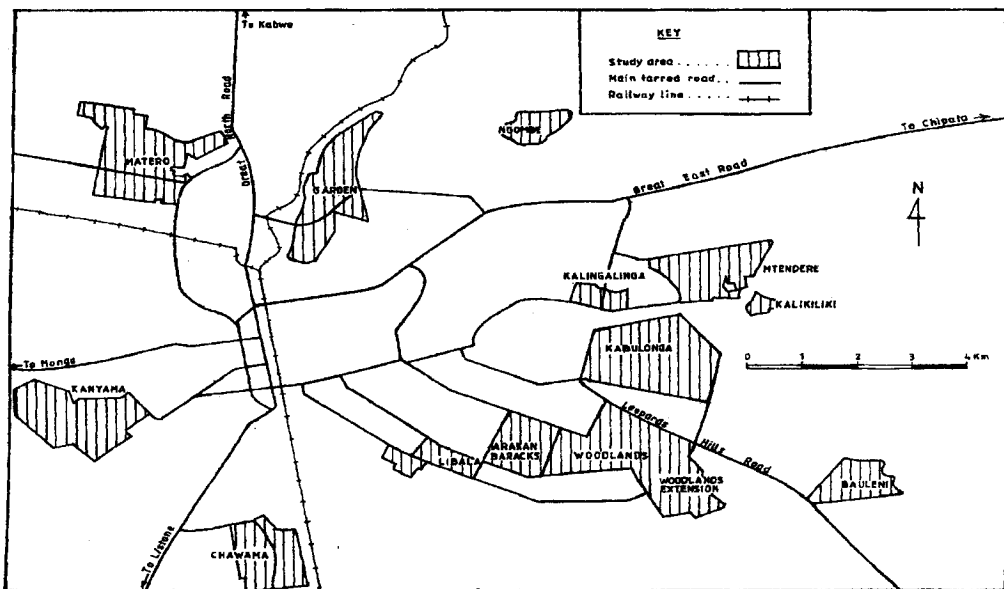


Figure 1: Map of Lusaka showing areas covered during fieldwork.

3.5 SAMPLING PROCEDURE

Convenient sampling technique was used to select the subjects for the study. The choice of technique was necessitated by the case-study research design as well as the low numbers of both staff in the institution and the parents who were eventually located in the process.

The staff sample consisted of nine professionals and six auxiliary workers. The total sample size was fifteen. However, two professionals were unwilling to participate in the study. No reasons were offered for their stance. Their decision was respected and accepted. The two categories of staff were selected because it was assumed that they were the ones directly responsible for childcare, as well as staff – parent interaction.

3.5.1 Parents

Parents included in the aggregate population were biological parents resident in Lusaka who had children discharged from Cheshire Home within the five- year period, up to the date of the data collection. The emphasis on the selection of biological parents was to ensure that only the feelings of biological parents were studied. In order to identify these parents, the children's hospital files as well as admission register were scrutinised. A list of all households of the parents who had children discharged starting from January, 1994 was drawn. A total of twenty-eight households were included on the list. The researcher then set out to verify the location of the parents whose households were listed by physically going to the stated homes using the stated house numbers, as well as sketch maps prepared with the aid of the institution's driver. This exercise resulted in a final sample of twenty parents.

3.5.2 Drop outs

During the sampling procedure it was observed that some of the parents listed under the twenty-eight households were unavailable for the exercise. This was because five of the parents had since died and their children were under the care of foster parents. Other children were being looked after by their grand-parents, as well as other relatives even at the time of their admission to the home. Some of the parents had since moved leaving their homes occupied by tenants who did not know their whereabouts. There were three households that the researcher failed to locate owing to the fact that the house numbers were erroneous. One couple declined to participate in the study because they said they had not received adequate help for their child and did not want to discuss the child's condition with any professionals.

3.6 DATA COLLECTION

No research assistants were used for data collection due to inadequate finances. Primary data was collected using the three data collection instruments. The combination of the three instruments helped to achieve triangulation of findings for the presentation of a holistic picture.

3.6.1 Administration of Questionnaires

The staff questionnaires were administered to the professional staff. This method was decided upon because the staff are literate. The questionnaire method gave them freedom to respond freely without feelings of intimidation. In addition, the self-administered questionnaire was less time consuming. The researcher distributed and collected the questionnaires personally. The exercise took three days.

3.6.2 Administration of Semi-Structured Interviews

Interviews were administered on a one-to-one basis in either English, Bemba or Nyanja in accordance with the respondent's preference. Care was taken to avoid distortion of the meaning due to language medium. This method of data collection was the most appropriate for the parents because it presents the opportunity for interviewees to express their experiences, views and feelings freely. The researcher was given the opportunity to make clarifications through the use of probing questions.

3.6.3 Focused Group Discussion

The staff and parents who had not been subjected to the questionnaire and interview schedules respectively were included in the Focus group discussions. The two discussions were held separately; one with either group. The discussions were recorded using audiotape and recorder so as to avoid missing any details of the discussion. The discussions were later transcribed from tape. In order to allow for free flow of information, the respondents were guaranteed confidentiality.

3.7 DATA PROCESSING AND ANALYSIS

Data was analysed in two stages. All the quantitative data collected using the staff questionnaire and parent interview schedules was cleaned and coded. Data was then

entered into the computer using Statistical Package for Social Sciences (SPSS). Data was further cleaned by running frequency tables for the various factors to rule out errors and inconsistencies. Finally, the data from the parent interviews was further analysed and presented as cross tabulations between the factors being investigated and the emotional symptoms expressed by the individual. Qualitative data collected through the use of FGDs was transcribed from the audiotapes and subjected to thematic analysis. It is presented in form of verbatim reports under subheadings guided by the main emerging themes.

3.8 CONSTRAINTS ENCOUNTERED DURING FIELD WORK

The lack of records of house numbers of the discharged children made it extremely difficult to locate their parents. In some instances, the researcher had to trace the parent to the working places. This made the subject tracing a tedious and slow process. In addition to this, poor town planning and lack of civil authority maps of unplanned townships made it extremely difficult for the individual households to be located. This was particularly so where the absence of street names and house numbers were concerned. The houses in most cases were not numbered and even where the researcher had a sketch map of the directions, it was not easy to locate the houses. For example, on two instances, despite having a sketch map drawn with the aid of the driver, the researcher was compelled to return to the institution in order to find out the primary school being attended by children. The schools did not offer much help because they too, did not have knowledge of where the children were living. The researcher had to wait for schools to re-open in order to locate the children's parents.

Limited financial resources made it extremely difficult for planning and efficient data collection. For example, the amount of money allocated for transport was inadequate. As such the researcher utilized her personal commercial vehicle and in the process incurred heavy fuel costs during the period of data collection.

Adverse weather conditions also affected the data collection process. The researcher had no protection against the heavy rain and on occasions got wet when walking

between homes in the same neighbourhood. On one occasion the researcher caught bronchitis after being soaked by rain. This further slowed down the data collection process.

3.9 ETHICAL CONSIDERATIONS

Before the study was embarked on, permission was sought from the Sister-in-charge of Kabulonga Cheshire Home. All the subjects recruited for their interview gave an informed verbal consent and nobody was interviewed against their will. The interviews were conducted on a one-to-one basis in privacy. Spouses were not allowed to sit in during interviews. During the FGDs the parents were promised anonymity and no names have been included in the report.

The staff were also assured of privacy and requested not to share information they entered in the questionnaires. In addition no names appeared in the instruments or analysed data. All respondents were identified by serial numbers.

Chapter Four

4.0 RESULTS AND DISCUSSION

4.1 INTRODUCTION

This chapter presents results and discusses the emotional adjustments made by parents of the physically disabled children who were studied. The discussion is guided by the research objectives and is based on the evidence obtained from data collected in the field.

4.2 SOCIO-ECONOMIC BACKGROUND

4.2.1 *Sex*

A total of fifteen parents who included both male and female were interviewed. Of these parents, five (33.3%) were male and 10(66.7%) were female.

4.2.2 *Age*

Of the fifteen parents who were interviewed, fourteen had a knowledge of their age while one female respondent did not know her age. The mean age of the fourteen subjects who knew their age was 33 years. The minimum age of the group was 25 years, with the maximum age being 65 years.

4.2.3 *Religion*

The majority of the parents who were interviewed were Christians, represented by 87%. Two respondents in the group (13%) belonged to other religious. None of these parents were Muslim, Buddhist or traditional worshippers. This information is illustrated in table 1 below.

Table 1: Religious Affiliation Of Parents

RELIGIOUS AFFILIATION	FREQUENCY		TOTAL
	MALE	FEMALE	
Christian	4(26.7%)	9(60%)	13(86.7%)
Muslim	0(0%)	0(0%)	0(0%)
Buddhist	0(0%)	0(0%)	0(0%)
Traditional	0(0%)	0(0%)	0(0%)
Other	1(6.6%)	1(6.7%)	2(13.3%)
TOTAL	5(33.3%)	10(66.7%)	15(100%)

n=15

As Table 1 shows almost all the parents are Christians, with female parents being the majority. This is shown by the ration 9:4 female to male Christian affiliation.

The table also shows that the ratio of male to female respondents in the sample is 1:2.

4.2.4 Education

On the education level of the respondents, data revealed that twelve of them (80%) had been to school while the remaining three (20%) had never been to school. Of those who had been to school, eight (67%) had attained secondary education whilst four (33%) had been to primary school. None of them had gone beyond college level of education.

4.2.5 Social Economic Status

Eleven of the fifteen parents interviewed, representing 73% said that they were not in gainful employment. The four parents who were in gainful employment were asked what their monthly income was. The responses are illustrated in the table below.

Table 2: Monthly Income of Parents

INCOME EARNED PER MONTH	FREQUENCY
Less than K50,000	1(25%)
K50,001 –K100,000	2(50%)
K100,001 – K200,000	1(25%)
K200,001 – K300,000	0(0%)
Above K300,000	0(0%)
TOTAL	4(100%)

n= 4

We can deduce from table 2 that at least all the parents who were in gainful employment earned K50,000 and K200,000. None of them earned an income exceeding K200,000.

The four parents were further asked as to whether or not they thought the money they earned was adequate. In response two (50%) said that they considered their monthly income to be inadequate whilst the other two said that it was just adequate with no money left over.

4.2.6 Traditional Beliefs

The parents were asked to give responses to a set of three statements designed to help depict their traditional beliefs. The results are illustrated below:

Table 3: Parents Traditional Beliefs

STATEMENT: Disability is caused by witchcraft	
Response	Frequency
Indifferent	1(6.6%)
Strongly agree	1(6.6%)
Agree	2(13.3%)
Disagree	4(26.6%)
Strongly disagree	7(46.6%)
TOTAL	15(100%)

n =15

The table shows that the majority of the parents (seven representing (46.6%) strongly disagreed with the statement, whilst the majority (6.6%) were indifferent and agreed strongly respectively. Two of the parents (13.3%) agreed whilst four (26.6%) disagreed with the statement.

In response to the statement that said all children including the physically disabled should undergo initiation when they came of age, the parents gave varied answers. Six parents (40%) agreed with this statement while one parent disagreed. Three of the parents were indifferent to the statement while the other three strongly agreed.

4.2.7 Number of disabled children

The average number of disabled children per parent was one child, with the maximum number being three.

4.2.8 Birth order

The majority of parents who were interviewed representing 40% said that their disabled children ranked second in the birth order. However, one parent did not respond to the question.

4.2.9 Sex of the child

The majority, 8(53%) had male children only. Six (40%) of the parents had female disabled children only while one of the parents had two female children and one male child.

All the data shown in the above section was obtained from a Draft Data analysis sheet, shown in appendix 2.

4.3 EMOTIONAL ADJUSTMENTS MADE BY THE PARENTS

Data from the field reveals that the emotional adjustments expressed by parents in response to their children's disabilities were not uniform. This is evidenced by the fact that parents expressed varied symptoms, which lasted for varying duration of

time. For example, the minimum duration for shock and disbelief that was recorded for the group was 3 months whilst the maximum duration for the same was 36 months. This data shows that the difference between the two experiences was quite marked irrespective of the fact that all the parents in the group were coping with a similar disability. Also, the results show that there are individual differences in the time taken for individual parents to pass from one emotional experience to the next. In addition to this, parents had an assorted combination of triggers of the emotional symptoms they reported to have experienced. These triggering factors varied for the different emotions experienced, as illustrated in Table 4 below.

Table 4: Trigger of the Emotion Expressed

TRIGGER OF THE EMOTION EXPRESSED	FREQUENCY
(a) Sadness(change in behaviour & mood)	
Nil	4(26.7%)
Husband (step father's failure to accept the child)	1(6.7%)
Child's failure to help with household chores	2(13.3%)
Child's inability and helplessness	1 6.7%)
Child's withdrawal from school	1(6.7%)
Husband's death	1(6.7%)
Sight of disabled child	1(6.7%)
Wish of having whole child	1(6.7%)
Child's wish to go back to Cheshire homes	1(6.7%)
Illness of second disabled child	1(6.7%)
Child's refusal to co-operate	1(6.7%)
Total	15(100%)
(b) Denial	
Nil	12(80%)
Pursuit of traditional healers	2(13.3%)
Watching child at play with able bodied peers	1(6.7%)
Total	15(100%)

Of the three parents who experienced denial for example, two (67%) said that faith in and pursuit of traditional healers caused this experience. The third parent said that it was triggered off each time he watched his disabled child at play with other 'normal' peers. On the other hand, the emotion of sadness was triggered off by factors such as the child's refusal to co-operate with the care being given at home. The wish to have a 'whole child' as well as other factors such as the child's desire to go back to the institution also triggered off these emotions.

The sequence or order in which the parents experienced these symptoms of grief was also varied and did not follow any orderly pattern. A notable observation is that most of the parents when asked to rank their experience according to the sequence in which the symptoms occurred, did not go beyond the fifth ranking position. This is suggestive of the fact that on average, most parents experienced an assortment of the seven stages of the adaptation process without necessarily going through the whole continuum suggested by Hornby (1995).

These results obtained through the parent interview were supported by the staff questionnaire results. The staff explained that they had observed the various patterns of parental emotional adjustments. For instance, 36% of the staff interviewed responded that they noticed that parents did not accept their children's disability, while 14% said that the parents did accept their child's condition and co-operate with the staff in their child's care and management. Results are illustrated in table 5 below.

Table 5: Parents Response to Child's Condition

OBSERVED RESPONSE	FREQUENCY
Parents do not accept child's disability	5(36%)
Parents are sad	4(28%)
Parents are expectant and hopeful	3(21%)
Parents accept their child's condition and co-operate with staff	2(14%)
Parents display unreasonable expectations and demands	0(0%)
TOTAL	14(100%)

n = 8

(Members of staff were allowed to give more than one response). The majority, 36% of responses given were that the parents do not accept their children.

The FGDs revealed that the parents react differently to the disability of their child.

“You may think that you have accepted the problem but, from nowhere the thought of your child crosses your mind. Even if you are happy, you begin to cry.”

Stated the mother of a well adjusted disabled boy who had been discharged from the institution and had lived at home with the biological parents for five years. One male parent however, said that he had experienced no problems in his emotional adjustment. He explained that he had had a quick transition.

“I have no problems accepting my child. It is something that I have had to accept and the return of the child from Cheshire Home has been very welcome.”

Based on this evidence it can be deduced that this group of parents did not express the postulated behaviour peculiar to grief contrary to Lindemann (1944)'s views. Lineman's theory states that when persons suffer loss they have to work through the tabulated stages of grief in neat progression in order to reach the final stage of acceptance of the loss. These findings are more inclined towards Gerety (1991)'s views. Gerety states that while grief and mourning do not proceed in a linear fashion, they generally occur in a sequence of phases, clusters of reactions or stages that change over time.

Hornby (1995) expresses views that best summarize our findings. He states that in reality, the adaptation process is not as clear-cut as simply moving from stage to stage would suggest. He further states that in real life situations, one reaction maybe uppermost at a particular time. However, he lays emphasis on the fact that certain amounts of the other reactions involved in the process may also be present. Hornby's

views are a possible explanation for the fact that in this study, it was not easy to identify a clear cut and uniform emotional transition made by the parents through the adaptation process. However, a diffuse picture of emotional adjustments that did not follow any organized pattern of occurrence can be seen. This is highly indicative of the fact that emotional adjustment is a highly individualized experience.

4.4 RELATIONSHIP BETWEEN SOCIO-ECONOMIC BACKGROUND FACTORS AND THE PARENT'S EMOTIONAL ADJUSTMENT

Much of the evidence discussed in this section of the study is based on data obtained through the questionnaires and Focus Group Discussions held with parents and members of staff of Cheshire Homes. It was necessary to use this methodological approach in order to present a comparative analysis for the purpose of verifying certain responses. In addition, to see the consistency in various views held by parents and staff.

4.4.1 Family Size

The views expressed by both parents and members of staff were that the size of the family does not necessarily have an adverse effect on the parent's emotional adjustment. The larger the family the easier the burden of care on the parent as there is increased help for the care of the child. Conversely, the smaller the size of the family, the greater the burden of care on the parent. However, some parents linked the family size to economic implications.

“In addition to having to provide for a large family, they have the special needs of the “lame” child to cater for...”

This evidence gives us reason to believe that this is a relationship between the family size and emotional adjustments. The importance of the extended family system cannot be over emphasized in this part of the world. The African family members have tended to be closely knit and have often been the source of comfort and support during situations of grief. There has always been support for the grieving persons in

spite of the current breakdown of the family system, that has resulted from globalization and resultant adaptation of the more western family and cultural trends.

4.4.2 Sex of Parent

Evidence from the field revealed that the sex of parents had some influence on their emotional adjustment. The two FGDs strongly supported the evidence obtained through the parent interview.

Table 6: Sex of Parent and Symptoms of Grief

Sex	Sum of symptoms expressed												
	Shock and disbelief			Denial				Guilt					
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total			
Male	3 60%	2 40%	5 100%	3 60%	2 40%	-	5 100%	5 100%	-	5 100%			
Female	8 80%	2 20%	10 100%	8 80%	1 10%	1 10%	-	7 70%	3 30%	3 70%			
Total	11 73%	4 26.7%	15 100%	11 73.3%	3 20%	1 6.7%	15 100%	12 80%	3 20%	15 100%			
Sex	Sum of symptoms expressed												
	Anger			Sadness				Detachment			Reorganisation & adaptation		
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total	Nil	One	Total
Male	4 80%	1 20%	5 100%	1 20%	3 60%	1 20%	5 100%	5 100%	-	5 100%	1 20%	4 80%	5 100%
Female	7 70%	3 30%	10 100%	2 20%	6 60%	2 20%	10 100%	8 80%	2 20%	10 100%	3 30%	7 70%	10 100%
Total	11 73%	1 26%	15 100%	3 20%	9 60%	3 20%	15 100%	13 86%	2 13%	15 100%	4 26%	11 73%	15 100%

Though there were a higher percentage of males than females who experienced shock and disbelief as well as denial; there were 80% of males as compared to 70% of females who had experienced re-organization and adaptation. This data is suggestive of the fact that the male parents tended to accept their child's disability more easily than female parents.

The FGDs revealed that single male parents experienced more emotional problems as they adjust than do the female parents. "...*fathers are less kind*" reported one of the male members of staff and he gave an example of a male parent who dumped his disabled child outside the gate of the institution with no provisions. Another example

of a child named “K” who often complained against his single father’s neglect was also given.

“... although, I am going home to my father, he does not care”.

The female staff however, had different views from those expressed by the male staff. They generally felt that there were no gender differences in the way parents respond to their disabled children.

*“...take for example “L” his mother abandoned him when his step
father chopped off his leg with an axe.”*

The discussions also revealed that female parents engaged in second marriages have problems coping with their children’s disabilities. This is because they very often face undue pressure to neglect their children in conformity with their spouses’ demands. They are often not empowered and are vulnerable and often chose to neglect their children in order to maintain the new marriage. Although they expressed divergent views, both the staff and parents agreed that both male and female parents were affected by the stigma attached to having a disabled child. They also concluded that this, to some extent does affect the parents’ adjustments to the child’s disability. From this data we see that there is a relationship between the sex of the parent and their emotional adjustment of the child’s disability. These findings are similar to Krauss (1993) whose study revealed that there are emotional differences between mothers and fathers of children with disabilities.

4.4.3 Age of Parents

Both the parents and members of staff expressed the view that the younger parents are often more negligent towards their disabled children. They said that this was attributable to the fact that they find it difficult to accept their disabled children. They also explained that parents having a disabled first child take it very badly unlike the older more experienced parents who adjust much better.

Table 7: Age of Parent and Symptoms of Grief

Age	Sum of symptoms expressed												
	Shock and disbelief			Denial				Guilt					
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total			
Don't know	1 100%	-	1 100%	-	1 100%	-	1 100%	1 100%	-	1 100%			
25-29	2 66.7%	1 33.3%	3 100%	3 100%	-	-	3 100%	2 66.7%	1 33.3%	3 100%			
30-34	2 100%	-	2 100%	2 100%	-	-	2 100%	1 50%	1 50%	2 100%			
35-39	2 66.7%	1 33.3%	3 100%	2 66.7%	-	1 33.3%	3 100%	3 100%	-	3 100%			
40-44	3 100%	-	3 100%	3 100%	-	-	3 100%	2 66.7%	1 33.3%	3 100%			
45-49	1 100%	-	1 100%	1 100%	-	-	1 100%	1 100%	-	1 100%			
55-59	-	1 100%	1 100%	-	1 100%	-	1 100%	1 100%	-	1 100%			
65-69	-	1 100%	1 100%	-	1 100%	-	1 100%	1 100%	-	1 100%			
Total	11 73.3%	4 26.4%	15 100%	11 73.3%	3 20%	1 6.7%	15 100%	12 80%	3 20%	15 100%			
Age	Sum of symptoms expressed												
	Anger			Sadness				Detachment			Reorganisation & adaptation		
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total	Nil	One	Total
Don't know	-	1 100%	1 100%	-	1 100%	-	1 100%	1 100%	-	1 100%	-	1 100%	1 100%
25-29	2 66.7%	1 33.3%	3 100%	-	2 66.7%	1 33.3%	3 100%	2 66.7%	1 33.3%	3 100%	1 33.3%	2 66.7%	3 100%
30-34	2 100%	-	2 100%	1 50%	1 50%	-	2 100%	1 50%	1 50%	2 100%	-	2 100%	2 100%
35-39	2 66.7%	1 33.3%	3 100%	1 33.3%	1 33.3%	1 33.3%	3 100%	3 100%	-	3 100%	-	3 100%	3 100%
40-44	3 100%	-	3 100%	1 33.3%	2 66.7%	-	3 100%	3 100%	-	3 100%	2 66.7%	1 33.3%	3 100%
45-49	1 100%	-	1 100%	-	1 100%	-	1 100%	1 100%	-	1 100%	1 100%	-	1 100%
55-59	1 100%	-	1 100%	-	1 100%	-	1 100%	1 100%	-	1 100%	-	1 100%	1 100%
65-69	-	1 100%	1 100%	-	-	1 100%	1 100%	1 100%	-	1 100%	-	1 100%	1 100%
Total	11 73.3%	4 26.4%	15 100%	3 20%	9 60%	3 20%	15 100%	13 86.7%	2 13.3%	15 100%	4 26.7%	11 73.3%	15 100%

However, results obtained from the parent interview show that though parents aged between 25 – 34 years expressed more guilt, anger and detachment, they also expressed having experienced more re-organization and adaptation. From this data it can be seen that though the younger parents of children with disabilities did

experience apparently more symptoms of grief, only 33% of them did not reach the level of acceptance of the child's condition.

From this evidence it can be concluded that there is a possible relationship between parent's age and emotional adjustment. And further that though the younger parents are said not to take the child's condition very well, they however, do go through a similar experience as their older counterparts. Evidence from Hornby (1995)'s study reveals that younger families are likely to experience stress than older more experienced ones. This is highly supportive of the results obtained in the current study.

4.4.4 Parents Religious Beliefs

Data collected from the FGDs suggests that there is a possible relationship between the parent's religious beliefs and emotional adjustment. It was generally agreed that Christian parents are much kinder to their children and take better care of them. This was attributed to the fact that they were assumed to have accepted their children's condition much more easily than their non-Christian parents. The parents supported this argument with an example of discordant couples.

“... if one parent is christian and the other is not, the non christian partner often does not care for the child as much as the religious one does.”

However, this notion was counteracted with an example of a female parent who stated that though her husband was a non-Christian he accepted their child's condition sooner than she did and even initiated the rehabilitation process.

The main emerging reason for the non-Christian parents' lack of care for their children was that they often indulge in escapist vices such as excessive beer drinking. As a result they often failed to care for the child and the adaptation process was greatly disturbed as they failed to live [^]the child's disability. In addition to what was discussed by the parents, the staff felt that the children of religious parents were often well adjusted and settled down well even after they left the institution.

From these discussions we see that both the parents and members of staff held divergent views about the effects that religion has on the parents' emotional adjustment. This finding is highly supportive of Bronfenbrenner (1979)'s ecological model which states that religious beliefs have a part to play on how families cope with having a disabled member. Bronfenbrenner further states that if the family believes that the disabled child is a gift from God then it will be much easier for them to accept the situation. If on the other hand the disability is seen as a form of punishment for some sin which has been committed, acceptance is delayed. Data collected in the current study does reveal that some of the parents explained that their faith in God did help them to accept their child.

4.4.5 Educational level of the Parents

Views expressed by both parents and members of staff during FGDs were that there is some relationship between parent's educational level and their emotional adjustment.

***“... educated parents have more exposure and knowledge
They therefore, accept the child's state more easily and
Co-operate with us care givers.”***

Another reason advanced for the difference in emotional adjustment was that educated parents were able to detect their child's hidden potential. As a result, they tended to accept them more easily and tried to assist them to attain this potential. Parents supported this view and stated that often times the uneducated parents often did not see this potential and regarded their disabled children as a ***“useless source of family burdens.”*** Often due to this belief, the parents said that uneducated parents tended to abandon these children as they were seen as a liability. However, other parents argued strongly that there was no relationship between education and emotional adjustment. The view that educated parents were also negligent also emerged. This was attributed to the belief that they were ashamed of their children.

“Education does not determine a parent’s emotional adjustment. My educated neighbour locks up her disabled child and says that she would like the child to be admitted to Cheshire Home and be kept there for good.”

Table 8: Educational Level of Parent and Symptoms of Grief

Educa-tional level	Sum of symptoms expressed												
	Shock and disbelief			Denial				Guilt					
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total			
No education	2 66.7%	1 33.3%	3 100%	1 33.3%	1 33.3%	1 33.3%	3 100%	2 66.7%	1 33.3%	3 100%			
Primary	3 75%	1 25%	4 100%	3 75%	1 25%	-	4 100%	3 75%	1 25%	4 100%			
Secondary	6 75%	2 25%	8 100%	7 87.5%	1 12.5%	-	8 100%	7 87.5%	1 12.5%	8 100%			
Total	11 73.3%	4 26.7%	15 100%	11 73.3%	3 20%	1 6.7%	15 100%	12 80%	3 20%	15 100%			
Educa-tional level	Sum of symptoms expressed												
	Anger			Sadness				Detachment			Reorganisation & adaptation		
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total	Nil	One	Total
No education	1 33.3%	2 66.7%	3 100%	1 33.3%	2 66.7%	-	3 100%	3 100%	-	3 100%	-	3 100%	3 100%
Primary	4 100%	-	4 100%	-	3 75%	1 25%	4 100%	4 100%	-	4 100%	2 50%	2 50%	4 100%
Secondary	6 75%	2 25%	8 100%	2 25%	4 50%	2 25%	8 100%	6 75%	2 25%	8 100%	2 25%	6 75%	8 100%
Total	11 73.3%	4 26.7%	15 100%	3 20%	9 60%	3 20%	15 100%	13 86.7%	2 13.3%	15 100%	4 26.7%	11 73.3%	15 100%

The quantitative data (Table 8) does not show any significant relationship between education and emotional adjustment. This data shows that there is no indication of a significant relationship between the parents’ educational level and emotional adjustment; cases cited as examples during the discussion could be as a result of individual differences between parents.

4.4.6 Socio-Economic Status

The FGD revealed that the parents generally held the opinion that the socio-economic status has no effect on them emotionally. On the other hand, the members of staff’s

discussion revealed that they too felt that the parents' SES did not have any effect on the parent's emotional adjustment.

G.M .had no arms yet by the time he was brought to the institution, his poor father had taught him how to feed himself using his feet. To me this shows that the poor father had accepted his child.”

The data collected from the FGD was highly suggestive of the fact that there is no relationship between the socio-economic status and the emotional Adjustments.

Table 9: Gainful Employment of Parent and Symptoms of Grief

Gainful employment	Sum of symptoms expressed													
	Shock and disbelief			Denial				Guilt						
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total				
Yes	4 100%	-	4 100%	4 100%	-	-	4 100%	4 100%	-	-	4 100%	4 100%	-	4 100%
No	7 63.6%	4 63.4%	11 100%	7 63.6%	3 27.3%	1 9.1%	11 100%	8 72.7%	3 27.3%	11 100%	8 72.7%	3 27.3%	11 100%	
Total	11 73.3%	4 26.7%	15 100%	11 73.3%	3 20%	1 6.7%	15 100%	12 80%	3 20%	15 100%	12 80%	3 20%	15 100%	
	Sum of symptoms expressed													
	Anger			Sadness				Detachment			Reorganisation & adaptation			
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total	Nil	One	Total	
Yes	4 100%	-	4 100%	-	3 75%	1 25%	4 100%	4 100%	-	4 100%	2 50%	2 50%	4 100%	
No	7 63.7%	4 36.4%	11 100%	3 27.3%	6 54.5%	2 18.2%	11 100%	9 81.8%	2 18.2%	11 100%	2 18.2%	9 81.8%	11 100%	
Total	11 73.3%	4 26.7%	15 100%	3 20%	9 60%	3 20%	15 100%	13 86.7%	2 13.3%	15 100%	4 26.7%	11 73.3%	15 100%	

Table 9, shows that the parent interview yielded slightly different results. It can be seen that parents in gainful employment on the whole express less symptoms of grief, than the parents who were not in gainful employment. These parents also experienced no symptoms of shock and disbelief, denial, guilt, anger and detachment. From these results, It can be seen that there is a relationship between the parents' socio-economic status and their emotional adjustment. These findings are supported by Bradshaw and Lowton (1978), who found that the socio-economic status of the parents of children with special needs, whom they studied may have an impact on the stress levels.

Also, Bronfenbrenner (1979), emphasizes that the economic situation in the society in which the family lives, will affect many aspects of how the family copes with having a child with special needs. This statement is true of the group under study as they are in a developing country in which there is limited social support. Also notable is the fact that many of the goods and services available at Cheshire Home are not available to the child once discharged. Some children have to be carried away on their parents' back due to none availability of wheelchairs.

From the discussed data, we can conclude that the socio-economic situation in which the parents find themselves does to a large extent dictate their ability to cope with the added responsibilities of caring for the special needs child. This in turn does have an effect on their emotional adjustment to the child's disability.

4.4.7 Traditional Background

The discussion held with the parents revealed that they all agreed that though they hold different traditional beliefs, they were not influenced by them emotionally. They attributed this to the fact that the majority of them usually ended up seeking professional help. However, the staff discussion, shows they believe that tradition does affect the parent's response to their child's disability in varying degrees,

“Some parents insist that their children are lame due to witchcraft and they take time to accept the condition.”

From the discussions It can be seen that staff hold the view that parents who are less traditionally inclined seem to accept the children's condition much more easily. It further shows that the staff attributed the delays in seeking medical attention with resultant worsening of the child's condition to the pursuit of traditional medicine.

“They came to the institution as a last resort, some go back to traditional healers even after their child has left this place.”

This evidence shows that the parents' traditional beliefs do have a bearing on the parents' emotional adjustment. This finding is supportive of Bronfenbrenner (1979) and Max (1985) whose works emphasise that factors such as the ethnic background and belief system of a particular parent exerts an influence on the way the family reacts to the child's disability.

4.4.8 Number of Disabled Children

Results of the FGDs revealed that both the staff and parents agreed that there is a difference in the way parents with more than one disabled child adjust emotionally. They attributed this to the pressures associated with childcare.

“These parents often find it a relief to bring the children to the institution.”

The staff noted that this relief was often associated with the fact that the parents often brought their children to the institution early and picked them up late at the beginning and end of the school term respectively.

In addition to the pressures associated with child care, parents with more than one disabled child have to cope with the associated stigma as was noted during the discussions.

“The neighbours seem to be asking “why” What is wrong with my family. Though they do not say anything- I can sense it. It has been extremely difficult for me to settle down in spite of the fact that I have lived with these three children for over 10 years.”

From these results it is evident that there is a relationship between the number of disabled children and the parent’s emotional adjustment. This could be attributed to the fact that having a child with special needs is a source of stress for the parents and other family members. This finding tallies with those by researchers like Burton (1974) and Eiser (1993). They have reported higher levels of stress and associated psychological problems in families with chronically ill and disabled children. It can then be seen that the amount of stress or other emotional problems faced by parents with more than one disabled child are likely to be higher than those faced by parents of one child.

4.4.9 Child’s Birth Order

Data obtained through the parent interview reveals that parents with first and second born children generally expressed more symptoms of shock and disbelief, anger, sadness and detachment than did parents of third and fourth born children.

Table 10: Birth Rank of Child and Symptoms of Grief

Birth rank of child	Sum of symptoms expressed									
	Shock and disbelief			Denial				Guilt		
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total
1 st	3 75%	1 25%	4 100%	3 75%	1 25%	-	4 100%	4 100%	-	4 100%
2 nd	4 66.7%	2 33.3%	6 100%	4 66.7%	1 16.7%	1 16.7%	6 100%	5 83.3%	1 16.7%	6 100%
3 rd	3 100%	-	3 100%	3 100%	-	-	3 100%	2 66.7%	1 33.3%	3 100%
4 th	1 100%	-	1 100%	1 100%	-	-	1 100%	-	1 100%	1 100%
No response	-	1 100%	1 100%	-	-	1 100%	1 100%	1 100%	-	1 100%
Total	11 73.3%	4 26.7%	15 100%	11 73.3%	3 20%	1 6.7%	15 100%	12 80%	3 20%	15 100%

Birth rank of child	Sum of symptoms expressed												
	Anger			Sadness				Detachment			Reorganisation & adaptation		
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total	Nil	One	Total
1 st	3 75%	1 25%	4 100%	1 25%	3 75%	-	4 100%	3 75%	1 25%	4 100%	-	4 100%	4 100%
2 nd	3 50%	3 50%	6 100%	2 33.3%	2 33.3%	2 33.3%	6 100%	5 83.3%	1 16.7%	6 100%	2 33.3%	4 100%	6 100%
3 rd	3 100%	-	3 100%	-	2 66.7%	1 33.3%	3 100%	3 100%	-	3 100%	2 66.7%	1 33.3%	3 100%
4 th	1 100%	-	1 100%	1 100%	-	-	1 100%	1 100%	-	1 100%	-	1 100%	1 100%
No response	1 100%	-	1 100%	1 100%	-	-	1 100%	1 100%	-	1 100%	-	1 100%	1 100%
Total	11 73.3%	4 26.7%	15 100%	3 20%	9 60%	3 20%	15 100%	13 86.7%	2 13.3%	15 100%	4 26.7%	11 73.3%	15 100%

This data shows that the parents of disabled first and second born children experienced more symptoms of grief and that they were more affected than the parents whose children ranked lower in the birth order. These findings are supported by Hornby (1995) who states that the child who is the first born of young recently married parents has a very different effect from a child with the same kind of disability who is born of older parents who already have several other children.

4.4.10 Sex of the child

Based on Data from the FGDs, it is evident that the sex of the child does not have a very significant effect on the parents' emotional adjustment. However, a female parent expressed that the parents tend to be concerned as the female child progressed towards her teens.

“... it is troublesome, female children have menstrual periods and we parents often worry that they may mess themselves up. We also worry about the girls getting pregnant.”

Besides issues of menstrual hygiene and pregnancy, parents also expressed worry about their children's uncertain future love life. They said that they often worried about whether or not the female child with disabilities would be able to get married and raise a family of her own. The parent interviews revealed no significant differences in the emotional adjustments made by parents of children of different sexes.

This data shows that there seems to be no major differences between the emotional adjustments of parents based on the sex of their disabled children. However, the evidence shows that the issue of puberty in female children does trigger off a certain amount of concern in the parents of female children. It can be argued that this concern though it is common to all parents of female children, is especially of major concern to the parents of disabled children.

4.5 EFFECT OF THE CHILD'S TRANSITION BETWEEN HOME AND CHESHIRE HOME ON THE PARENT'S EMOTIONAL ADJUSTMENT

From the data we see that the parents had mixed feelings. Some said that they were generally apprehensive and sad when they had to take the child to Cheshire Home. ***“I was sad and even developed high blood pressure...”*** explained one male parent. Reasons given for this range from feelings that the parent had rejected the child to the fact that the child cried when left at the institution.

Table 11a: How Parents felt during Childs Transition to Cheshire Home.

PARENT'S FEELINGS	FREQUENCY
Very happy	3(20%)
Happy	5(33%)
Unhappy	5(33%)
Very unhappy	1(7%)
Indifferent	1(7%)
Total	15(100%)

n=15

There was a balance between parents who were happy (33%) and those who were unhappy (33%).

Table 11b: Child's Transition from Parental Home and Symptoms of Grief

Transition from parental home to Cheshire home	Sum of symptoms expressed												
	Shock and disbelief			Denial				Guilt					
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total			
Very happy	2 66.7%	1 33.3%	3 100%	2 66.7%	1 33.3%		3 100%	2 66.7%	1 33.3%	3 100%			
Happy	3 60%	2 40%	5 100%	4 80%		1 20%	5 100%	5 100%		5 100%			
Unhappy	4 80%	1 20%	5 100%	4 80%	1 20%		5 100%	3 60%	2 40%	5 100%			
Very unhappy	1 100%		1 100%		1 100%		1 100%	1 100%		1 100%			
Indifferent	1 100%		1 100%	1 100%			1 100%	1 100%		1 100%			
Total	11 73.3%	4 26.7%	15 100%	11 73.3%	3 20%	1 6.7%	15 100%	12 80%	3 20%	15 100%			
Transition from parental home to Cheshire home	Sum of symptoms expressed												
	Anger			Sadness				Detachment			Reorganisation & adaptation		
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total	Nil	One	Total
Very happy	3 100%		3 100%		2 66.7%	1 33.3%	3 100%	3 100%		3 100%	1 33.3%	2 66.7%	3 100%
Happy	4 80%	1 20%	5 100%	3 60%	2 40%		5 100%	4 80%	1 20%	5 100%	1 20%	4 80%	5 100%
Unhappy	3 60%	2 40%	5 100%		3 60%	2 40%	5 100%	4 80%	1 20%	5 100%	2 40%	3 60%	5 100%
Very unhappy		1 100%	1 100%		1 100%		1 100%	1 100%		1 100%		1 100%	1 100%
Indifferent	1 100%		1 100%		1 100%		1 100%	1 100%		1 100%		1 100%	1 100%
Total	11 73.3%	4 26.7%	15 100%	3 20%	9 60%	3 20%	15 100%	13 86.7%	2 13.3%	15 100%	4 26.7%	11 73.3%	15 100%

The results reveal that the majority of parents were either happy or very happy that their child was going to the institution. These parents gave various reasons for this reaction. Among the reasons cited by those who were happy were that they were sure that the child would receive help.

The data collected from the field also shows that parents had mixed feelings when fetching their children from the institute after discharge. This data further reveals that 53% of them preferred their child not to be discharged from the institution. Of these parents, 50% said that they felt incapable of caring for their child.

“I am worried that now that the boy has come back home, I will not be able to care for him. He should have been kept there because I am too old and poor and will not be able to afford to give him what he was receiving at Cheshire Home.”

The parents' data also reveals that there were more parents who were happy to take the children to Cheshire Home and less who were happy to receive them back after discharge. It can be assumed that this is highly suggestive of a failure to fully accept the child's presence in the home. In addition to this, there is a desire by the parents to relieve themselves of the burden of caring for the disabled child.

“Some parents neglect their children so much that the children often came back to the institution worse than they were before the discharge.”

The discussion further revealed that some parents never get over the initial emotional reaction. They tend to react the same way each time they have to take the child to the institution.

“Mrs. “M” has been bringing her child for over a year yet she cries each time she has to part with the child at the beginning of the term”.

This data, shows that there is a relationship between the child's transition between home and Cheshire Home. This finding is supported by Chilman, Nunnally and Cox (1988)'s proposition that movement of a family member results in a change in family dynamics. They cite an example of the transfer of a child with special educational needs from a special institution to a mainstream placement. They explain that this movement will affect not only the child but also other members of the family.

4.6 EFFECT OF PREVIOUS PROFESSIONAL COUNSELLING ON THE PARENT'S EMOTIONAL ADJUSTMENT

Table 12: Parent's Opinion on whether Counselling helped Emotionally and Symptoms of Grief

Whether counselling helped emotionally	Sum of symptoms expressed												
	Shock and disbelief			Denial				Guilt					
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total			
Yes	1 100%	-	1 100%	1 100%	-	-	1 100%	1 100%	-	-	1 100%		
No	3 100%	-	3 100%	3 100%	-	-	3 100%	3 100%	-	-	3 100%		
Were not counselled	4 66.7%	2 33.3%	6 100%	4 66.7%	2 33.3%	-	6 100%	5 83.3%	1 16.7%	-	13 100%		
Total	-	1 100%	1 100%	-	-	1 100%	1 100%	1 100%	-	-	15 100%		
Whether counselling helped emotionally	Sum of symptoms expressed												
	Anger			Sadness				Detachment			Reorganisation & adaptation		Total
	Nil	One	Total	Nil	One	Two	Total	Nil	One	Total	Nil	One	Total
Yes	1 100%	-	1 100%	-	1 100%	-	1 100%	1 100%	-	1 100%	1 100%	-	1 100%
No	1 100%	-	1 100%	-	-	1 100%	1 100%	1 100%	-	1 100%	-	1 100%	1 100%
Were not counselled	9 69.2%	4 30.8%	13 100%	3 23.1%	8 61.5%	2 15.4%	13 100%	11 84.6%	2 15.4%	13 100%	3 23.1%	10 76.9%	13 100%
Total	11 73.3%	4 26.7%	15 100%	3 20%	9 60%	3 20%	15 100%	13 86.7%	2 13.3%	15 100%	4 26.7%	11 73.3%	15 100%

From the data it can be seen that only 25% of the members of staff were trained counselors in possession of counselling skills. It further shows that only 38% of the staff felt that the counselling received by parents had an effect on the parent's emotional adjustment to the child's disability. These low figures were possibly as a result of the fact that counselling services were not available and in addition were not among the main activities carried out by the members of staff. This is confirmed by evidence from the FGDs with parents, the evidence revealed that counselling services are not available at the institution. It further shows that the parents are rarely counselled. This evidence is consistent with data collected from the parent interview. It can be seen that of the fifteen parents who were interviewed, only two (13.5%) said

that they had received counselling during their child's stay in the institution. Of these, one said that the counselling received did not have any effect on emotional adjustment, while the other one said it helped to prepare her psychologically for the outcome of the child's surgical treatment.

From this data it can be concluded that it is extremely difficult to measure the effect that counselling has on the emotions of parents under study. This is basically due to the fact that the service is not readily available and that too few parents had received the service. As such it was extremely difficult to meaningfully establish any significant relationship between previous parent counselling and the emotional adjustment.

Chapter Five

5.0 CONCLUSION AND RECOMMENDATIONS

5.1 CONCLUSION

From the information obtained during field research and support by the literature review, the study makes the following conclusions:

5.1.1 Objective One: Emotional Adjustments Made by the Parents

The parents under study's emotional adjustment was highly individualized and varied from parent to parent. The variance observed was in the duration of experience of the various emotional symptoms, the intensity as was indicated by the sum of symptoms expressed as well as the range of triggering factors. It is evidently clear that despite all the theories that advocate a neat transition through the continuum of emotional adjustment, the parents under study expressed clusters of symptoms that did not follow any particular order. In some cases parents experienced re-currencies of sadness which was highly suggestive of chronic grief/sorrow.

The fact that parents of disabled children experienced emotional adjustments of varying degrees after surgical treatment of their children's disability is in this researcher's view a pointer to the fact that perhaps there is no point at which the adaptation process comes to an end. On the basis of this finding, this researcher would like to suggest that instead of the linear depiction of the continuum of emotional experiences; it maybe described as spiral in nature with no abrupt end.

5.1.2 Objective Two: Relationship Between Socio-Economic Background Factors and the Parent's Emotional Adjustment

From the evidence presented and discussed, it is apparent that most of the socio-economic background factors do have a significant relationship with the parents' emotional adjustments. However, the study also concludes that there is no significant relationship between the child's birth order, the sex of the child and the parent's educational level on the parent's emotional adjustment.

5.1.3 Objective Three: Effect of the Child's Transition Between Home and Cheshire Home on the Parent's Emotional Adjustment

The study reveals that the children's movement between home and Cheshire home did have some effect on the parent's emotional adjustment. The parents expressed mixed feelings in this area. However, on the whole, the emotional feelings were highly individualized and varied from individual to individual. The transition period was highly associated with practical problems encountered by the parents. These problems were related to the care of the child in their homes in the absence of the necessary material, emotional and logistical support.

5.1.4 Objective four: Effect of Previous Professional Counselling on the Parent's Emotional Adjustment

The non-availability of counselling services made it virtually impossible for the study to establish any relationship between previous counselling and the parents' emotional adjustment. However, the study concludes that there is a great need for these services though the need had not been addressed.

5.2 RECOMMENDATIONS

In order to address some of the issues that have been raised from the study, the following recommendations are proposed:

5.2.1 In view of the established relationship between low socio-economic status and the parents emotional adjustment, the government through the Ministry of Community Development, should consider poverty alleviation programmes for the parents of disabled children.

5.2.2 The Cheshire Homes society of Zambia, in collaboration with Ministry of Health, should embark on psycho-social counselling training for the members of staff. In addition, there is a need to integrate counselling services in the daily running of the Homes.

5.2.3 In view of the apparent lack of counselling and other support for parents of children with disabilities, local non governmental organizations (NGOs) should consider forming community based out reach programmes for the parents' psycho-social support.

5.2.4 *Recommendations for Future Research*

5.2.4.1 As the area of emotional adjustments made by Zambian parents of disabled children is still quite under explored, scholars in the department of Education Psychology, Sociology and Special Education should undertake studies in this area. Particularly with emphasis on the socio-economic background.

5.2.4.2 The researcher needs to replicate the study on a larger scale in order to be able to generalize the results to a wider population.

5.2.4.3 The researcher would like to carry out experimental studies aimed at assessing the impact of counselling on the parents of disabled children.

5.2.4.4 In view of the fact that a considerable number of children are living with foster parents; there is a need for special educators and psychologists to investigate any existing differences in the emotional adjustments made by the foster parents in comparison to those made by the biological parents.

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APPENDICES

Appendix 1

THE UNIVERSITY OF ZAMBIA SCHOOL OF EDUCATION DEPARTMENT OF EPSSE

STAFF QUESTIONNAIRE

Respondent ID

Date _____

Dear Respondent,

The purpose of this research is to establish the emotional adjustments made by parents of disabled children after the children have been discharged from your institution. The questions will help me gather information from the perspective of the staff. This will help to complement information gathered through other methods. Your co-operation is therefore of paramount importance in this regard.

Below are simple instructions to guide you as you complete the questionnaire.

INSTRUCTIONS

DO NOT write your name on the questionnaire.

Answer questions by ticking [✓] in the space provided.

For those questions that require an explanation write in the space provided.

Answer the question by ticking the answer you perceive to be applicable to you.

For official
use only

BACKGROUND CHARACTERISTICS

Q1. Sex

1. Male []

2. Female []

--	--	--

Q2. Age (in years) _____

--	--	--

POSITION, QUALIFICATIONS AND EXPERIENCE

Q3. What post do you hold in this institution?

--	--	--

Q4. What is your profession?

1. Primary school teacher []

2. Secondary school teacher []

3. Nurse []

4. Physiotherapist []

5. Psychologist []

6. Social worker []

Other (specify) _____

--	--	--

For official
use only

Q5. How many years of working experience do you have?

--	--	--

Q6. For how many years have you been working in this institution?

--	--	--

Q7. List down your main duties in order of importance.

--	--	--

EMOTIONAL ADJUSTMENTS OF PARENTS

Q8. What are some of the common emotional reactions that you have observed in parents when their children are admitted into the institution? (Tick as many as you have observed)

- 1. They do not accept the child's condition []
- 2. They are sad []
- 3. They appear angry and easily irritable []
- 4. They are expectant and hopeful that the child's condition will be rectified []
- 5. They accept their child's condition and co-operate []
- 5. They exhibit unreasonable hope and make unreasonable demands
- 7. Other observations (specify) _____

--	--	--

For official
use only

COUNSELLING

Q9. Have you had formal training as a counsellor?

1. Yes []
2. No []

--	--	--

Q10. Are the parents counselled by a professional counsellor?

1. Yes - go to 13a []
2. No - go to 13b []

--	--	--

Q11. How often are they counselled?

1. Once on admission []
2. Through the child's stay []
3. Once before the child goes home []
4. Other (Specify) _____

--	--	--

Q12. Do you think that the counselling given to parents has any effect on their emotional adjustment to the child's disability

1. Yes - go to 14a []
2. No. - go to 14b []

--	--	--

Q13a. Why do you think counselling has an effect on parents emotional adjustment?

--	--	--

Q13b. Why do you think counselling does not have an effect on the parents emotional adjustment?

--	--	--

TRANSITION PERIOD

Q14. How do parents react when they hand over the children to the staff?

- 1. They part easily []
- 2. They express reservation []
- 3. The reactions vary from parent to parent []
- 4. Any other (specify) _____

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Q15. How do they react when they have to pick up their child after discharge?

- 1. They are fearful []
- 2. They are reluctant []
- 3. They do it willingly []
- 4. Other (specify) _____

--	--	--

Q16. Do you think the parents are prepared for care of the children at home?

- 1. Yes []
- 2. No []

--	--	--

Q17. Do parents visit their children in the home?

- 1. Yes []
- 2. No []

--	--	--

Q18. Do some parents prefer that their children be kept without discharge?

- 1. Yes []
- 2. No []

--	--	--

PSYCHO SOCIAL SUPPORT

Q19. Does the institution have adequate services for parental support?

- 1. Yes []
- 2. No - proceed to 21 []

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Q20. Make suggestions for the improvement of psycho-social support
for parents.

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Appendix 2

UNIVERSITY OF ZAMBIA
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EPSSE DEPARTMENT

PARENTS INTERVIEW SCHEDULE

Respondent ID

Date _____

BACKGROUND

Q1. Sex

- 1. Male []
- 2. Female []

Q2. Age: _____

Q3. Religious affiliation

- 1. Christian []
- 2. Muslim []
- 3. Buddhism []
- 4. Traditional []
- 5. Other (specify) _____

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EDUCATION

Q4. Have you ever been to school?

- 1. Yes - if yes, go to 6 []
- 2. No []

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Q5. If the answer to Q4 is Yes, what is the highest level of education You have attained?

- 1. Primary school []
- 2. Secondary school []
- 3. College/University []

--	--	--

SOCIAL ECONOMIC STATUS

Q6. Are you in gainful employment?

- 1. Yes - if yes, go to Q7 []
- 2. No []

--	--	--

Q7. How much do you earn per month?

- 1. Below K50,000 []
- 2. K50,001 – K100,000 []
- 3. K100,001 – K200,000 []
- 4. K200,001 – K300,000 []
- 5. Above K500,000 []

--	--	--

Q8. How adequate do you consider the amount of money you earn per month?

- 1. Inadequate []
- 2. Just adequate with no money left over []
- 3. Sufficient to *meet all* family needs []
- 4. Sufficient with some money left over []

--	--	--

EMOTIONAL ADJUSTMENT

Q9. Describe in detail what your emotional experiences have been from the time your child was discharged from Cheshire home to date.
(Interviewer refer to the table below and fill in appropriate information)

Scale number	Scale Name	Sum of positive symptoms expressed	Sequence of occurrence	Trigger of the emotion expressed	Duration
01	Shock and disbelief				
02	Denial				
03	Guilt				
04	Anger				
05	Sadness (change in behaviour and mood)				
06	Detachment				
07	Reorganisati on and adaptation				
Total					

TRADITIONAL BELIEFS

Q10. Do you agree or disagree with the following statements?

	Indifferent	Strongly agree	Agree	Disagree	Strongly disagree
	1	2	3	4	5
a. Disability is caused by witchcraft					
b. Physical disability can be treated by traditional medicine					
c. All children including the physically disabled should undergo initiation when they come of age					

NUMBER OF DISABLED CHILDREN

Q11. How many disabled children do you have? []

--	--	--

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CHILD'S BIRTH RANK ORDER

Q12. What rank in the birth order does your disabled child occupy? []

--	--	--

SEX OF CHILD

Q13. What is the sex of your disabled child?

- 1. Male []
- 2. Female []

--	--	--

TRANSITION

Q14. How did you feel when your child had to move from parental home to Cheshire home?

- 1. Very happy []
- 2. Happy []
- 3. Unhappy []
- 4. Very unhappy []
- 5. Indifferent []

--	--	--

Q15a. Why were you happy?

--	--	--

Q15b. Why were you not happy

--	--	--

Q16a. Would you have preferred your child not to be discharged from the Cheshire home?

- 1. Yes - go to Q16b []
- 2. No []

--	--	--

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Use only

Q16b. Why?

1. Because I feel incapable of caring for her []
2. Because his/her presence in the home affects
My emotions adversely []
3. Because the child belongs to the home for the
disabled and should be cared for with other
disabled children []
4. Other reason (specify) _____

--	--	--

COUNSELLING

Q17. Have you received any professional counselling?

1. Yes []
2. No []

--	--	--

Q18. If the answer to Q17 is yes, who conducted counselling?

1. A religious leader []
2. A member of staff at Cheshire home []
3. The medical practitioner at the local health centre []
4. Other (specify) _____

--	--	--

Q19. How many times did you receive counselling since the child's admission and subsequent discharge? _____

--	--	--

Q20. Did the counselling help you emotionally?

1. Yes – if yes, go to Q21a []
2. No – if no, go to Q21b []

--	--	--

Q21a. How did it help?

--	--	--

Q21b. Explain why counselling did not help you.

--	--	--

KEY FOR SYMPTOM CHECKLIST.

SHOCK AND DISBELIEF

EXPRESSED

SYMPTOM	YES	NO
Shock & Disbelief 1. Confusion 2. Numbness 3. Disorientation 4. Helplessness 5. Inability to understand what is being discussed in connection with the child's condition 6. Other symptoms		
TOTAL (SUM)		
Denial 1. Difficulties in believing that the child still has a problem 2. Belief that there must have been a mistake 3. Search for second opinion for example traditional healers 4. "shopping around" for favourable diagnosis or better services 5. any other symptom suggestive of denial		
TOTAL (SUM)		
Anger 1. Search for cause of the problem or someone to blame 2. Investigations in the family history to find out the source of the problem 3. Displacement of anger 4. Unexplained out bursts of anger 5. Other symptom suggestive of anger		
TOTAL (SUM)		
Guilt 1. Feeling responsible for the child's condition 2. Wandering what they could have done to prevent the event that let to the child's condition 3. Any other symptom suggestive of self- blame.		
TOTAL (SUM)		

<p>Sadness</p> <ol style="list-style-type: none"> 1. Grieves for the loss of the perfect child he/she thought they would have after treatment 2. Parent sad about the loss of opportunities and ambitions which the child may not be able to fulfil 3. Crying 4. Cutting self off from society because the parent “could not bear” meeting anyone. 		
<p>TOTAL (SUM)</p>		
<p>Detachment</p> <ol style="list-style-type: none"> 1. Feelings of emptiness 2. Nothing seems to matter 3. Life going on from day to day 4. Parent reluctantly begins to accept the reality of the situation 		
<p>TOTAL (SUM)</p>		
<p>Reorganisation and Adaptation</p> <ol style="list-style-type: none"> 1. Development of realism about the situation and a hope for the future 2. Parent focuses more on what the child may achieve and less on what they may miss out 3. Coming to terms with the situation 4. Mature emotional acceptance of the child’s condition 5. Parent is fully aware of the child’s special needs and strives to provide for them 		
<p>TOTAL (SUM)</p>		

Appendix 3

UNIVERSITY OF ZAMBIA

SCHOOL OF EDUCATION

EPSSE DEPARTMENT

**EMOTIONAL ADJUSTMENTS MADE BY PARENTS OF DISABLED
CHILDREN AFTER THEIR DISCHARGE FROM INSTITUTIONS:**

CASE STUDY OF CHESHIRE HOMES. LUSAKA, ZAMBIA

September – December 1999

Focus Group Discussion Guide

FOCUS ON GROUP DISCUSSION (STAFF)

Date of Discussion

Time

Place

Participants: Male [] Female []

Facilitator

Note taker

Introduction (Facilitator)

Welcome the group and explain that the objective of the meeting is to discuss the emotional adjustments they have observed in parents whose children are admitted to the institution.

(Obtain consent to record the discussion and pledge confidentiality).

A. Common Experience during Transition

- What are the common emotional reactions observed in parents as they bring their children for admission?
- What are the common emotional reactions observed when they come to pick up their children?
- What emotional/psychological assistance is given to parents during the transition period as well as during the child's admission days?
- Is the support adequate?

B. Presence of Other Disabled Children

- Do some parents bring more than one disabled child to the home?
- How do parents of more than one disabled child behave emotionally – have staff observed any differences in their behaviour?
 - (d) During admission?
 - (e) On discharge?
 - (f) After discharge?

C. Effect of Background Factors

- How do staff think the following background factors influence the parents' emotional adjustments.
 12. Family size
 13. Age of parent
 14. Age of child
 15. Sex of parent
 16. Sex of child
 17. Child's birth order
 18. Educational level of parent
 19. Parents' socio-economic background

20. Parents' religious background
21. Parents' traditional background
22. Other background factors that the staff have observed/identified and feel are important and need to be discussed.
12. Conduct an exercise to rank the listed factors in order of importance.

Recommendations:

What do the staff feel should be done to provide psychosocial support for the parents?

Appendix 4

FOCUS GROUP DISCUSSION (PARENTS)

Date of Discussion:

Time:

Place:

Participants: [] Female[]

Facilitator:

Note taker:

Duration:

INTRODUCTION: (By Facilitator)

The purpose of this discussion is to share experiences that you as parents of disabled children went through after your children sent to Cheshire Homes as well as after they came back home. This discussion is specifically tailored to probe the emotional adjustments you made during this period to date.

The discussion shall be guided by the themes, questions outlined by the researcher. Please feel free to participate. Thank you for your co-operation.

A. Common Experiences during Transition

- How did you feel when you had to part with your children?
- What did you feel each time you visited the children at Cheshire Home?
- What emotions did you experience during the period of your children's absence from home?
- Do you think that the children should not be discharged to their homes?

B. Parents Experiences after the children's Return to their biological homes

- Did the parents experience emotions similar to those experienced before the children's admission?
- What were their emotional experiences and adjustments?
- Did parents experience any new health problems during this stage?
- Did they experience any relapses of the emotions experienced during the pre-admission period?

- What factors/incidences triggered off the relapses? (these should be ranked in order of importance)
- What factors/incidences affected the parents' overall emotional adjustment?
- What factors/incidences assisted parents to stabilise emotionally after the relapses? (Rank in order of importance)
- How long did it take parents (on average) to stabilise emotional?

C. Presence of Other Disabled Children

- Do some of the parents have more than one disabled child?
- How have parents with more than one disabled child adjusted emotionally?

D. Effects of Background Factors

- How do they think the following background factors influence parents' emotional experiences and adjustments?
 1. Family size
 2. Age of parent
 3. Age of child
 4. Child's birth order
 5. Sex of parent
 6. Sex of child
 7. Educational level of parent
 8. Parent's socio-ec
 9. Parent's socio-economic status
 10. Parent's traditional background
 11. Other Background factors that the parents identify and feel are important and need to be discussed
 12. Conduct a small exercise for parents to rank the listed factors

At the close of the discussion the Facilitator should thank the group.

