

AN ORTHOPEDAGOGICAL PERSPECTIVE ON THE ATTITUDES OF
XHOSA PARENTS TOWARD THE EDUCATION OF THEIR CEREBRAL
PALSIED CHILDREN

by

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"I declare that: AN ORTHOPEDAGOGICAL PERSPECTIVE ON THE ATTITUDES OF XHOSA PARENTS TOWARD THE EDUCATION OF THEIR CEREBRAL PALSIED CHILDREN is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references".

T. M. Sello

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XHOSA PARENTS TOWARD THE EDUCATION OF THEIR CEREBRAL
PALSIED CHILDREN

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SUMMARY

Parents of cerebral palsied children have the duty of educating and leading their children towards adulthood. Parents, as educators, must know about cerebral palsy and its effects on the child and the whole family. The success of the parents in assisting the child is influenced by numerous factors.

One factor is the manner in which parents understand themselves as parents of a cerebral palsied child. Such an understanding directs their behaviour positively or negatively. Another factor is the involvement of parents in the child's life. Involvement demands perseverance, dedication, and understanding of cerebral palsy. Parents may also experience feelings of frustration or acceptance. Experience influences the quality of relationships as well as the parents' view of life and

the quality of their educational role. If parents lack understanding, have an apathetic involvement and unpleasant experiences, the progress of a cerebral palsied child towards adulthood will be hampered.

KEY TERMS:

Attitude; cerebral palsy; cerebral palsied children; children with disabilities; incidence; orthopedagogical perspective; parents; specialised education; Transkei; Xhosa.

PREFACE

This study was begun in 1990, before the reincorporation of the Transkei "homeland" into South Africa. The study focuses on the geographical area once covered by that "homeland" (delineated in Chapters 1, 5, and 6). The writer of this dissertation considers the geographical area of the Transkei as specified still to be the main Xhosa speaking area of South Africa with an almost monolingual home language Xhosa speaking population. The former Transkei is thus still a valid area for the research undertaken into the attitudes of Xhosa-speaking parents towards children with disabilities.

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CHAPTER 1

INTRODUCTION

1.1 Introduction

Cerebral palsy is the focus of this study, more particularly the incidence of this disability in the Xhosa population in the Transkei, and the attitudes towards and treatment of cerebral palsied children in this group. The condition will be discussed objectively in more detail in Chapter 2.

For the moment, as an introduction to the subject, it might be more useful to highlight the subjective or emotive issues which surround cerebral palsy. Consider, for example, the following quotation: "my stiffness or extension (throwing myself backwards) may frighten you or make you feel awkward, and may make me seem "uncuddly." Let me assure you, I am very cuddly..." (Delventhol 1991:17).

The quotation above describes the child who is experiencing a problem and the body posture that may indicate that the child suffers from a disability such as cerebral palsy: stiffness and extension. The quotation further reveals that another person is likely to respond by fearing the child or by feeling awkward. Having fear or feeling awkward are some of the non-verbalised attitudes a person or parent can have towards a cerebral palsied child. According to Smith et al (1983:215) such unvoiced attitudes may be negative.

The causes for non-verbalised attitudes, as revealed by the quotation, are the abnormal postures and movements of the child. It can be added that the cause can also be the distorted bodily appearance of the child. Such postures and appearances tend to repel other people as they "make me seem uncuddly." The quotation, therefore, shows that a cerebral palsied child is likely to be the target of negative attitudes.

Further information from the quotation is that the cerebral palsied child can be aware of other people's negative reactions towards him or her. The implication is that such awareness may cause the child to withdraw from the family and community members, his or her motivation and initiative may be inhibited, the child may feel insecure or become rebellious, asocial and may even exhibit antisocial behaviour. All these types of behaviours may affect the child's learning.

The last sentence of the quotation shows that the cerebral palsied child is appealing and yearns to be treated like other non-handicapped children for he or she is also a child. The quotation thus shows that the upbringing and education of a cerebral palsied child is affected by other people's attitudes.

How relevant is the quotation to the situation in the Xhosa speaking population in the Transkei? In order to be able to answer this question and have a deeper understanding of the effects of cerebral palsy on parents and the education of their cerebral palsied children in the Transkei, an empirical study was undertaken as part of this study (see Chapter 6).

Chapter 1 will commence by providing a background study to the problem. However, before the background can be discussed, certain terms have to be clarified.

1.2 Concept clarification

1.2.1 Disability

Numerous and varying definitions are used by various authors to define a disability. In the United States of America Smith et al (1983:213) define a disability as: "an objectively defined deviation in physique or functioning that, through interaction with a specific environment, results in behavioural inadequancies or restrictions for the person". According to the International classification Naidoo (1993:4) states that the term disability refers to a "restricted ability to perform an activity". Thus, for the purpose of this dissertation a disability will be defined as: limitation of performance in one or more abilities or faculties which are generally accepted as being essential for coping with the activities of ordinary daily living, such that a partial or complete mobility to perform such activities necessitates a degree of dependence on a compensatory device and/or another person.

1.2.2 Children with disabilities

Children with disabilities are identified by being different, conspicuous and having educational needs (Du Toit 1989:23-25). Children having limitations in learning skills behave differently from non-disabled children. If they are aware of their difference they

tend to regard themselves as inferior. Non-disabled children can even exclude and avoid different children. Limitations in learning skills with regard to conspicuousness are visible in social, medical, psychological and pedagogical areas. With regard to educational needs limitations in learning skills are shown by a child needing specific teaching where programmes may be more structured. Sometimes such children need the assistance of the inter disciplinary team. With regard to this dissertation a child with a disability can be regarded as one who has deviated from the norm (to the specific). In other words the child needs a specialised type of education owing to the problem he or she has.

1.2.3 Children with special educational needs

Special educational needs, according to the African National Congress Education Department (1994:104), include the following: "special academic and learning problems, physical health problems, emotional concerns, and particular social needs (which are often related)". Special educational needs are also explained by Donald (1992:8) who places children with special educational needs on the continuum which ranges from serious and chronic to temporary and remediable. He divides the causes of special educational needs into the following: intrinsic, extrinsic and a combination of both the intrinsic and the extrinsic. The intrinsic causes are inherent in the person: for instance, physical, neural, mild to severe mental disabilities and multiple disabilities. Extrinsic factors do not necessarily depend on intrinsic factors for they originate from the child's environment. Such causes may lead to lack of

basic numeracy and literacy skills. Causes for the combined intrinsic and extrinsic factors may be due to physical deficiencies as well as environmental factors.

Thus, for the purpose of this dissertation, children with special educational needs are the ones whose upbringing and teaching have become more complex and problematic than expected owing to the disabilities they have.

1.2.4 Specialised education

Children with disabilities are children like other non-disabled ones and, therefore deserve to be given education. The word 'special' shows that the disabled children need specialised material, methods and environments so that they can progress in their learning and in life (Smith et al 1983:32).

In South Africa, the Education Affairs Act No.70 (1988:1489) also uses the term specialised education and defines it as follows: "Education of specialised nature provided to suit the needs of handicapped children, as well as-

- a) the psychological, medical, dental, paramedical and therapeutic treatment of, including the performance of operations on, handicapped children;
- b) the provision of artificial medical aid and apparatus to handicapped children;
- c) the care of handicapped children in hospital, hostel or other institution;

- d) the provision of transport, escort and such other services that the Minister may deem necessary to meet the needs of handicapped children; and
- e) the provision of guidance to the parents of handicapped children who are not yet subject to compulsory school attendance, with a view to the instructions, teaching, training or treatment of such children".

For the purposes of this dissertation specialised education by its nature provides for the needs of children with disabilities.

1.2.5 Orthopedagogical perspective

An orthopedagogical perspective is an approach used to investigate the research problem in this study. This approach suits a study of the problems/attitudes that affect the education of cerebral palsied children in the Transkei. The term orthopedagogics refers to:

the collection, organisation and controlling of existing knowledge concerning problems in the education and teaching of children; the deepening and broadening of such knowledge and the development of new knowledge through active research; making available the acquired knowledge and insights to those in practice with a view to improving the quality of the aid to children in problematical situations (Du Toit 1989:13-14).

Thus, for the purpose of this dissertation, an orthopedagogical perspective refers to the focusing on the child and his or her particular physical and psychological situation as well as his or her educational and social situation.

1.2.6 Cerebral palsy

A child needing specialised education may suffer from a disability such as cerebral palsy.

Numerous definitions have been formulated to define the term 'cerebral palsy'. A satisfactory definition contains the following four main facts (Botha 1989:317-318):

1. Part of the brain has been damaged, or did not develop before the brain was fully grown.
2. Certain signs show that the motor system has been affected owing to a lesion or because of insufficient development of the central nervous system.
3. The disability may vary in degree, from the mild (or hardly noticeable) to severe.
4. The disability is complex because of additional disabilities (malfunctions) of the motor system.

The National Council for the Care of the Cripples in South Africa (1973:3) has proposed the following definition:

Cerebral palsy is a general term indicating basically a physical disability caused by damage to, or the failure to develop of an area in the brain before the brain has matured. The damage may have

occurred before or during birth or in early childhood. The effect is that the control of the brain over the the functioning of the musculature and co-ordination of the body is disturbed. There is no direct injury to the limbs as such.

According to the World Commission for Cerebral Palsy cerebral palsy is: "a persistent but not unchanging disorder of posture and movement due to a dysfunction of the brain before its growth and development are completed. (Many other features may be part of the condition)". (Arens 1984:53).

Thus, for the purpose of this study, cerebral palsy is a physical disability resulting from damage to or a failure to develop of a part of the brain before the brain could attain its maturity. The damage can occur prenatally, perinatally or postnatally. The result is that the brain cannot properly control the muscles and co-ordination of the body.

1.2.7 Cerebral palsied children

(Botha 1989:318) defines cerebral palsied children as follows:

Children with disturbed function caused by a defect or damage to the brain tissue, whose chief problem is not, however, that of mental retardation. The defect or damage may be localised or diffused, and may occur before, during or at any time after the birth of the child. Where organic brain damage is the cause of neuromotor, perceptual or communication deviations, these defects may be present singly or in combination.

In this study the term cerebral palsied children refers to children suffering from cerebral palsy. Such children may also experience an associated disability.

Having defined the various concepts relevant to this study - particularly disability, specialised education and cerebral palsy, and how each relates to children - the dissertation now proceeds to discuss the target group of this study, the Xhosa population of the Transkei and the incidence of cerebral palsied children in this group.

1.2.8 The Xhosa

Black people occupying the former areas of the Eastern Cape Province such as the former Transkei and Ciskei are referred to as the Xhosa. The Xhosa are the descendants of fragments of the tribes that fled from Shaka during the early 1800s. This implies that the Xhosa belong to the Nguni group in Southern Africa. The Nguni group comprises of the Xhosa, Swazi, Zulu, Ndebele and other minor groups. The Xhosa group consists of various tribes such as the Pondo, Thembu and the Bomvana (for additional tribes see Appendix A). All these tribes speak a common language, Xhosa, and their traditional customs are more or less the same (Levitas 1983:116; Pauw 1975:2-3; Soga 1974:5-13).

1.2.9 Xhosa parents

The Transkei Government Education Act (1986:146) defines a parent as the father or mother or the legal guardian of a pupil. According to Xhosa custom every adult is a parent to the Xhosa child. For the purposes of this

dissertation a Xhosa parent refers to the biological father or mother of the child. The father or mother has the function of supporting, educating, disciplining, providing food, clothing and shelter for the child. Any person who takes over the duty of the parent towards the child on a temporary or permanent basis is referred to as being in "loco parentis," that is, in place of the parent. Teachers, hostel mothers, grandmothers and guardians act in "loco parentis".

1.2.10 Attitude

An attitude can be described as any feeling or tendency or opinion about an object (Urdang 1991:21). According to Kretch and Crutchfield (1960:671) an attitude can be defined as follows: "An attitude may be described as an enduring organisation of perceptual, motivational, emotional and adaptive processes centering on some object in the person's world".

For the purpose of this study an attitude is an acquired feeling, belief or disposition which is revealed by the way a person reacts towards another person, object or experience.

Besides the definition of terms some background data is necessary for it forms the basis for the problem to be investigated.

1.3 Background to the problem

This study is limited to parents of cerebral palsied children in the former Transkei. Transkei traditionally or historically is regarded as the land of the Xhosa, hence its selection for the problem to be studied.

According to Wood and Van Schoor (1976:4) and Champion (1976:6) the Transkei is in the Eastern Cape Province and lies approximately between 30 and 33 South, 26 45' and 30 15' East. It borders on the Indian Ocean and extends from the Kei river in the South to the Umtamvuna and the Umzimkhulu rivers in the North. In the north west Transkei is bounded by Lesotho. It has a total area of approximately 41620 square kilometres. Three blocks of land form what is called the Transkei, the main land, and its two outlying districts, Umzimkhulu and Herschel. The area consists of twenty eight districts (see Appendix A).

1.3.1 Geographical factors

The topography of the Transkei is characterised by broken landscape and narrow valleys. The Transkei lies within an area of good rainfall. The rains are, unfortunately, unreliable and the result is that agricultural products do not sustain the country. Geographical factors play a role in influencing the economy of the country. Droughts, low production of crops owing to lack of flat land, soil erosion and unscientific farming methods cause lack of interest in farming (Ngubentombi 1984:139). Lack of interest in agriculture causes the Transkei to loose human resources, for about two thirds of the labour force migrate to industrial areas.

Labour migration is referred to in this chapter because it has an effect on the education of children in this country. One parent, mostly the mother, educates children in the absence of the father. Geographical factors also mean that most Xhosa children, especially

the ones with disabilities, are placed in far away boarding schools.

1.3.2 Demographic factors

Demographic factors should also be considered in this study for they provide a better understanding of the education situation in the Transkei. Du Preez (1980:44) states that they influence the determination of future educational needs and the planning of educational provision.

Wallis (1989-90:2) reveals that the Transkei experiences a six percent population growth rate per annum. This implies, according to Wallis, that fifty percent of the population is under the age of eighteen. This young and unproductive generation must be cared for and educated by parents. A high number of young people affects the education of children for schools cannot accommodate all of them. This results in drop-outs and illiteracy. If schools try to accommodate as many children as possible, the quality of education offered to children is affected. The high population growth rate also causes starvation and poor health. It also leads to unemployment. Such factors affect the education of children.

The Xhosa nation was regarded as the second largest indigenous/Black population in South Africa and seventy percent of the Xhosa population lives in rural areas. Verwey (1979:43-44) has shown that the rural population and its distribution causes specific problems in the education of children. Parents' interest in the school education of children is affected by long distances and

the resulting transport problems, the provision of boarding facilities and the provision of schools within reach of each child. Such factors prevent the successful introduction of compulsory education in the Transkei. Other factors are the illiteracy of parents and the migratory labour force, which have impact on the education of Xhosa children.

It can be assumed that conditions revealed by Verwey in 1979 are still prevalent in the Transkei.

1.3.3 Economic factors

Schools exist mainly to educate children for their future jobs. This shows that there is a link between education and the economy of the country. Schools supply human resources to the economy yearly in the form of pupils leaving the school to start work. In short, education forms the basis for the development of a country (Verwey 1979:1). An educational planner has, therefore, to consider what the educational system can give to the economy and what the education system requires from the economy.

The former Transkei was a very poor country and had a shortage of funds, lack of private initiative and know-how (Du Preez 1980:8). Pupils leaving school after standard seven or ten did not contribute much to the economy in the sense that the schools had not trained them, at school, for the type of work they would do in future. The result was unemployment in the Transkei and migration to industrial areas in South Africa. Untrained workers might also not be employed in South Africa. All

such factors lead to frustration in parents who had spent the little they had on the education of their non-disabled children.

With regard to children with disabilities the degree of severity of the disabilities in their children might influence parents not to educate such children. In other words, the role played by children with disabilities in the economy and development of the Transkei might be very small owing to parental attitudes towards educating such children and also owing to reactions of employers to children with disabilities who try to obtain work (they may not be employed because of their problematic movements and unusual postures).

1.3.4 History and development

The Xhosa, after migrating with other blacks from central Africa, entered the Transkei area in the sixteenth century. They made their first contact with white hunters and farmers in 1730 on the Eastern boundary of the then Cape Colony and conflicts began. Contact was intensified as more missionaries and traders moved into the Transkei. In 1778, owing to wars resulting from the contacts, the British Government declared the Fish river as the boundary between the Cape Colony and the Xhosa territory. This boundary and other boundaries that were fixed did not solve the conflicts and the British Government decided to annex black territories including the Transkei area. The British Government used indirect rule by introducing the Council System which was functioning over the whole of Transkei by 1926. The Council System used western methods of administration. Gradual independence of the Transkei

area was started when, in 1956, the Council System was replaced by the territorial, regional, district and tribal authorities. Thereafter various Acts were passed which eventually led the country to independence in 1976 (Champion 1976:4, Muller 1977:81). By 1989 Transkei was under the black military rule (Wallis 1989-90:2) and in 1994 it was reincorporated into South Africa.

1.3.5 The birth of the Transkei Education Department

Ngubentombi (1977:116) states that soon after the proclamation of the Self-Government Act of 1959, the Transkei Territorial Authority requested the South African Government to grant the Transkei self-government. South Africa acceded to the request and Act No. 48 of 1963 led to self-government. The Constitution provided for a Cabinet consisting of the Chief Minister and five other ministers administering six departments, one of which was the Department of Education. The main educational aim of this department was to perpetuate the cultural heritage which is fundamentally conservative and to transform and modernize human resources in the Transkei (Ngubentombi 1977:116).

1.3.6 The beginnings of special education in the Transkei

According to Ngubentombi (1977:147) South Africa transferred special schools for the Bantu children to the Department of Education in the Transkei on 1 April 1961. In this manner two special schools Efata - for the blind and the deaf and Ikhwezi, Lokusa - for the cerebral palsied children and the orthopaedically disabled - fell under the jurisdiction of the Education Department of the Transkei Government. The Department of Education

undertook the task of subsidizing these schools on the same basis as South African special schools for black children with disabilities. Special schools were regarded by the then Minister of Education as very expensive because of being highly specialised and requiring costly special equipment.

The Transkei has additional special schools. Four schools are for the mentally retarded: namely, Khanyisa at Cala, Tembisa in Umtata, Nompumalanga at Bizana and Vulekani at Umzimkhulu. The cerebral palsied children and the orthopaedically disabled are at Vukuzenzele at Bizana. Zamokuhle, also at Bizana, is for the deaf and blind. The Transkei has, therefore, eight special schools (Republic of Transkei Annual Report 1992:25).

The increasing number of special schools in the Transkei indicates that the number of children with disabilities is increasing. It might also indicate that more Xhosa parents are accepting that their children with disabilities should be educated. The third reason could be that more money is available owing to social awareness of the need for education of children with special needs.

1.3.7 High prevalence of children with disabilities in the Transkei

Some of the more obvious deficiencies in learners may be physical, neurological and sensory disabilities. Cases having such disabilities may be counted and the figures obtained may represent the special educational needs of children with disabilities. In western countries figures obtained may be regarded as small while in South Africa

and the Transkei the figure may be over a million or over twenty percent of the population. Such high figures may be caused by widespread poverty, malnutrition, diseases, general lack of access to health services and the traditional birth customs of the people (Donald 1992:8; Human Sciences Research Council 1987:62). The incidence of a disability such as cerebral palsy will be discussed in detail in Chapter two.

Literature further shows that parents have problems in coming to a full acceptance of children with disabilities. Tacke (1989:13-15) is of the opinion that the culture of the Xhosa is not positive towards children with disabilities and this will be discussed in detail in Chapter five.

1.4 Problem formulation

The background study indicates that there are certain factors that may influence parents to react towards the education of their children, be they non-disabled or children with disabilities. The existence of such factors motivated the investigation undertaken. The problem to be investigated is "What are the attitudes of Xhosa parents towards the education of their cerebral palsied children?" The following aims will be pursued for they clearly indicate what needs to be investigated before the answer to this question can be obtained.

1.5 Aims of the study

1.5.1 General aim

The general aim of the study is to investigate what the attitudes of Xhosa parents are towards the education of their cerebral palsied children.

1.5.2 Specific objectives

In order to attain the above-stated general aim, more specific objectives are required, inter alia the following:

1. to analyse and describe the phenomenon of cerebral palsy and how it affects the development and education of a child suffering from it (see Chapter 2),
2. to describe the education of cerebral palsied children and investigate what type of impact cerebral palsy may have on the education of such children (see Chapter 3),
3. To investigate parental attitudes to the birth of a child with a disability (see Chapter 4),
4. to study how Xhosa parents bring up and educate their cerebral palsied children (see Chapter 5),
5. to conduct an empirical investigation, which will supplement literature study (see Chapter 6).

1.6 Methods of study

Two methods will be used to investigate the problem: namely, a literature study and a limited empirical investigation.

1.6.1 Literature study

Available and suitable overseas and South African literature were studied because literature provides a frame of reference and allows the research problem to have a meaningful context. Literature study also allows

the data to be interpreted and findings to be made. Literature indicates what needs to be known about the impact of parental attitudes on the education of their cerebral palsied children and what can be done about such a situation. The literature study was supplemented by limited empirical research.

1.6.2 Empirical investigation

No standardised research instrument was used during the empirical investigation. The researcher constructed a questionnaire schedule with a multiple-choice format to be used with parents of cerebral palsied children. Parental information was verified by information from secondary resources such as teachers, social workers and hostel mothers. A section in the questionnaire was included where the respondents were allowed to make suggestions. The suggestions were intended to give information omitted by the questions which might be more informative to the researcher. The questionnaire was constructed around issues arising from the literature survey. The empirical investigation aimed at obtaining information relevant to parental attitudes towards the education of their cerebral palsied children.

1.7 Demarcation for the empirical investigation

The Transkei was selected as the area where the empirical investigation would be carried out. Both rural and urban respondents were included. The choice of the respondents was determined by the number of cerebral palsied children in the two special schools for children with cerebral palsy.

1.8 Study programme

The study is organised as follows:

Chapter one serves as an introduction to the following problem: What are the attitudes of Xhosa parents towards the education of their cerebral palsied children?

Chapter two concentrates on cerebral palsied children. The phenomenon of cerebral palsy will be discussed according to its incidence, classification, causes, results, associated disabilities and its prevention.

The third chapter discusses the education of cerebral palsied children. Aspects such as the structure of education, the role of the home and the school and the role of team members in the education of cerebral palsied children are included.

The fourth chapter is concerned with the parents of cerebral palsied children. Some of the reactions of the parents are discussed.

Chapter five will investigate how Xhosa parents bring up and educate their cerebral palsied children.

Chapter six explains how the empirical research was conducted and also contain findings from the data collected.

Chapter seven consists of a summary of the investigation, recommendations and a conclusion.

CHAPTER 2

CEREBRAL PALSIED CHILDREN

2.1 Introduction

Cerebral palsy as a disability was first described by William J. Little in 1861 and the term cerebral palsy was coined by Dr. Winthrop in 1937 (Bleck & Nagel 1982:59). The term cerebral palsied children appears in Schedule 1 of the Educational Services Act No. 41 of 1967 (Kapp 1989:318). According to this Act children who are cerebral palsied are those who have brain damage but are not suffering from mental retardation. The injury, which is localised or diffused, must have occurred prenatally, perinatally or postnatally. Children may also suffer from neuromotor, perception and communication problems (see 1.2.7).

2.2 The incidence of cerebral palsy

Literature reveals that cerebral palsy is not a disease but the result of an injury to or maldevelopment of the brain before, during or after birth. To obtain the exact indication of the number of individuals suffering from the disability is not easy. It is usually estimated that the incidence varies from 1,0 to 5,0 per thousand live births. Variation is due to the different methods of case identification and the numerous ways of defining cerebral palsy. Variation may also result from increasing medical knowledge and preventive skills (Bleck & Nagel 1982:59; Sillipp 1987:4).

In Western countries there appears to be a general decline in the incidence of cerebral palsy (Rudolf &

Hoffman 1987:1596). Special attention will be given to the figures for a number of countries.

2.2.1 The United States of America

The report of the United Cerebral Palsy Foundation confirms that the incidence of cerebral palsy is declining in the United States. In 1965 the incidence was 6/1000 live births and by 1978 it had declined to 3/1000 live births. The drop was due to intensive neonatal care, the prevention of blood incompatibility (see 2.4.1.2) and the use of phototherapy which assists the liver to function in infants. This treatment reduces jaundice (Sillipp 1987:16).

2.2.2 The United Kingdom and Sweden

The study of Rutter *et al* in 1970 indicated that the incidence of cerebral palsy on the Isle of Wight, in the United Kingdom, was 2,9/1000 live births. In Sweden Hagberg in 1978 and Aply in 1979 undertook research into the incidence of cerebral palsy. The studies showed that the incidence of cerebral palsy dropped from 2,24/1000 live births in 1954 to 1,34/1000 live births in 1970 (Sillipp 1987:16).

2.2.3 Canada and Australia

The report of Whittaker (1985) states that in Canada the incidence of cerebral palsy in 1962 was 11,69/1000 live births. In Australia the study of Stanley showed that the incidence before 1975 was 3,9/1000 live births and by the end of 1975 it had dropped to 1,2/1000 live births (Sillipp 1987:16).

2.2.4 South Africa

For South Africa the actual incidence figures are unfortunately not available (Coovadia & Loening 1988:277). Some studies indicate that the incidence of cerebral palsy in South Africa is increasing. According to Botha (1989:317) the incidence ranges from 1,5/1000 live births to 3/1000 live births. Grabe (1985:115) records the average estimated incidence as 2,5/1000 live births. According to him this means that one out of every four hundred children born in South Africa is affected. The implications are that South Africa is facing a major problem as ten percent of this number need special care for the rest of their lives. Another ten percent are slightly affected and can be placed in mainstream education. The remaining eighty percent need to be educated in special schools.

Arens et al (1978:319-324) studied Coloured and White cerebral palsied children in this country. Between 1964 and 1975 they saw 331 cerebral palsied Coloured children and 175 White cerebral palsied children in their clinics in Cape Town. They compared the etiology and changing incidence over two six year periods and found out that among White cerebral palsied children the incidence was decreasing. They concluded that the decrease was due to the fact that few White cerebral palsied children were being referred to their clinics. With regard to Coloured cerebral palsied children the incidence was increasing. They concluded that perinatal causes, especially asphyxia, contributed to the increase.

With regard to Black cerebral palsied children in South Africa, incidence figures are also lacking (Human Sciences Research Council 1987:53). It can be assumed

that the incidence figures will not be less than those of White and Coloured cerebral palsied children. They may be between 1,5/1000 live births and 3/1000 live births.

The Human Sciences Research Council (1987:62) is of the opinion that cerebral palsy in South Africa may be attributed to factors such as poverty, malnutrition, undernourishment, diseases (epidemics), population mobility, ignorance, deficiencies in medical services and facilities, the use of African medicines, shortcomings in respect of the dominant culture, congenital defects, traditional birth procedures, neglect and superstition.

2.2.5 Transkei

The general belief today is that the least developed countries have an incidence figure of 2,5/1000 children born with cerebral palsy. This incidence is equal to that of the 1960s in the Western countries (Bowley & Gardner 1980:25). The report of the Human Sciences Research Council (1987:53) states that in the Black States in South Africa data on incidence are lacking owing to the fact that some children with disabilities are in mainstream education.

Another reason may be that in the rural Transkei some children with disabilities cannot be traced (Eastern Cape Regional Welfare Board 1982:4). In both South Africa and the Transkei there are no studies on early school leavers who are children with disabilities. Moreover, in some Third World countries some children with disabilities may be kept at home owing to factors such as poverty, ignorance and customs of the people.

Also, a high infant mortality rate may hamper any attempts to obtain stable incidence figures of children with disabilities (Jelliffe 1985:2-4; Human Sciences Research Council 1987:53).

While incidence figures for the Transkei are lacking, it can be assumed that they will not be less than those of cerebral palsied children in South Africa and may be between 1,5/1000 and 3/1000 live births.

Having taken a brief look at some of the figures for cerebral palsied children in a number of countries it would be appropriate to look into the classification of cerebral palsy.

2.3 Classification of cerebral palsy

Cerebral palsy is classified differently by various authors. Keats (1965:38-49), for instance, lists six classification systems:

- * the physiological classification which includes motor symptoms resulting from brain damage,
- * the topographical classification which shows the parts of the body that are affected,
- * the etiological classification which is concerned with the causes of cerebral palsy,
- * the supplementary classification which accommodates the associated symptoms,
- * the functional classification which is according to the extent and degree of the impairment of the child's functional ability and
- * the therapeutic classification which is concerned with the method of treatment.

For the purpose of this study only the topographical and the physiological classification systems will be discussed.

2.3.1 Topographical classification

Fig. 2.1 (see page 28) shows the topographical classification which is based on the part of the body affected. This classification ranges from one limb being slightly affected to severe involvement of all the limbs. The sub-types of this classification system are:

- Monoplegic : one limb, the left or the right arm or leg is affected (this condition is rare).
 - Hemiplegic : the left or right side of the body is affected (35-40%).
 - Triplegic : three limbs are affected, mostly the legs and one arm. (a rare condition).
 - Paraplegic : only legs are affected (10-20%).
 - Quadriplegic : all four limbs are involved (15-20%).
 - Diplegic : major involvement of lower limbs while upper are mildly affected (10-20%).
- (Powell 1986:308; Sillipp 1987:12).

Figures 2.2 and 2.3 (see page 29) show parts of the brain which, when damaged, affect the functioning of the body.

2.3.2 Physiological classification

2.3.2.1 Spasticity

The incidence of spasticity among people with cerebral palsy is fairly high. Hilt and Cogburn (1980:375) are of

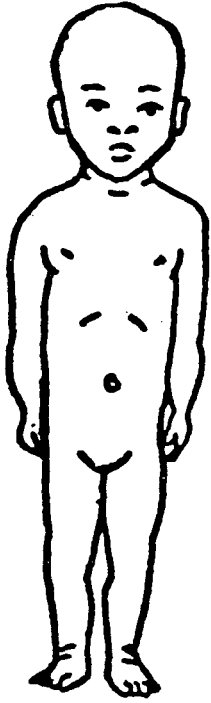
the opinion that it is between fifty and sixty percent while Bowley and Gardner (1980:29) cited seventy five to eighty percent. Spasticity results from lesions in the motor areas of the brain, the pre-motor area, the pyramidal and extrapyramidal tracts (Cruickshank 1976:90;Boone 1972:5).

Injury to these areas results in the loss of voluntary muscular control and the clinical picture is that of stiffness. This stiffness is caused by the impairment of normal muscle tone and by too much contraction when the muscle is stretched (Delventhol 1991:17).

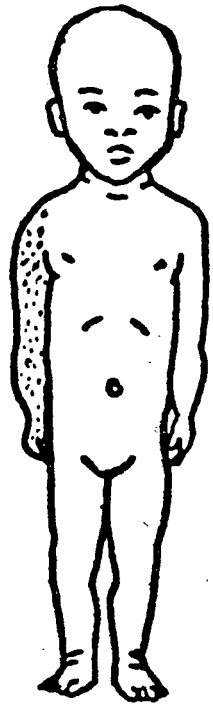
If the spastic muscles contract more than others they may become permanently shortened. Spasticity may also cause deformities of upper and lower limbs such as the "chicken wing" position of the arm, the "thumb in palm" condition and adduction of the shoulders. The hips may also be adducted, this means that thighs are together and cause the limbs to turn inwards. The result is "scissor-gait" in lower limbs. The child with severe spastic diplegia or paraplegia may show these deformity characteristics and the deformity of both legs and the flexion of hips and knees is referred to as equinus. The child may walk on his toes (Bleck & Nagel 1982:61-63; Botha 1989:332).

Other characteristics of spasticity include severe trembling, awkward gait, unsteadiness, tense and irregular movements. When the child tries to control jerkiness and lack of co-ordination the condition is aggravated. Moreover, diaphragm muscles and those of the throat that are involved in speech production, may be affected, for example, the voice may be hoarse and not clear (Poonsamy 1984:10).

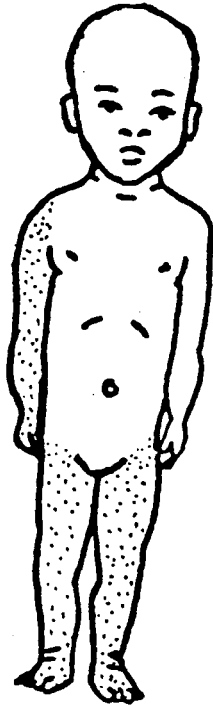
Fig. 2.1



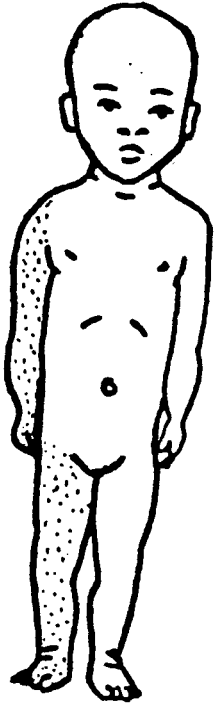
Unaffected



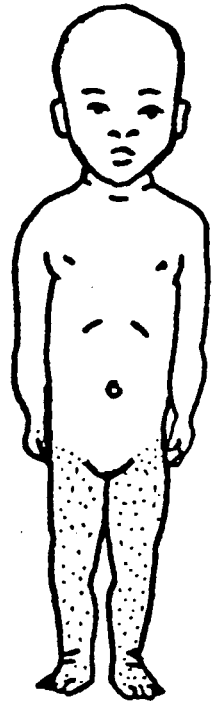
Monoplegic



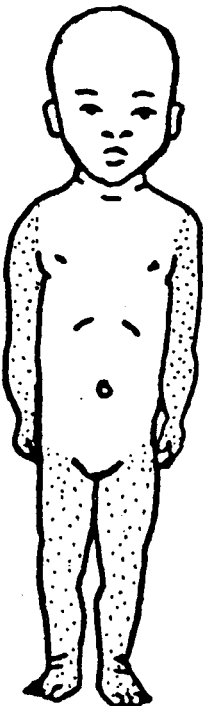
Triplegic



Hemilegic



Paraplegic/
Diplegic



Quadriplegic

Figures 2.2 and 2.3 : show three brain parts which, when damaged, result in cerebral palsy.

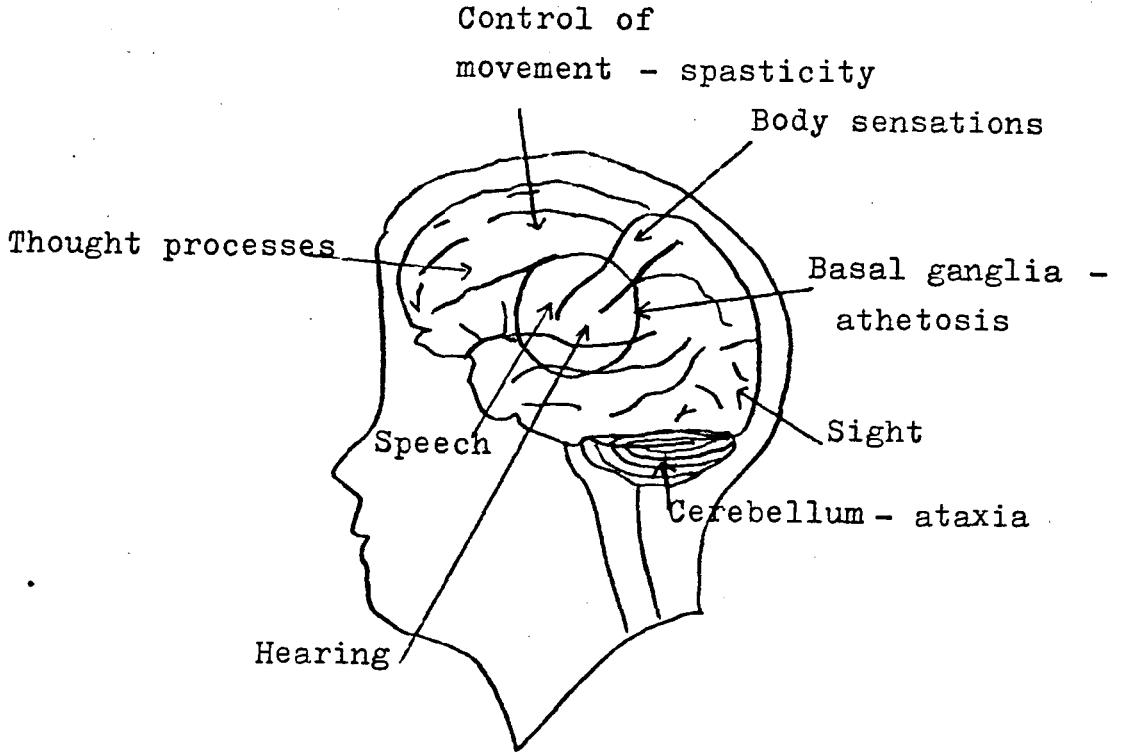


Fig. 2.2

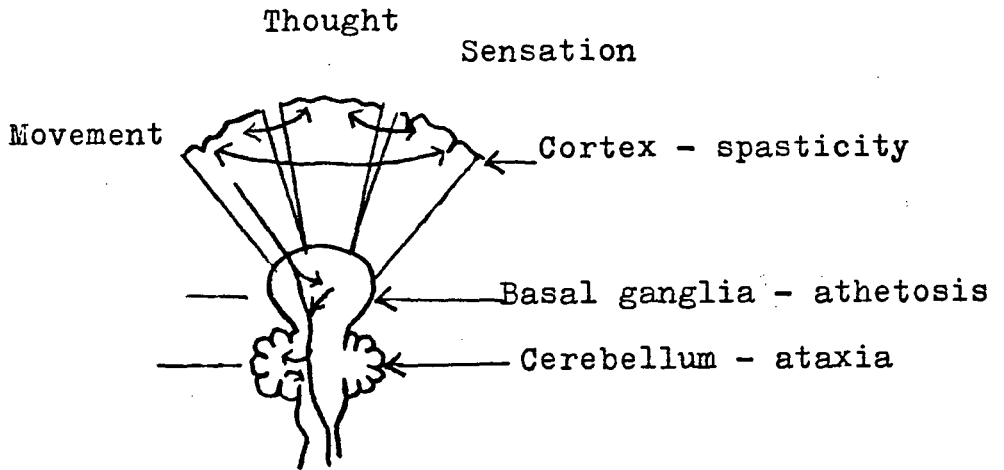


Fig. 2.3

The child suffering from spasticity may be unwilling to use the affected limbs. To assist such a child the shortened muscles may be operated on in order to lengthen them, for instance, the Achilles tendon (Low & Carter 1987:1596-1597; Sarkin 1989:184). Some cerebral palsied children suffer from athetosis.

2.3.2.2 Athetosis

In some children the damage to the basal ganglia and the extrapyramidal tracts results in athetosis. These brain areas may be injured by jaundice or kernicterus or anoxia at birth. Less than ten percent of all cerebral palsied children have athetosis (Telford & Sawrey 1967:335; Hewett et al 1970:32; Bowley & Gardner 1980:30).

In an athetoid the muscular contraction is not rhythmical and the pattern may be irregular, wriggling and writhing. The child cannot use his hands well owing to continuous movements of arm-hand. The characteristics of an athetoid child may be involuntary facial movements, hampered speech and swallowing as a result of the affected muscles of the tongue and throat. Since movements cannot be well controlled, an athetoid experiences posture problems in activities such as sitting and walking. When the child is sleeping or relaxed involuntary movements may gradually decrease until they stop (Botha 1989:324; Boone 1972:6).

In some athetoids' muscles may become very tense and such tension is called tension athetosis and cannot easily be distinguished from spasticity. If tension becomes very severe the child is incapable of moving. Athetosis may also be accompanied by high frequency

hearing loss. Athétosis, as figures 2.2 and 2.3 show, is caused by damage to the basal ganglia and as the centre for hearing is situated near the basal ganglia it may be affected (Bowley & Gardner 1980:30).

2.3.2.3 Ataxia

Ataxia is another form of cerebral palsy. Ataxia is caused by damage to the cerebellum and about five percent of all cerebral palsied children suffer from ataxia. The child with ataxia may be conspicuous owing to a disturbed equilibrium. Such a child may have a disturbed sense of spatial posture and may have a drunken gait. The child may also have writing and reading problems because of the disturbed hand and eye-muscle co-ordination. Ataxia also causes tremor, causing the child to shake when trying to do something. In other cases the child may be clumsy when playing. Ataxia, in some children, can disappear as they grow older (Bobath 1980:57; Bleck & Nagel 1982:62).

2.3.2.4 Rigidity

Rigidity is one of the most severe forms of cerebral palsy and is caused by damage to the basal ganglia. Approximately five to seven percent of all cerebral palsied children suffer from rigidity. This condition is characterised by muscles that continuously resist movement. If resistance is overcome the resulting movement is jerky (Cruickshank 1976:32; Samilson 1975:13). Another disturbing condition is tremor.

2.3.2.5 Tremor

Tremor is one of the rare forms of cerebral palsy. Movements are involuntary, regular, spontaneous and

rhythmical. The cause of tremor is injury to the basal ganglia. Tremor interferes with the child's efforts to stand, walk, climb or use his hands. If tremor occurs in the lower limbs, balance and gait will be affected (Bleck & Nagel 1982:66; Botha 1989:325).

2.3.2.6 Mixed types

Some children have mixed types of cerebral palsy. A child may simultaneously suffer from spasticity and athetosis while another may have tremor in addition to his or her disability (Bleck & Nagel 1982:66).

The topographical and physiological classifications of cerebral palsy show that cerebral palsied children may experience difficulties, for instance, in their movement, speech, hearing, balance and perception. Some problems may, directly or indirectly, influence the attitudes of parents who bring up cerebral palsied children. In order to understand problems of cerebral palsied children and the predicament of their parents it is necessary to delve into factors causing cerebral palsy.

2.4 Factors causing cerebral palsy

Not all factors will be included in this section, only those that seem to be the most significant have been selected for discussion and will be grouped under prenatal, perinatal and postnatal causes.

2.4.1 Prenatal factors

Prenatal development begins at conception and ends when labour commences. It is likely that injury to the brain

may occur during this stage and result in cerebral palsy in children. A number of factors causing cerebral palsy during this stage will be discussed in the following paragraphs.

2.4.1.1 Genetic factors

According to Mendel's law a parent passes only one allelic (term for genetic pair) gene to the child. Some authors are of the opinion that conditions such as familial rigidity, familial athetosis, congenital familial spastic paraplegia and atonic diplegia may be transmitted by genes from parents to their children. To confirm that cerebral palsy can be inherited, Lessel and Van Dalen (1988:158) studied six family members representing three generations. They found that all six patients suffered from primary position vertical nystagmus owing to the fact that their parents had hereditary cerebellar ataxia. It may be concluded that, whether the defective gene is dominant or recessive, the children may have the condition of the parents or become carriers (Levitz 1991:39; Botha 1989:276; Stanfield 1983:7; Keats 1965:14).

Factors that may cause defects in genes are high doses of X-rays and other kinds of radiation which may cause mutations. Some authors are of the opinion that certain powerful chemicals may affect the genes and their functions (Edge 1986:316; Powell 1986:270; Berger 1983:69; Berkov 1982:1201-1202). The blood incompatibility of parents may be another factor that causes cerebral palsy in children.

2.4.1.2 The Rh-factor (blood incompatibility)

The Rh-factor is transmitted by genes. An Rh-negative woman may be made pregnant by an Rh-positive man, the resulting foetus may be Rh-positive. The Rh-negative woman reacts to the foetus's Rh-positive blood cells by producing antibodies called anti-agglutinins. These antibodies are not harmful to the foetus but tend to destroy red blood cells of the second and the subsequent pregnancies. The fact is that the placenta is permeable and allows the destructive antibodies of the mother to enter the foetus's blood stream (Botha 1989:289; Shaffer 1985:32; Cavalli-Sforza 1977:147).

The brain of the foetus is injured when brain cells are deprived of oxygen owing to a shortage of red blood cells that supply it. Dead red blood cells may cause the overproduction of bile or what is termed bilirubin which causes jaundice. Before birth the liver of the mother reduces the amount of bilirubin in the foetus but after birth the bilirubin tends to accumulate because the immature liver of the infant cannot cope. High concentrations of bilirubin may injure brain cells (Bleck & Nagel 1982:68; Low & Carter 1987:1594; Botha 1989:290).

The results of Rh-blood incompatibility may be very serious or even fatal. Such results are shown by spontaneous abortions, premature births, still births, erythroblastosis foetalis which is a severe reduction of red blood cells in the foetus, kernicterus or jaundice that injures the basal ganglia and results in mental disability and deafness (Botha 1989:290).

The consequences of an Rh-factor may continue occurring because it is estimated that one out of every eight women is Rh-negative. Such a state of affairs needs to be addressed if the incidence of cerebral palsy is to be reduced in South Africa as well as the Transkei. The mother is usually given vaccines which prevent her from producing antibodies against her future offspring. In severe cases pregnancy may be terminated or the foetus may receive a transfusion of Rh-negative blood through the umbilical vein. In some cases infants may receive repeated blood exchange or phototherapy (Berger 1983:76; Edge 1986:248). It has been stated that the Rh-factor may cause premature births.

2.4.1.3 Prematurity

There are certain factors that cause some babies to be born prematurely, that is, before full term and some of these babies may not have developed fully. Other babies may have undergone the full term but are small for their age. This implies that they weigh less than the average weight of full term babies. Twins also tend to be born prematurely owing to an overdistended uterus which is inclined to go into labour ahead of term (Biehler & Hudson 1986:159; Berkov 1982:1734).

Babies ought to weigh approximately 2,5 kilograms at birth. A lower birth weight may be due to the undernourishment of the mother, problems in the placenta (see 2.4.1.9) and the umbilical cord, prenatal infections (see 2.4.1.5), drugs and smoking (see 2.4.1.8), maternal diseases, the age factor of the parents (see 2.4.1.10) and the low-socio-economic status of parents (McFayden 1985:62; Berger 1983:98).

Low birth weights may cause injuries during birth because of the fragile skull and underdeveloped blood vessels that may rupture and result in haemorrhage. About sixty percent of all cerebral palsied children can be traced to low birth weight and prematurity (Sillipp 1987:19; Botha 1989:291). Besides prematurity irradiation may be another factor that injures the brain of the foetus and results in cerebral palsy.

2.4.1.4 Irradiation

Doctors have come to the realisation that the use of X-rays to examine the position of the foetus within the womb of a pregnant woman may be harmful to the foetus. Sometimes the patient and the doctor may not be aware that the woman is pregnant when abdominal X-rays are taken to examine other ailments. In such situations harm may be prevented by carefully examining the woman for pregnancy before subjecting her to X-ray examinations. The fact is that any over-exposure to X-rays may result in damage to the brain tissue of the foetus, thus causing cerebral palsy (Botha 1989:288; McDonald & Chance 1964:21). Cerebral palsy not only results from factors such as irradiation but also from viral infections.

2.4.1.5 Viral infections

The most damaging infection during the second to fourth months of pregnancy is German measles. Rubella not only affects the neurological development of the foetus but may also affect sight, hearing and even the heart. The infection may be transferred to the foetus through the placenta and affect the brain (Boone 1972:10).

Other infections such as chicken pox, influenza, mumps, shingles (herpes zoster) and syphilis may also cause brain damage that results in cerebral palsy (Glenting 1970:119; Bleck & Nagel 1982:68; Sillipp 1987:18). It also appears that harmless family pets may contribute towards cerebral palsy in children as the discussion that follows shows.

2.4.1.6 Toxoplasms

There are certain parasites (toxoplasms) such as those found in domestic animals, that can land in the blood stream of the mother and eventually invade the brain of the foetus. In the brain the parasites may cause meningo-encephalitis which is inflammation of the meninges of the brain or the spinal cord (Berkov 1982:885; Botha 1989:288). The result may be cerebral palsy. Another dangerous brain damaging factor is poisoning.

2.4.1.7 Poisoning

Cerebral palsy in a child may also result from the intake of poisonous substances such as, for instance, lead by the mother. Other poisonous substances that may also reach the brain of the foetus and injure, it are poisons originating from the affected heart or kidneys of the pregnant woman (Stocker & Dehner 1992:249). Besides poisoning drug and alcohol abuse and smoking by the pregnant mother seem to be harmful to the foetus as well.

2.4.1.8 Drugs, alcohol and smoking

A mother who uses drugs may cause neonatal jaundice in a child. Jaundice, when it affects the basal ganglia, is called kernicterus or "yellow stained basal ganglia". Kernicterus causes choreo-athetosis, asymmetrical spasticity and various intellectual impairments (Lamont 1982:191).

Excessive smoking, on the other hand, may cause severe mental retardation in the foetus. The foetus and even the newborn child may exhibit retarded growth. Brain damage resulting from alcohol may cause joint contractures (Berkov 1982:1782).

Like drugs and alcohol, smoking may cause cerebral palsy in the foetus. Smoking causes congenital abnormalities such as neural tube defects and low birth weight. Tobacco damages the vessels of the placenta and causes a decrease in the placental oxygen supply to the foetus. Shortage of oxygen causes anoxia. Nicotine may also induce premature labour and thus cause pre-term deliveries and premature babies are more prone to suffer brain injury. Apart from the ill effects the child may suffer, any pre-term labour may also result in serious economic implications because neonatal care is very expensive (Crowley 1983:155; Bolton 1983:128-129; Achenbach 1982:159; Riccardi 1977:148). The permeable placenta also appears to play a role in causing cerebral palsy.

2.4.1.9 Placenta problems

Sometimes the placenta may be planted low in the uterus, close to the internal os. The implantation may cover the

opening completely or partially. This type of implantation is not normal and it leads to severe bleeding in late pregnancy. Haemorrhage reduces oxygen and nutritional supply to the foetus and cerebral palsy may be the result (Berkov 1982:1728-1729; Keats 1965:16). The age of the mother may be another factor that may be the cause of injuries to the brain of the foetus. Old or underdeveloped placenta in women may not be functioning well and thus affect the development of the foetus.

2.4.1.10 Maternal age

Very young mothers, such as those under sixteen years of age, and older mothers of forty years of age or older, have a tendency to produce children with disabilities. This may be caused by the reproductive system. In very young mothers it is inadequately developed and, therefore, not being able to function well. In older women the reproductive ability may be declining owing to ageing of the reproductive system. These factors may lead to cerebral palsy in the offspring (Lerner et al 1987:26). Anoxia may also cause cerebral palsy (see also 2.4.3.3).

2.4.1.11 Prenatal anoxia

Anoxia means lack of oxygen. Factors that reduce oxygen in the foetus are, for instance, the Rh-factor (see 2.4.1.2) and the mother suffering from lung, heart or kidney problems which cause harmful toxins that injure the brain of the foetus. The mother's having a severe haemorrhage during pregnancy is likely to cause brain damage that results in cerebral palsy (Boone 1972:10; Bleck & Nagel 1982:68; Keats 1965:16).

Problems of the placenta (see 2.4.1.9) may also cause anoxia. The amount of oxygen passed by the placenta to the foetus may be reduced by maternal use of drugs (see 2.4.1.8) or by maternal allergies and shock. Sometimes the twisted or compressed umbilical cord prevents a sufficient supply of oxygen to the foetus. If the umbilical cord is strangling the foetus it causes suffocation (asphyxia) especially during the birth process. The result may be brain damage (Walshe & Walshe 1970:332).

There are also unknown causes that give rise to cerebral palsy in children.

2.4.1.12 Unknown causes

The most important phase in the development of the foetal brain is the first twelve weeks after conception. During this time other unknown factors may interfere with brain development of the foetus and result in cerebral palsy. About thirty percent of all cerebral palsied children fall into this category (Bleck & Nagel 1982:19; Sillipp 1987:19).

Some children escape brain damage during the prenatal stage but may be injured during birth as the following paragraphs will show.

2.4.2 Perinatal causes

Some authors maintain that this period starts at birth and continues for the first ten days after birth. They are also of the opinion that the problems of fifty five percent of all cerebral palsied children are due to

perinatal causes (Grabe 1985:119). Some of these perinatal factors causing cerebral palsy will now be examined.

2.4.2.1 Perinatal anoxia

Anoxia may occur immediately after birth. The neonate may not be able to breathe because of obstructions caused by the secretions of the mucus membrane, lungs that do not function well and reduced oxygen content in the blood. Brain damage may then occur. In other cases blood vessels may rupture during the birth process and haemorrhage may follow. Blood may then seep into the brain of the baby, injure the brain and result in cerebral palsy (McDonald & Chance 1964:24; Botha 1989:293).

It is possible that an infant may, during the birth process, draw amniotic and other fluids that are in the birth canal into his lungs. By the time the child is born he or she may be suffering from pneumonia. Owing to fluid in the lungs, the oxygen content in the blood stream of the neonate may be lowered and cause anoxia (Boone 1972:11).

Other factors that may affect the infant during the perinatal stage are drugs. Drugs administered to the mother during labour tend to depress the neonate's respiratory system for up to twenty four hours after birth. Anoxia may also be the result of the umbilical cord being compressed between the child's head and the mother's pelvis during the birth process. The cord may also twist and even strangle the child during the birth process resulting in suffocation or what is called asphyxia (Botha 1989:292).

2.4.2.2 Cerebral trauma

Cerebral trauma is another major cause of perinatal injury. Birth becomes traumatic when prenatal factors have already affected the foetus causing a very difficult birth. Births of premature babies may be difficult in that babies are susceptible to head injuries. Brittle bones and easily rupturing blood vessels may result in haemorrhage (Boone 1972:12). The birth of any child is regarded as normal if, for instance, the head appears first. Sometimes this type of birth does not occur and problems result as shown in the following paragraphs.

2.4.2.3 Birth presentation

There are certain abnormal birth presentations which may injure the brain of the neonate. These include breech delivery where the buttocks appear first. Such a position may prevent a proper oxygen supply to the brain of the neonate during the birth process (Botha 1989:292). Sometimes some women experience labour that lasts longer than expected. Such prolonged labour may affect the child.

2.4.2.4 Prolonged labour

A woman who goes into labour for the first time may be in labour for anything up to eighteen hours. For the woman who has had multiple deliveries labour may last for about twelve hours. If labour goes beyond these lengths of time uterine contractions may distort the baby's head, thus causing injury resulting in cerebral palsy. A very quick birth may also be harmful for it does not give the neonate's head and lungs sufficient

time to adapt to atmospheric situations. This may, once again, lead to brain injury (Keats 1965:21; Botha 1989:292). In some cases instruments must be used during delivery owing to complications that arise and their use and effects will now be discussed.

2.4.2.5 Mechanical intervention

Sometimes the mother's downward pressure is very weak and the baby cannot be born. Doctors use various methods to assist the delivering woman. Instruments such as forceps are placed on either sides of the baby's head and the child is thus pulled out. Forceps and other obstetrical tools are used especially in cases where the head of the baby is too large. The use of these instruments requires careful manipulation for any abnormal pressure may tear or bruise brain tissue, resulting in brain injury. Any torn blood vessels result in haemorrhage which in turn may cause blood to clot. Thrombosis may block a blood vessel and thus injure brain cells by depriving them of oxygen or essential nutrients (Botha 1989:292; Sillipp 1987:20). Sometimes the use of instrumental intervention, according to obstetrical judgement, may not be effective owing to pelvic problems of the pregnant mother. In such cases a Caesarean section may be helpful.

2.4.2.6 Caesarean section

Caesarean section refers to the delivery of the child by cutting through the walls of the abdomen of the pregnant woman. This type of operation may be done when the pelvis of the woman is too narrow or when doctors try to save the life of the foetus in cases where the mother

suffers from complications, for example, severe epilepsy or very high blood pressure or haemorrhage. Some form of anaesthetic is used during such an operation.

Anaesthetics may be dangerous for they depress the baby's respiratory system, thus affecting the breathing process. The child born by Caesarean section may also sustain head injuries. Trauma may occur when the head is pulled out through a small hole in the uterus using forceps. The result may be intercranial haemorrhage causing cerebral palsy. Injury of the brain may also occur because a Caesarean section may be a quick birth that does not give the circulatory system of the foetus a chance to adapt to conditions outside the uterus (Botha 1989:292; Ayim *et al* 1986:37; Keats 1965:21).

Besides anaesthetics pain killers also seem to contribute towards brain injury which results in cerebral palsy in the child.

2.4.2.7 Analgesia

It has already been stated that the permeable placenta allows some medication to enter the bloodstream of the foetus. Pain killers, for instance, can be administered to a woman in labour or during childbirth. Analgesia may have serious results for the baby especially during birth. The baby's respiratory system may be depressed and this also results in anoxia (see 2.4.2.1) which in turn causes cerebral palsy (Keats 1965:23; Botha 1989:293). Besides medication, direct head injuries may result in cerebral palsy.

2.4.2.8 Cerebrovascular accidents

The term cerebrovascular accidents refers to various types of accidents that injure brain blood vessels. Some of these accidents may be caused by lack of oxygen or thrombosis or embolism. Lack of oxygen weakens blood vessels and blood may seep out through the walls of the blood vessels and embed itself in the brain tissue. Extra weight on the brain is dangerous. Thrombosis, on the other hand, blocks the blood supply to some parts of the brain. Brain cells may then die and the death of brain cells is called necrosis. The problem is that dead brain cells cannot be replaced and this implies that motor parts that were controlled by dead cells cannot function properly. Sometimes there is a localised shortage of blood supply and this is referred to as ischaemia. Some infants may have dilated blood vessels (aneurisms) which tear easily, resulting in haemorrhage in the brain and haemorrhage results in cerebral palsy. (Botha 1989:292). Another factor causing cerebral palsy is the atmospheric pressure.

2.4.2.9 Atmospheric pressure

Sudden changes in atmospheric pressure may be a cause of damage to the baby's blood vessels. Injury occurs when the atmospheric pressure affects the chest and head of the infant during quick birth, premature birth or even during Caesarean section. The result may be cerebral palsy (Botha 1989:293).

2.4.2.10 Congenital infections

Besides atmospheric pressure maternal infections are also factors causing brain injury. The infections may

have been contracted by the child while in the mother's womb. These infections may still be in the child's bloodstream during birth and may be dangerous to the child after birth. Congenital syphilis of the mother may cause kernicterus in the child and kernicterus, in turn, may injure the baby's brain. The mother may also suffer from other infections which the child may contract during birth. Such infections may injure the child's brain during its perinatal stage, resulting in cerebral palsy (Botha 1989:293). A child may escape injury before birth or from congenital infections during birth only to suffer from the effects of subsequent insufficient care.

2.4.2.11 Insufficient care

The neonate needs special care after birth. The absence of such care may result in injury to the brain or even infections that lead to encephalitis and meningitis. Some infants may suffer from high fevers, owing to lack of care, which harm the infant and cause infantile epileptic convulsions. Some cerebral palsied children do suffer from these convulsions. Insufficient intake of fluid or diarrhoea may lead to dehydration in babies. Dehydration may cause cerebrovascular injuries or haemorrhage which results in cerebral palsy (Botha 1989:294).

Some cerebral palsied children acquire cerebral palsy during the postnatal stage and some of the factors causing cerebral palsy at that stage are discussed below.

2.4.3 Postnatal factors

There are, among other things, four main factors that may cause lesions to the brain of the child during the

postnatal stage and result in cerebral palsy. The following discussion looks critically at these factors.

2.4.3.1 Brain trauma

About eighty percent of all cerebral palsied children have a history of head injuries. Factors causing brain injuries may be car accidents and blows to the head. These result in haemorrhage, clots, skull fractures, thrombosis, tearing and bruising of the brain tissue (Berkov 1982:883; Bleck & Nagel 1982:69).

2.4.3.2 Infections and illnesses

Infections and illnesses may also cause brain injury after birth. The most dangerous infections are those that cause encephalitis and meningitis. Meningitis not only results in cerebral palsy in the child but may also lead to deafness and blindness. Other factors which may result in cerebral palsy are viral infections such as measles, small pox and allergies (Botha 1989:294).

2.4.3.3 Anoxia

Cerebral palsy in infancy may also be caused by oxygen deprivation through poisoning, strangulation or the inhalation of carbon monoxide. Oxygen deprivation may also be the result of the intake of arsenic, lead or coal and of being exposed to very high altitude where there is a decrease in the oxygen supply (Boone 1972:13; Sillipp 1987:21).

2.4.3.4 Child abuse

Child abuse can be defined as the harm or the threatened harm to a child's well-being which results in physical or mental injury (Stocker & Dehner 1992:286). A study by Diamond and Jaudes (1983:169-174) reveals that child abuse can also be a cause of cerebral palsy in children. Of the eighty six cerebral palsied children seen in one of Chicago's care centres over the period of one year (September 1979 to August 1980) eight children suffered from cerebral palsy owing to being abused. In order to counteract child abuse Diamond and Jaudes (1983:173) suggested that a plan that protects children from being battered should be devised by the pediatric team. In this manner cerebral palsy resulting from child abuse can be reduced.

The factors stated above may cause the child to have cerebral palsy which may also give rise to numerous associated problems. These associated problems occur when injury to motor areas also affects adjacent areas and hampers their functioning. The child's disability then becomes more complex. Some of these additional problems deserve attention.

2.5 Cerebral palsy as a multifaceted phenomenon

Motor problems result from brain damage and neuromuscular problems. A cerebral palsied child may also suffer from additional defects, for example, epilepsy, have nutritional problems and sensory defects and these problems will be the topics of the following paragraphs.

2.5.1 Epileptic seizures

Epilepsy can be regarded as the flooding of the brain with electric charges (Leary s.a.:16). In a cerebral palsied child the brain may be unable to control and regulate sudden and irregular electric charges and the result may be a seizure. The ability of a cerebral palsied child to learn may then depend on the severity of the seizures. Severe cases are excluded from school owing to serious physical and intellectual problems caused by epilepsy. Those attending school may have to take anticonvulsant drugs which may lead to drowsiness which affects the alertness of the child. In some cases epilepsy may hamper brain development in very young children (Boone 1972:135; Bowley & Gardner 1972:8; Harris & Mawdsley 1974:135).

2.5.2 Problems related to orthopaedic surgery

A cerebral palsied child may also suffer from abnormal posture and from deformities of limbs (see 1.1; 2.3.1). These deformities may be caused by weak muscles. Some children may be unable to stand or walk. They may then sit continuously and sitting may cause deformities of the lower limbs. Deformed limbs may need surgery in order to restore them to their proper configuration. Muscle, tendon and bone alterations are essential but they may affect the child in that he may have to adapt to new posture and movement (Boone 1972:16).

2.5.3 Feeding and nutritional problems

A cerebral palsied child may experience nutritional problems owing to his or her spasticity (see 2.3.2.1) or athetosis (see 2.3.2.2). which makes it difficult for

him or her to feed himself or herself. Owing to affected mouth and throat muscles the child may be unable to swallow properly or may drop, spit or push the food out with his tongue. Lack of proper nutrition may affect all aspects of the child's development (Finnie 1974:118).

2.5.4 Visual defects

Between twenty five and fifty percent of all cerebral palsied children suffer from visual defects. These children may have an imbalance of eye muscles and thus suffer from diplopia where the two images recorded by the two eyes do not correspond. The brain does not accept two separate images and will then suppress the image received in one eye. The eye will eventually become blind (Sillipp 1984:14; Keats 1965:275-277).

Yet other children suffer from a squint (strabismus) and will not be able to see clearly. The brain will once again suppress the distorted picture in the squinting eye which will also eventually become blind. To encourage the squinting eye to see, the healthy one is covered, but the covering technique may cause psychological problems in the child. The squinting eye may also be treated surgically and the two images are integrated by correcting the distortion (Boone 1972:17).

Another eye defect that cerebral palsied children may suffer from is nystagmus (jerky to-and-fro movements of the eye). Others have hemianopia where only half of the eye sees. Hemianopia is mostly found in hemiplegics. In other cases the child may be able to use only the centre of the eye for seeing and not the peripheral area. The child will then have to move his or her head sideways like a fowl in order to see. Some of the children may be

shortsighted (myopia) and others may be longsighted (hyperopic) (McDonald & Chance 1964:53; Scherzer & Tscharnuter 1982:55).

2.5.5 Auditory problems

Hearing problems are prevalent among children suffering from athetosis, resulting from the Rh-incompatibility (see 2.4.1.2). The child may then suffer from high frequency hearing loss. Some children may also suffer from auditory agnosia where the child hears the sounds but cannot attach meaning to them (Bowley & Gardner 1980:32). Other cerebral palsied children may have internal or alternating hearing loss. This causes the child's attention to fluctuate. A severe hearing loss affects the learning of the child and such a child needs an adjustable hearing aid. Approximately fifteen percent of all cerebral palsied children need a hearing aid (Bowley & Gardner 1980:32).

2.5.6 Tactile problems

There is evidence that some cerebral palsied children suffer from tactile problems and that this condition is mostly found among spastic hemiplegics. Some children may be unable to learn by identifying objects placed in their hands or mouths. Moreover, tactile problems tend to affect chewing, drinking and the child's articulation (McDonald & Chance 1964:50).

2.5.7 Laterality problems

The majority of children prefer to use one hand as opposed to the other. Though the preference to use a particular hand is genetically determined, the child can

be environmentally influenced to use either the right or the left hand (Mwamwenda 1989:345). In hemiplegics the preferred hand may be severely affected and the tendency would be to train the child to use the healthy hand. The training takes place while the child is still young and it must be total. This is done by binding the affected hand to immobilize it. If the shifting is incomplete the child will continue to use the affected hand and the hemiplegic child may then suffer from speech and behaviour disorders (Keats 1965:325-326).

2.5.8 Speech problems

Speech problems prevent the child from articulating clearly. Such disorders may even lead to emotional problems and affect the child's learning. Speech problems may be caused by affected speech muscles because of brain damage. The child may have no control over his tongue, jaw or throat (affected oral articulators). Other areas that may be affected are the thorax, diaphragm and the abdomen. They may not be functioning together and thus hamper speech production. If there is any delay in the acquisition of speech, the motor areas of the brain that control speech muscles may have been injured or the child may have a hearing loss or may be suffering from aphasia (aphasia is a loss of speech or understanding of language owing to brain damage, the child is speechless) (Lerner et al 1987:29).

2.6 Other problems related to cerebral palsy

2.6.1 Mental disability

Research reveals that twenty five to thirty five percent of all cerebral palsied children may have normal to

superior intelligence. The remaining percentage may have an IQ that is below 90. Those whose IQ is below 70 are classified as mentally disabled. Among cerebral palsied children the results of the IQ tests tend to be highly affected by the psychological state of the child at the time when the tests are administered. The tests may not reflect the true ability of the child who may be regarded as mentally disabled though he is not (Boone 1972:18-19). On the other hand, owing to the therapy and social education procedures, the child may test higher than his or her ability. Some children experience perceptual problems.

2.6.2 Perceptual problems

Not all cerebral palsied children have perceptual problems. A few basic skills that may be affected will now be discussed.

Some children are able to perceive part of the object while others notice small details of the whole. For these children the parts they see form the whole and may cause confusion, distortion and learning problems and may even lead to behaviour disorders. The child may not be able to understand the realities of life and his or her readiness for school may be affected (Blacha 1982:1; Eleck & Nagel 1982:72-73).

Cerebral palsied children may experience problems in visual, auditory and tactile perceptions. Some spastic children may have visual perception disturbances. They may be unable to recognise similar shapes or to match them. They may encounter difficulties when trying to distinguish a picture from its background. The direction of letters such as "b" and "d" may be another perceptual

difficulty. Some cerebral palsied children may be unable to perceive the three dimensions of the object (Kephart 1971:143; Berkov 1982:850).

Cerebral palsied children may also suffer from disturbances to or irregularities in auditory perception. When listening the cerebral palsied child may be unable to distinguish between foreground and background noises. The result is confusion and distraction in the child which affects the child's learning (Boone 1972:20).

Tactile problems are also experienced by cerebral palsied children. Some of these children cannot perceive shapes, weights and the texture of the objects. Some are unable to distinguish, by touch, the object from its background (Poonsamy 1984:20).

Some children suffer from visual-motor perception disorders. This implies that these children may not be able to copy (when writing) what they see owing to motor developmental lag. Cerebral palsied children who mostly exhibit visual-motor perceptual problems are mainly the spastic hemiplegics (Bleck & Nagel 1982:72).

2.6.3 Behaviour problems

Cerebral palsied children who suffered from anoxia (see 2.4.1.11; 2.4.2.1) tend to have behaviour problems. Such children may be impulsive, have a short attention span or suffer from hypermobility. It can be explained that one of the functions of the cortex is to inhibit sudden motor reactions to stimuli. In certain cerebral palsied children the inhibition function of the cortex

may be reduced, hence the sudden responses to any stimulus. Not all behaviour problems will be discussed but only those that seem more obvious.

2.6.3.1 Distractibility

Any child may be distracted intentionally. If a teacher, for example, rebukes the child, he or she may pay attention to what is taught at that moment. A cerebral palsied child may be distracted unintentionally and no amount of threats and scoldings will make him pay attention. The distractibility in the child may be caused by external and internal stimuli. External stimuli may be in the form of auditory or visual stimuli. Internal distractions may be due to thoughts where the child may appear to be daydreaming and not paying attention to what is said or taught. Distractibility, therefore, hampers the learning of the child (Cruickshank & Johnson 1975:60; Levitz 1982:73; Keats 1965:181).

2.6.3.2 Hyperactivity

Some cerebral palsied children may also suffer from two types of hyperactivities, namely, motor and sensory hyperactivities. With regard to the motor hyperactivity the child may touch whatever he sees or simply walk towards the stimulus. His or her movements are usually sudden and unpredictable. The sensorily hyperactive child does not move or act. What he or she sees or smells or hears distracts him to such an extent that he or she forgets what he or she was doing. Both motor and sensory hyperactivities have negative effects on the

child. The motor hyperactivity causes control problems while the sensory hyperactivity causes learning problems in the child (Keats 1965:181).

2.6.3.3 Perseveration

Perseveration can be described as the opposite of distractibility. In distractibility attention fluctuates while in perseveration the cerebral palsied child seems to be unable to stop what he is doing. This situation implies that the child is unable to move from one activity to another, be it verbal or non-verbal, visual or auditory. Perseveration has negative effects on the child for it hampers learning and also interpersonal relationships (Derbyshire 1989:467; Telford & Sawrey 1967:83).

2.6.3.4 Catastrophic reactions

The cerebral palsied child who suffers from catastrophic reactions may be noticed as having emotional outbursts. He or she may cry or laugh or lie flat on the floor. His or her responses are disproportionate to the circumstances. Factors causing the breakdown may be, among other things, frustration, anger, feelings of helplessness and extreme fatigue. Catastrophic reactions also affect the learning of the child (Cruickshank & Johnson 1975:262).

Cerebral palsy reveals itself as a very complicated and problematic disability and there is an urgent need for its prevention. Some of the measures that could be useful in its prevention are discussed below.

2.7 Prevention of the incidence of cerebral palsy

Factors discussed above that result in cerebral palsy may be prevented by using existing knowledge about the disability. Some of the authors are of the opinion that mothers suffering from repeated bleeding during pregnancy should be informed about the causes and results of bleeding and how to prevent such a situation. Women could also be told about the effects of infections and illnesses suffered by mothers during pregnancy, on the foetus. Moreover, better health care and obstetrical services advocating the prevention of giving birth to premature babies may also reduce the incidence of cerebral palsy (Botha 1989:295).

Other measures to reduce the incidence figures of cerebral palsy would be improved ante-natal care where mothers with diseases such as diabetes could be identified and their sickness kept under control. Another method would be to identify underweight babies (under 2 kgs). Such underweight cases need well equipped hospital units and mothers who tend to produce such babies must receive medical care and advice (Grabe 1985:117).

Another area of concern is the reduction of postnatal infections, birth trauma and road and home accidents. Girls who are capable of falling pregnant can also be advised about dangers of drug abuse, smoking, alcohol, the age factor and child abuse. Regular prenatal examinations of pregnant women can be engaged in and the women be encouraged to attend clinics. Mothers whose children are cerebral palsied can be monitored until the child reaches school going age (Sillipp 1987:2; Sarkin 1989:179).

2.8 Summary

It can be deduced from the discussion in this chapter that cerebral palsied children are those who have a physical problem owing to a lesion or malfunction in the brain. The lesion or the malfunction results in various sub-types of cerebral palsy such as spasticity, athetosis, ataxia, rigidity, tremor and mixed types. Cerebral palsy is a motor problem where gross as well as fine motor abilities are affected. Gross motor problems are exposed as affecting movement.

The chapter also exposes cerebral palsy as a complex disability because multiple disabilities are often associated with it. This implies that the child who is primarily cerebral palsied may also have secondary disabilities. The fact is that the brain controls not only the muscles but also intelligence, behaviour, emotions and the personality. The control of the damaged brain over these functions may be weak or limited.

The causes of brain damage or maldevelopment, depending on the stage and age at which they occurred, are usually classified into three groups, namely, the prenatal, perinatal and postnatal causes. Some of the more prevalent causes may be brain injury, anoxia and prematurity. Chapter two also shows that in some cases cerebral palsy is preventable and that in certain countries such as the United States, the United Kingdom, Sweden, Canada and Australia they have succeeded in lowering the prevalence of cerebral palsy. In South Africa and the Transkei they have not yet succeeded in lowering the incidence. In fact, the chapter reveals that the numbers of cerebral palsied children are increasing.

Cerebral palsy can, therefore, be regarded as a serious disability which affects children in various ways. Not only is the mobility affected but also, in some cases, intelligence, behaviour and personality. Such a complex disability needs further research which will be undertaken in Chapter three, in order to find out how this problem affects children's education and their educators.

CHAPTER 3

EDUCATION OF CEREBRAL PALSIED CHILDREN

3.1 Introduction

From the beginning of time man has regarded the education of children as of prime importance. Although the upbringing of a child remains the prime responsibility of the parents, it must be complemented by the school because parents on their own are seldom, if ever, sufficiently well informed to educate their child adequately for work and life (Levitz 1991:149). Thus the education of a child becomes the joint effort of the home and the school. This is especially true in the case of the cerebral palsied child. Cerebral palsied children require extra assistance in their education.

3.2 Education

3.2.1 The necessity of education

The term education refers to the leading of children by adults from childhood towards adulthood (Van Rensburg & Landman 1988:331). Education in the life of a child is, therefore, necessary and this necessity is based on the fact that each individual child desires to become somebody in his or her own right. Owing to their youth and inexperience children may not know how to reach such a goal, hence the necessity of education by adults. Assistance may be in the form of providing the children with, for instance, skills, techniques, knowledge of objects, language and norms which may help them to understand reality. This implies that the main indicator

of the necessity of education is the helplessness of the child in the life-world and the involvement of adults in the education of their children. (Stuart et al 1987:12; Viljoen & Pienaar 1971:14).

In the case of children with disabilities education is also necessary but the realisation that they have physical deformities may affect their desire to be the adults they ought to become in future. The type of education given by educators may also be affected by the children's disabilities. Motor problems, for instance, may cause children to be unable to use their limbs and carry out the functions that would enable them to learn what is prescribed or shown to them by adults. In short, cerebral palsy in children may cause problems in their life-world and also determine the degree of parental participation in their education. The brief discussion above concerning the necessity of education also indicates that education is an occurrence and that as a phenomenon it is bound to have a structure.

3.2.2 The structure of education

The term structure refers to the whole matter or entity which consists of various components. Education is regarded by various authorities as having a structure and this structure gives education the characteristics of a phenomenon. This means that education manifests itself in educational activities. The term phenomenon may be defined as something that appears to people but may be obscure (Stuart et al 1987:12; Viljoen & Pienaar 1971:14). The structure of the educational phenomenon consists of a number of aspects.

3.2.2.1 The nature of education

Education consists of various concrete life situations in which children are born and led towards adulthood. At birth children are helpless and weak and this helplessness appeals to adults for help. It is characteristic of man not to allow children to grow up on their own. Adults may take on the responsibility to assist, protect, care for, love and support children until they can fend for themselves. The helplessness of the children and the responses of the adults constitute what is referred to as the educational situation (see 3.2.2.4). In such situations adults lead children to adulthood and the children willingly respond by undergoing changes which eventually transform them into adults (Van Rensburg & Landman 1988:308; Van Niekerk 1982:2; Gunter 1978:12).

In the case of children with disabilities, such as cerebral palsied children, their weakness and helplessness may elicit even stronger responses in parents. The adults may, for instance, become concerned when they notice that their children are disabled. The adults' concern may grow into over-concern. This excessive concern may, in turn, cause over-protection and over-protection may result in over-indulgence. This implies that extreme responses may prevent the child from learning. Over-concern may, for instance, prevent children from exploring the environment and the process of socialisation may be disrupted. Over-protection and over-indulgence may deny children with disabilities the opportunity to face life's demands, accept responsibility, attain success and accept disappointments (Botha 1989:546). In order to be able to assist children with

disabilities adults usually bring them up having certain aims in mind which indicate the direction to be followed towards the attainment of adulthood.

3.2.2.2 Aim of education

Education appears to be an activity which is directed towards attaining a goal. Before such a goal can be reached adults must first know the children they are educating, envisage the type of adulthood they want to lead their children to and also know the type of assistance children need. If adults are clear about these aspects they will be able to know their children's abilities and limitations and may then find ways and means of assisting them. The adults may also be encouraged to pursue their educational goals if they notice certain signs in their children which indicate that children are gradually becoming independent, physically, intellectually, socially and morally. Such cues inform parents whether their children are on their way to becoming the human beings they ought to become or not (Du Plooy & Kilian 1981:80-81; Duminy & Steyn 1983: 18-19).

With regard to children with disabilities adults may know the children but not understand them. This may be due to complications caused by cerebral palsy in children. Cerebral palsy may even cause parents to be unsure of the type of adulthood to which they wish to lead their children. Moreover, the parents may not know the type of assistance that is needed by cerebral palsied children. All these shortcomings may give rise to problems in the education of cerebral palsied children, especially when there is little or no

indication from these children that hints at the fact that they are attaining independence in various aspects of development. Such a state of affairs may prevent the proper attainment of the educational aim, namely, adulthood.

Du Toit (1989a:58) explains that the term adulthood does not refer to perfection or completeness. It also does not mean that it should be completely or fully attained in all children. She is of the opinion that "every child, no matter how handicapped or impaired, should therefore be helped to reach the level of moral, independent adulthood that is open to him in terms of his potential".

3.2.2.3 Limits of education

The question may be posed whether a phenomenon such as education has any boundaries. This implies that the discussion that follows intends to explore when the education of children begins and ends and how cerebral palsy affects the limits of education. Education, in the case of all children, has a beginning which is called the lower limit of education. The starting point of this limit can unfortunately not be chronologically determined. The beginning may depend on when children became aware of the existence of other people such as parents.

Adults, when noticing that their children are aware of their presence, may start acquainting children with the way human beings live. The children may be made aware of the necessity of taking baths, having meals, resting or dressing (Du Plooy & Kilian 1981:151-152).

Owing to developmental lag in children with disabilities, the process of becoming aware of the existence of other people may be delayed. Such a delay may affect parents especially if they compare the development of their children with disabilities with that of non-disabled children. Adults may also experience problems when trying to socialise children by teaching them to wash, eat, or rest. Some cerebral palsied children may also be unable to perform these activities owing to spasticity (see 2.3.2.1), athetosis (see 2.3.2.2) or ataxia (see 2.3.2.3). This may lead to frustration in parents and the disruption of the education of children with disabilities especially at the lower limits of education.

Education also has an upper limit or boundary. Like the lowest level, this level cannot be chronologically determined because children differ in their rates of development. The upper limit is attained when children realise that they are becoming adults and when they notice that they do not need to depend on adults' guidance and assistance as they did in the past. Children also show adults that they are attaining the upper limit when they perform certain activities on their own, make their own decisions and accept the results of their activities and decisions (Du Plooy & Kilian 1981:152; Gunter 1978:88-89; Van Zyl 1973:162).

Some cerebral palsied children may not readily attain the upper limit of education. This may be due to the fact that they find it difficult to perform certain muscular activities independently even when they are at this level. Such children may function well intellectually but adults may be affected by their

children's physical disabilities and then disrupt their education (Du Plooy & Kilian 1981:152-154). Another aspect that needs to be examined is the education situation.

3.2.2.4 The education situation

The word situation originates from Latin words such as "situs" and "sinere". "Situs" means the geographical location or position and also includes circumstances such as the financial, cultural, political or educational conditions. "Sinere" means to put, place or allow (Du Plooy & Kilian 1981:57; Viljoen & Pienaar 1971:45).

The possibility for an educational situation to arise commences when the child is born and accepted into the geographical setting such as the home where parents and the children live. Parents also create the educational situation when they willingly accept the responsibilities of supporting and bringing up the child with the aim of leading him or her towards adulthood. This implies that the parents help the child to fit into cultural, political and educational life. The child also contributes towards his or her own education by becoming involved and also through the use of his or her own experiences, ideas, emotions, observations, imaginations and dreams. The manner in which children respond helps them to know their capabilities and limitations and parents in turn learn about their children's strengths and weaknesses. Such knowledge may assist parents to formulate their short-term and long-term goals in the education and upbringing of their children. Other factors that also influence the educative situation are

the areas and conditions in which children grow up (Du Plooy & Kilian 1981:56-57; Gunter 1978:25).

The educative situation reveals itself as being triangular in nature for it consists of the adult, the child and the aim. If one of these components is missing there will be no educative situation (Van Niekerk 1982:3; Duminy & Steyn 1983:18).

In the case of children with disabilities the educative situation may be affected. Parents may allow children with disabilities to live in a setting such as the home but the physical deformities may cause parents to distance themselves from their children. Such a distance may widen if parents limit themselves to the physical care of their children. Gaps that have thus been created weaken the bonds between the parents and their children and such breakdowns are likely to affect the education of children with disabilities.

Botha (1989:544) is of the opinion that the gaps which arise may also be due to frustrations, disappointments, uncertainties and feelings of embarrassment and shame on the part of parents of children with disabilities.

Another aspect of education that needs to be looked into is the course of education.

3.2.2.5 The course of education or pedagogical sequence structure

The term pedagogical sequence structure refers to the cycle according to which education occurs and also the actions performed by the adults in the educative situation. The pedagogical sequence may be explained in

terms of association, encounter and dissociation. Association refers to the togetherness of adults and their children. During this phase the adults do not consciously educate children but the presence of adults directs and controls children. With regards to the encounter adults have a deeper awareness of the children with whom they are associating. Adults realise that their children need to be supported and guided because on their own they cannot reach adulthood. These adults may use educative interventions such as encouragement, praise or rebuke. Usually, when the intervention is over the situation returns to the associative one (Viljoen & Pienaar 1971:57-58; Levitz 1991:141-143).

During the encounter there is also periodic leave taking, affording the children the time to practise on their own what they have learned. This breaking away or leave taking is always accompanied by the knowledge that they may return to the educative encounter and that they will be welcomed back.

During a dissociation situation the adults and their children are drawing apart. This may be an indication of the beginning of the attainment of adulthood by the children. Parents may then realise that their children no longer need their continuous presence. Parents may notice this growth when their children apply what they have been taught in their own life situations (Levitz 1991:134-144).

In the case of children with disabilities parental feelings such as shame and frustration may reduce the association between parents and their children by dampening the eagerness of parents to encounter their children with disabilities. Parents may also become

indifferent and indifference may prevent parents and their children from knowing each other. Lack of trust and understanding may also hamper the parents' efforts to educate their children and the attainment of adulthood by the children, may not be easy (Kapp 1989:544). Educational relationships during the course of education also need to be examined.

3.2.2.6 Educational relationships

The occurrence of education in everyday life depends on the structure of relationships and it may also be assumed that education never occurs except through relationships. The term relationships, therefore, implies mutuality where people realise that existence is co-existence. Relationships may then be regarded as forming the basis for the educational event. Some of these relationships are trust, understanding or knowledge and authority.

* Trust

To trust is to have confidence in someone (Laird 1974:464). Children learn to trust parents as they associate with them for long periods and when they realise that parents give them a chance to do things either by being assisted or on their own. Parents also trust that their children will be able to achieve something in life. Trust may be strengthened by acceptance or love between parents and their children. Trust, therefore, seems to be the link with the present educational situation as well as the future situation. In such present and future oriented situations parents accompany

children with the intention of assisting them to become future adults (Du Plooy & Kilian 1981:66-67; Viljoen & Pienaar 1971:67).

Insufficient association between parents and their children with disabilities may prevent growth of trust and knowledge between them. Without mutual trust and understanding parents may be unable to teach their children and the children in turn may also be unable to learn from their parents. Children trust parents on two conditions: that they are accepted by parents and that parents respect them as people. If these two conditions are not satisfied, the education of children with disabilities may be affected by their becoming anxious, fearful and feeling insecure. Such feelings may be detrimental to the education of such children (Urbani 1980:44; Levitz 1991:134-135; Kapp 1989:544). Besides trust another relationship that is necessary in the education of children is understanding or knowledge.

* Understanding or knowledge

It has been stated that trust promotes children's education. Equally important is understanding and knowledge. In others words, adults may be regarded as bearers of knowledge which they pass on to their children. In order to be able to teach their children they should be aware of the child's character, attitudes, sex, age, physique, the family and cultural life for which they are preparing the child as well as their child's mental abilities. Children must also know their parents' intentions and aims and this may lead to co-

operation and acquisition of knowledge by children (Du Plooy & Kilian 1981:67-70).

With regard to children with disabilities, trust may have been affected and this may in turn influence their education. Parents may be knowledgeable but owing to their distancing themselves from their children, they are unable to pass on the educative information. Lack of thorough knowledge and understanding between parents and their children may be due to the child's suffering from cerebral palsy which parents may not understand. In such situations children with disabilities may also be unable to co-operate with their parents owing to sensory-motor or behaviour problems.

Authority is a relationship which forms part of the relationship structure and it also needs to be looked into.

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Authority

Authority is the right or power to guide others. Individuals that are being guided may either accept or reject authority. In an educative situation children show that they accept authority by being obedient. Obedience, therefore, encourages the children's growth to adulthood. This growth becomes possible if there is a strong bond between parents and their children and in such situations children may also learn by imitating and identifying with their parents. Obedience to authority, which is instilled in children while they are still young, may be necessary in their future life. The adult

world requires obedience to authority, peaceful working together, co-existence and adherence to certain moral norms (Van Rensburg & Landman 1988:292; Kapp 1989:548).

A disability such as cerebral palsy may prevent children from complying with social demands. The result may be the exclusion of children with disabilities from the company of non-disabled persons. Excluded children lack authoritative guidance for they tend to withdraw within themselves and thus miss the opportunity to interact with others. Rejection by others may also cause children with disabilities to have feelings of anxiety, indifference or even to regard themselves as inferior to other people who are not disabled. They may even feel that they are unworthy of authority, that is, they may shun authoritative responsibilities in their future life. Moreover, children with disabilities may develop psychological disturbances owing to being ignored or rejected by others. In short, lack of authoritative guidance leads to disturbed social relationships and a negative self-concept in children with disabilities which may affect their education (Kapp 1989:548-549). Another aspect that deserves attention is teaching as method of education.

3.2.2.7 Teaching as method of education

Teaching is an activity that is used by parents to impart knowledge to children. For teaching to be effective both adults and children take an active part,

the adults teach while the children learn. Teaching and learning occur informally at home and formally at school (Gunter 1978:10-11; Robinson 1980:42).

For all children teaching methods such as imitation, play and repetition are used. For children with disabilities ordinary teaching methods are not sufficient. Such children need highly specialised teaching methods that are used by trained teachers (see 3.5.1.6). In special schools teachers are assisted by experts forming part of an inter disciplinary team (see 3.5.2).

The discussion on the structure of education (see 3.2.2) reveals that problems are encountered in the education of children with disabilities. It can be assumed, therefore, that specialised education is more complex than mainstream education. It is also necessary to investigate the education of children with disabilities in their homes.

3.3 The parents as educators of children with disabilities

There are many reasons why married couples decide to have children. They want, for instance, to fulfil social expectations, to continue the family line or to have a living expression of their love. Once the children are born, they undertake the duty of bringing them up and educating them towards adulthood. They perform such duties in a space called a home, and at home children are assisted to develop physically, socially, emotionally, cognitively, morally and linguistically (Hildebrand 1981:21-23).

Parents usually carry out these duties willingly if children are not disabled. If children are born deformed or acquire disabilities during or after birth, parents may become affected and may neglect educating the children or they may over-protect them. The cause of such responses is not only the children's disabilities but also some factors that are linked to the disabilities.

3.3.1 Factors affecting parental responses

The reactions of the parents to children with disabilities differ because each individual parent is different. Some parents are affected by the nature and degree of the child's disability. Others are influenced by the fact that the child is developing contrary to their expectations. Some parents are affected by the realisation that they will incur heavy financial burdens when making special arrangements for the education of their child. Other parents are frustrated by the fact that their child will never reach independence or that the child will take a long time before gaining independence. They may also be anxious as to what other people think about them as parents of a child with a disability. All these factors which will be included in Chapter four, influence the extent to which parents will educate their child with a disability in all aspects of development (Kapp 1989:541; Hilt & Cogburn 1980:68).

The factors that have been briefly discussed above disrupt the home education of the children with disabilities. Some of the aspects of children's development that are affected also need to be discussed.

3.3.2 Educational functions of parents

3.3.2.1 Physical development

Parents start early in the life of a child to co-ordinate his or her sensory and motor skills. They assist the children in their learning to sit, crawl, stand and walk. They also train the children to be tidy, to dress and undress themselves and to feed themselves. These activities form an essential step towards school readiness and towards adult life. To enable children to master all these activities the parents give children love, care and protection. As children grow, parents teach them independence so that they can do things on their own and learn to explore the environment and the world they live in (Derbyshire 1989:220).

In the case of children with disabilities the sensory and motor skills that are needed in their future life may be affected. The children may then be unable to perform the activities expected of them, either because of cerebral palsy or the responses of parents, for instance, if they neglect to train the child in the use of affected limbs. Such neglect can affect their school activities and learning, for example, how to write or explore the environment (Bleck & Nagel 1982:68; Scherzer & Tshanuter 1982:13; Holt 1991:161; Sarkin 1989:180). Neglecting to take care of the bodily needs of children may result in affected social relationships between parents and their children with disabilities.

3.3.2.2. Social development

There are certain family relationships that enable children in the family to learn. Relationships such as

father-mother, father-child and mother-child, help children to develop socially. These home relationships encourage children to leave the safety of the home and to venture into the unknown. Such venturesomeness indicates that the children are socially ready, are gaining independence and can attend school (Battle 1974: 130; Derbyshire 1989:221).

The greatest trauma that children with disabilities can suffer is rejection by family members, especially the mother. The children are not only deprived of the opportunity to learn to interact with other people but they tend to feel threatened and insecure. These feelings cause them to stay away from other people and the result is that lonely, isolated and insecure children cannot learn much from other members of the family.

Other aspects that may be affected are the conative and emotional development of the child.

3.3.2.3 Conative and emotional development

The interest in the education of the children may also be the understanding of behaviour or causes of certain types of behaviour. The conative life of children consists of basic and driving forces which give rise to human behaviour. Emotions may be defined as responses to stimuli which cause, among other things, physiological changes and these emotions are part of human behaviour (Behr et al 1986:24). As children grow there may be changes in the way they behave or express their emotions and such changes are referred to as conative and emotional development.

Infants are usually not held responsible for their behaviour; instead parents are to blame. This is because parents are expected to assist as the children's responses develop. In the course of growth and development even non-disabled children may manifest disruptive behaviour when they experience problems in the family or owing to some traumatic or shocking experience such as rejection (Harmse & Kirsten 1979:114-115).

In children with disabilities problems arise when children suffer from stress, lack of parental love or from social and sensory problems. Sometimes the removal of children from their parents and their placement in an institution results in disruptive behaviour (Haskell 1964:51).

3.3.2.4 Moral development

Children also learn or are taught rules of behaviour that are applicable in a certain culture, for instance, fitting manners, customs and lifestyle. Behr et al (1986:29-30) are of the opinion that an indication that children are developing morally is noticeable when they can differentiate between various dichotomies such as lies and truth or obedience and disobedience.

Parents spend less time with their children, especially during the second and following years. They therefore teach the children how to behave during their absence. The learning of this moral aspect by children depends on parental love and control. Some parents may be strict, rejecting or permissive. Children are then likely to be affected by such parental behaviour in the learning of moral behaviour (Shaffer 1985:613).

Some children with disabilities are taught moral behaviour by their parents but the development of the conscience may be hampered by factors such as the child's inability to judge between right or wrong or even the inability to control his or her impulsiveness. Unless parents receive adequate guidance, they may not be able to understand their children's lack of self-control and adopt attitudes that may even further affect children's learning. Another aspect of development in children is cognition.

3.3.2.5 Cognitive development

The term cognition refers to the state of knowing. Adults guide children in their acquisition of knowledge and thus enable children to understand the world around them (Van Rensburg & Landman 1988:309). Cognitive theorists such as Piaget, state that children undergo four stages of cognitive development, namely, the sensory-motor, where learning occurs through use of senses and motor activities, the pre-operational where the words or objects represent people and other objects, the concrete operational stage where real objects are needed by the child before he or she can draw conclusions and the fourth stage is the formal operational level where the thinking of the child is abstract (Mwamwenda 1989:61; Behr et al 1986:36).

In the family parents also lay the foundation for children's future intellectual development. Mothers teach children how to organise their thinking by making use of the senses and motor skills. They use concrete objects in teaching them how to form concepts, how to

exchange ideas, how to be creative and how to generalise. The fathers contribute by being identification figures for their children (Derbyshire 1989:221).

It is evident that some children who suffer from cerebral palsy may cause problems when being assisted in their cognitive and development. It all depends on the degree of brain damage or limitations in the children's opportunities for learning. Children are also capable of learning the language of the cultural group to which they belong when exposed to it.

3.3.2.6 Language development

Parents see to it that children are exposed to language as early as possible. Children listen to the mother when speaking and also to other members of the family. Gradually the children begin making cooing sounds, then single or two words follow and eventually they can use sentences. Language acquisition is important in children for it is the medium of communication and gaining knowledge. Derbyshire (1989:220-221) adds that language is used by children when thinking and when controlling their behaviour.

Owing to motor problems caused by cerebral palsy, learning of a language may be delayed and develop later than it takes for language to develop in non-disabled children. This factor disrupts parents' efforts in assisting the development of language in their cerebral palsied children. Such disruptions are likely to cause parents to respond negatively to their children with disabilities. Parental responses and the delays in

language development are bound to affect the learning and education of the children with disabilities at home and at school.

3.4 The school and the child with a disability

When children reach school going age parents entrust them to the care and guidance of teachers. They hand their children over to the care of the school because, nowadays, learning content has become too complex for parents to manage on their own at home. Parents do not have sufficient time to spend on teaching their own children. Some parents lack modern knowledge which is characterised by specialisation and differentiation, hence the need for the assistance of the school (Duminy & Steyn 1983:5; Stuart *et al* 1987:10).

With regard to children with disabilities, special schools came into being in order to provide specialised education needed by such children. According to Education Affairs Act No. 70 (1988:1489) specialised education includes the psychological, medical, dental, paramedical and therapeutic treatment of, including the performance of operations on, children with disabilities (see 1.2.4).

The structure of education (see 3.2.2) and the home teaching of children with disabilities (see 3.3.2) were found to be aggravated by numerous problems. Special schools exist mainly for assisting such children. This situation implies that there are specific tasks that special schools perform.

3.4.1 The task of the school

The school complements home education by sharing with parents the responsibility of guiding children towards adulthood. Schools develop children as a whole so that they can accept the responsibilities of adulthood, choose a career in life, become independent, take the initiative and live with other people (Kapp 1989:555).

In the case of children with disabilities special schools become not just educational-teaching centres but also the supportive life-space and the hostels become their homes. Special schools also develop various aspects of children with disabilities (Poonsamy 1984:61).

The choice of placing children in special schools depends on the following factors.

3.4.1.1 Placement of children with disabilities

In western countries such as the United States of America, Sweden and Denmark, the tendency is to place children with disabilities in the mainstream of education. The aim is to integrate such children into social life. These countries advocate that the education of these children should occur in normal situations and they use the term "least restrictive environments" to refer to what they regard as normal situations. For children with disabilities the mainstream of education has its own advantages and disadvantages (Du Toit 1989:79-82; Heward & Orlansky 1980:19; HSRC 1981:6).

In South Africa and the Transkei the preference is to place children with disabilities who do not fit into the mainstream of education into special schools.

3.4.1.2 School readiness

At the time the child turns seven, he is expected to perform certain basic school activities. The child, in order to succeed at school, should be ready physically, perceptually, cognitively, linguistically, affectively, socially and morally. Some children, especially children with disabilities, may not be ready at this stage or age owing to the problems they experience.

3.4.1.3 Identification of the child with school-readiness problems

Not being ready for school can negatively affect the child's learning and growth towards adulthood. It is essential that such children are identified early so that they can be given the help they need. Some of the ways that are used for identification include informal and formal identifications. Informally, people such as parents, preprimary and primary teachers determine whether the child is school ready or not. They can also use formal media (tests) for judging school readiness (Derbyshire 1989:226). For formal identification teachers may use school-readiness tests that are available at universities, school clinics, other institutions and from the psychologists. Such tests include, group tests for five and half year old preschoolers, Nel-Sonnekus developmental scale for preschoolers, NE-group tests for five and six year

olds, M.J.L. Kruger school-readiness test. All these tests measure aspects of a child's development (Derbyshire 1989:226-227).

3.4.2 Types of aid offered by special schools for a child not ready for school

Aid offered to children who are found not to be school ready is divided into three groups. The first group prefers the child to remain at home for some time. The second group gives aid programmes to a child in the first year at school. The third group gives a bridging period of one or more years before allowing the child to proceed to Sub A or Grade 1 (Derbyshire 1989:227). It can be concluded then that the preprimary sections of the school, work on school readiness for these children. This situation implies that the curriculum is based on school readiness and focuses attention on activities for daily living and readiness for life.

3.5 Classroom teaching and the role of the inter disciplinary team

Children with problems need to be aided. Such aid is available in the classroom and is also offered by the inter disciplinary team. In class the following activities occur.

3.5.1 Classroom teaching

3.5.1.1 The initial situation

The teacher, in order to know the children, starts by collecting all the information about the children's background, social and cultural environments from which the children come and on the types of disabilities the

children suffer from. The teacher adds more data by observing the children as he or she teaches them (Derbyshire 1989:77). If the teacher neglects the continuous observation of the children in the classroom situation he or she will not be able to make the necessary adjustments and this can hamper the progress of the child. The teacher also takes into consideration the aim of special education as the following discussion shows.

3.5.1.2 Teaching-learning aims

In special schools the teaching and learning aims are derived from the curriculum. The aims are also based on the data collected by the teacher about the children with disabilities he or she has been observing. Such aims enable general and specific aims to be attained. The general aim in special education is to educate the child so that he or she can attain adulthood, so it is not different from that of educating non-disabled children. The specific aims are meant to help the children with disabilities to overcome their disabilities and to enhance the lives of the ones who are afflicted (Republic of Transkei Annual Report 1985:22; Stuart et al 1987:37).

In the case of children with disabilities the attainment of these aims is not easy owing to problems encountered while teaching. Such problems cause the personnel and the infrastructure to become more complex, more comprehensive and more specialised. The aims also tend to influence the type of curriculum used in special schools.

3.5.1.3 Curriculum

Without content the teaching-learning aims cannot be attained. The content is, therefore, a vehicle that is used to reach these aims. In order to encourage children to learn, the content should be intelligible to them and encourage them to take part in the teaching-learning situations. This can be done by reducing the subject matter and by pointing out what is essential. The subject matter can also be arranged in a meaningful and logical manner and by starting with the simple and progressing towards the complex (Du Toit 1989:78). The curriculum also considers the children's ages. The curriculum should, therefore, include activities that fit the children's stages of development. These activities should promote the children's growth in various aspects of development (Derbyshire 1989:219).

With regard to children with disabilities the choice of the content can be influenced by their disabilities. It is evident then that children with disabilities need special assistance which can be in the form of remedial teaching or individualised educational programmes. Such programmes, to be successful, need the help of the inter disciplinary team (Poonsamy 1984:744).

3.5.1.4 The scheme of work

In order to facilitate teaching and make it successful the teacher divides the content into units of work. He or she draws up the scheme of work with the disabled child in mind. The scheme should fit the child's abilities, interests, needs and the speed of learning. The teacher also considers the number of teaching

3.5.1.6 The methods and teaching aids

Children with disabilities need specialised teaching methods which are autogenous or distinctive. When choosing teaching methods the teacher firstly considers the findings which were discovered during the initial situation (see 3.5.1.1). The choice of the methods depends on the nature and degree of the child's disability (see 4.2.1.7). The teacher explores the methods to be used to find out if they will convey the content in such a manner that the child will understand it. The teacher also tests the teaching aids to find out whether they fit the child's level of development, and also to find out whether the teaching aids will improve the child's intellectual skills. The choice of teaching aids is influenced by the type of the child's disability, the attention span and the relationship between the content and the real life situations (Du Toit 1989:78: Kapp 1989:336).

3.5.1.7 Evaluation

Evaluation is the way of determining the value of learning through observations or tests (Seifert 1983:429). Evaluation is worthwhile for it reveals whether the educational aims are being attained or not. The type of evaluation used should, therefore, be accurate, detailed and measure what it is supposed to measure. The type of evaluation used by the teacher of children with disabilities can, for instance, be observation and criterion-referenced tests. Such tests tend to be qualitative rather than quantitative in nature. After testing, the results are examined. If results are poor then the factors that caused the children not to perform well are examined. The role

played by the teacher in teaching the content and in testing the child with a disability is also examined (Du Toit 1989:78-79).

The role played by the inter-disciplinary team in the education of children with disabilities also needs to be discussed.

3.5.2 The inter disciplinary team approach

An inter disciplinary team approach implies the most efficient contribution made by members from various professions or disciplines in achieving a common goal. The ultimate aim of an effective team approach is helping the cerebral palsied child to achieve maximum physical, social, emotional and religious maturity so as to fit into his or her cultural group. Levitz (1991:16) is of the opinion that attainment of such a goal depends on team members: understanding their roles, co-operating in their efforts and co-ordinating their tasks under the supervision of a leader. Those who are in the team are discussed below.

3.5.2.1 Medical personnel

Doctors such as the pediatricians, neurologists, orthopaedists and ophthalmologists play a major role in diagnosis and medical care of the child with a disability. They usually conduct an initial evaluation of the child which enables them to determine the nature and degree of the child's disability, to prescribe suitable medication and treatment and to determine whether the child needs placement in a special school or not. If the child is admitted to a special school, the doctors conduct follow-up examinations and

consultations. The aim is to find out the effect of medication on the child and, if necessary, prescribe further medication. Such activities are important because the physical problems of a child influence his or her mobility, emotional state and alertness. Such conditions greatly affect the learning of the child (Du Toit 1989:66-67).

3.5.2.2 Therapists

It is a fact that the cerebral palsied child, if left to himself or herself, would simply use strong muscles and neglect the weak ones (Poonsamy 1984:86). Therapists such as the physiotherapists, occupational therapists and speech therapists have a duty to conduct the initial testing of a child for evaluation purposes, give therapeutic treatment and retest the child in order to determine the progress of the child and, where applicable, make adjustments to the therapeutic programmes. The main aim is to help the child to attain independence and productivity which he or she will need in the labour market.

3.5.2.3 Psychologists and social workers

Psychologists in special schools have the function of initial testing, guiding the child, teaching staff and parents and retesting the child. According to Levitz (1991:166) psychologists also act as liaison officers between therapists, teachers and pupils. Social workers are mainly concerned, besides other duties, with assisting the cerebral palsied child to adjust in society.

3.5.2.4 Teachers

The teacher co-operates with other members of the team by providing information obtained through observing the child in class. The teacher also applies in class the guidelines the team provides.

3.5.2.5 Parents

Parents are important members of the team for they are the primary educators of the child and know their child. Moreover, parents need to be supported by other team members because parents often suffer from various emotions (see chapter 4). If parents receive assistance from team members they are likely to support various therapies, visit special schools and not engage in negative activities as stated in 3.5.3.

3.5.2.6 Hostel mothers

Hostel mothers should also be members of the inter disciplinary team. Like parents they know the child and may provide valuable information on the progress of the child in the hostel and also implement therapies.

3.5.3 Parents and special schools

Parents of children with disabilities tend to be reluctant to take part in the education of their children at school. The cause may be lack of interest, the fear of the staff because parents may not want to hear the truth or parents may be trying to avoid being blamed by the staff for school problems. Other reasons may be the feeling of guilt or that invitations sent to

them from the school do not reach them. Parents may also have been disappointed during the previous visits and then refuse to attend further school meetings. Disappointments may be caused by receiving no advice about their children's disabilities. Such a state of affairs influences the parents to conclude that the school staff is unable to assist them and the result is lack of trust on the part of parents (Van Niekerk 1982:165).

Another repelling factor may be that parents regard teachers as experts in their field and, therefore, dare not interfere. The teachers' pride, self-sufficiency and autocracy may encourage parents to stay away from such people. It is most unfortunate that such feelings exist between parents and teachers because they may lead to hostility, destroy trust and pave the way to accusations. All these negative relationships affect the education and learning of children (Van der Merwe 1989:97-104; Van Niekerk 1982:169). In a country such as the Transkei parents may be poor and unable to visit schools. Moreover, some illiterate parents may shun meeting educated people, such as teachers, who may despise uneducated parents.

The fact is that some parents avoid visiting the schools for various reasons. This implies that they are missing some of the advantages of visiting and participating in school activities. Benefits of participation include, among other things, the sharing of responsibility of educating children with disabilities, and the striving together towards a common goal that enables the child to attain adulthood. Parents may also receive information from the staff on how to assist the child in his or her growth, development and education. Teachers may also

gain from parents because they may use suitable methods that are used by parents at home (Van der Merwe 1989: 92-97).

3.6

Summary

This chapter investigated the importance of education in the life world of the cerebral palsied child. The necessity, nature, aim and limits of the education situation and pedagogic sequence structures were expounded. The importance of parents in the education of the cerebral palsied child was amplified. As the education of the cerebral palsied child necessitates the involvement of many specialists, great care should be taken by teachers and therapists to educate the cerebral palsied child as a total person. As parents play a paramount role in the education of their children, Chapter four investigates the parental reactions to the birth of a child with a disability and a cerebral palsied child in particular.

CHAPTER 4

PARENTS OF CEREBRAL PALSIED CHILDREN

4.1 Introduction

There exists a close correlation between the parents' early emotional reactions to the diagnosis of a disability in their child and the future handling of the child. Few parents are prepared, or in a position, to handle the trauma of the birth of a child with a disability. It is evident that the birth of a cerebral palsied child results in a life-long series of adjustments by the child's family, and by the parents in particular. This situation is aptly stated by Levitz (1991:79) who maintains that "the adjustments and reactions that parents of children with disabilities experience do not necessarily manifest to the same degree in all parents, but do manifest in most of them". It is thus evident that parental reactions to the birth of a cerebral palsied child may exhibit certain similarities, but reactions will indeed also differ.

4.2 Parental reactions towards the birth of a cerebral palsied child

It is not easy to predict the type of reactions parents will show when they notice that their child has a disability. In some families parents respond by regarding the child with a disability as a tragedy, in other families the situation is regarded as a crisis while in some the child is viewed as a problem to be solved (Gargiulo 1985:19; Schell 1981:21; Schreir 1991: 318; Smith et al 1983:60).

4.2.1 Some factors influencing parental reactions

The family usually functions as a whole and responses shown by one member will affect all other family members. These reactions depend mainly on the culture of the people, the size of the family, the sex of the child, religion, personality structure and the degree of the severity of the child's disability (Levitz 1991:18).

4.2.1.1 Cultural background

The ethnic group to which the family belongs has an influence on the family's rituals, traditions, values, the type of activities in the family and even on the outlook of the family on the world. These values and outlooks tend to shape parental responses to the child with a disability. The intensity of these culturally based attitudes depends on whether the family is parent oriented, where the interests of parents count more than those of their children, or whether it is family oriented where the interests of family members are considered first, or whether the family is child oriented and the well-being of the children is considered as most important. In parent oriented families the children with disabilities are more readily placed in an institution than in child oriented families (Turnbull & Turnbull 1986:31; Livneh 1982:339; Levitz 1991:82).

Besides cultural influences another factor that may give rise to parental reactions is the size of the family and its form.

4.2.1.2 Family size and form

Family size refers to the number of individuals constituting a family, for example, some families are small while others are large. It is claimed that in large families the stress caused by a child with a disability may be less intense. The reason may be that more people assist in taking care of the child with a disability and that parents feel less burdened. It is also believed that other children convince parents of their ability to produce non-disabled children. Reduced stress may also result from the fact that parents, especially where the child with a disability is the youngest, may have acquired valuable child rearing skills (Cunningham & Davis 1985:71; Barsh 1968:202). In smaller families tension and the responses may be caused when parents feel the burden or when they lack child rearing skills, especially when the child with a disability is the first born.

With regard to form, some families consist of two parents, others are single parent families while others may be remarried parent families. In two parent families the husband may influence the wife's reactions to the child with a disability. In single parent families financial problems may determine the responses of the parents to the child with a disability. More stress is felt when the single parent is isolated from friends, neighbours or relatives (Levitz 1991:81-82).

In remarried parent families, one spouse may not be sure of his or her rights over the children of his or her partner. The children may even worsen the situation by resenting the parent who is not their biological parent.

If one of the children has a disability tension and confusion may increase. It is clear then that the smaller the family the more problematic the education of the child with a disability may prove to be (Turnbull & Turnbull 1986:28-31). Another factor is of a socio-economic nature.

4.2.1.3 Socio-economic status

The socio-economic status of a family implies income, the level of education of the various family members, and the social status implied by the occupations of its wage earners (Turnbull & Turnbull 1986:33). It is assumed that the higher the socio-economic status the better the ability to cope with the child's disability. Unfortunately this is not always the case. Some families with a higher socio-economic status may feel less stress if the family does not emphasize educational achievements in their children. While on the other hand some families may have such survival problems that they are prevented from worrying too much about achievement (Levitz 1991:84, Turnbull & Turnbull 1986:34-36). In some of these families the sex of the child seems to affect parental responses.

4.2.1.4 The sex of the child

In some cultures the sex of the child is highly valued; males, for example, may be the sign, of manhood, independence and achievement. Some fathers may feel the impact of the birth of a boy with a disability more than the mother may feel for the daughter with a disability. It may also be that the mothers have acquired more skills in child rearing techniques than the fathers.

Another explanation could be that mothers have more contact with experts who deal with the child with a disability than the fathers (Cunningham & Davis 1985:75). The distance to towns where the experts work may be another factor.

4.2.1.5 Geographical location

Geographical location refers to where the homes of the families are. Some families live in rural areas while others live in urban areas. The socio-economic status of the family is usually linked with its geographical location. Children with disabilities in rural areas may be a source of worry for their parents. Usually experts are in urban areas and parents are burdened by the distance to and from town and also by the expenses they have to incur. Moreover, parents may experience hardships in trying to obtain specialised education for the child who is unable to attend the local school for non-disabled children (Hewett et al 1970:115; Turnbull & Turnbull 1986:36). In some communities religion may also play a role in influencing parents of children with disabilities.

4.2.1.6 Religion

Some families belong to a religious group and to some extent religion tends to influence parental responses. Some parents may regard a child with a disability as part of the divine plan and thus accept the child with a disability. Owing to this type of view the guilt feeling of parents may be reduced. Religion does not always have a positive influence on parents. It can strengthen negative responses if the child with a disability is

regarded as a punishment for the sins committed by parents (DeLoach & Greer 1981:17; Hegeman 1984:130; Seligman 1979:55-56). The degree of the child's disability may be another factor that highly affects parents.

4.2.1.7 The degree of the disability

The degree of the severity of the disability (cerebral palsy) refers to how badly afflicted the child is. Clinically the disability is classified according to whether it is mild, moderate or severe. In mild cases the fine motor movements are affected, in moderate cases gross and fine motor movements are hampered. The speech, when affected, also falls under the moderate disability. With regard to severe cases the children are hampered in performing daily activities such as walking, speaking or the use of the limbs (Sillipp 1987:12; Sillipp 1985:4).

In cases such as cerebral palsy parents may notice the condition early and start adjusting to it by passing through various phases. In some cases high parental expectations are shattered by the mildest disability. This may be due to the stigmatisation that may be associated with the disability. Fear of stigmatisation may even cause parents to deny that the child has a disability (Chinn et al 1979:354). A parent's reaction to a disability is also governed by his or her personality.

4.2.1.8 Personal characteristics of parents

Individual personal characteristics such as the intellectual and physical health of the parents can also determine the nature of parental responses and their tolerance to tension. Parents who are ill may

experience difficulties when trying to cope. These difficulties, in turn, increase parental stress and the increased stress may cause the parents to become more infirm. For example, parents may suffer from severe headaches, depressions and other stress related illnesses. Such parents may be unable to cope and adjust to the situation (Turnbull & Turnbull 1986:38). Other factors that influence the manner in which the parents respond to a child with a disability is the severity of the disability, the family stability, internal support in the form of medical, educational and counselling services (Peterson 1987:423; Levitz 1991:86-87).

4.3 The impact of a child with a disability on a family

4.3.1 The crises experienced by parents

There are three main reasons why parents respond strongly to the birth of a child with a disability. The parents are affected by novelty, personal value and reality crises. In the novelty crisis parents regard the child with a disability as a threat and danger to their self-worth, self-esteem and dignity. The reason is that their child with a disability may change the parental self-concept. Parents may regard themselves as being incapable of producing healthy, non-disabled children (Chinn et al 1979:17).

With regard to the crisis in personal value the parents are faced with the child who may be unattractive owing to the disability. As parents they are supposed to love the child who may have behavioural problems. In addition parents may realise that the child will not progress well in life. Such experiences intensify stress and conflict in parents.

Sometimes the parents experience a reality crisis, for example, if they have financial problems owing to the child's disability or when they are unable to afford a holiday. Overworking also increases stress and tension in parents (Ingalls 1978:313). In such crises parents use defence mechanisms which enable them to come to terms with their predicaments.

4.3.2 The defence mechanisms of parents

Parents use defence mechanisms in an attempt to cope (as do all parents with problems). The term defence mechanism was used by Sigmund Freud, a medical doctor and psychiatrist from Vienna (Mwamwenda 1995:331-333). Freud used the term to refer to a type of behaviour where the person "flies" away from a threatening situation. He subdivides this behaviour into ego and task oriented defence mechanisms. The ego defence mechanism operates on the sub-conscious level and protects the person by distorting reality. The task oriented mechanism does not distort reality. The person analyses the problem in order to find ways and means of solving it. Most parents tend to use the ego defence mechanism. This mechanism enables parents to begin adjusting themselves to the situation and to their child's disability (DeLoach & Greer 1981:22). The responses of parents may follow certain patterns.

4.4 Various patterns of parental reactions

Various authors indicate different responses when trying to explain how parents adjust to the child's disability. In this chapter the analysis is chiefly based on the work of Gargiulo. He states that parents progress

through primary, secondary and tertiary phases in their adjustment process (Gargiulo 1985:22).

4.4.1 Primary phase

A number of responses may manifest themselves during the primary phase.

4.4.1.1 Shock

Shock can be defined as a sudden change in a person's emotional state owing to a danger stimulus which forces the person to respond. A disability in their child such as cerebral palsy, is capable of producing shock in parents when they find out or are informed that their child has a disability. The intensity of the shock increases when parents regard themselves and their child as failures. The shock may then affect them physically by preventing them from working effectively. Intellectually shock prevents them from thinking clearly and logically. Emotionally shock generates fear, anxiety and depression and socially parents may start isolating themselves from other people owing to the intense shock (Selfde & Stow 1981:202; Sillipp 1987:85; Sieffert 1978:35).

The duration of shock in parents may be only a few hours or one or two days. It may also last longer or recur during various stages of their child's development. This shock is also capable of preventing parents from performing their educative duties adequately (Ingalls 1978:315; Levitz 1991:90-91).

4.4.1.2 Denial and disbelief

Another defence mechanism that is used by parents is denial or disbelief. Denial means that the person refuses to accept the fact that, for example, the child has a disability. The parents manifest denial and disbelief owing to fear of the unknown, uncertainties about the future life of their child who has a disability, doubt whether they will be able to cope and the realisation that their child with a disability is increasing their parental responsibilities (Gargiulo 1985:23; Griffiths & Russell 1985:42).

Denial in its first stage lasts for a few days and it helps to reduce the impact of the child's disability on parents. The parents then enter the second stage of denial when they realise that the disability is permanent. This second stage may last for years and can cause a child to feel insecure if he or she cannot attain goals set for him by parents (DeLoach & Greer 1981:23; Shea & Bauer 1985:42).

Denial has also an effect on parents. In the Transkei it may cause them to seek a cure or healing by consulting faith healers rather than learning to live with their child with a disability. Besides denial, mourning is another response that parents of children with disabilities may reveal.

4.4.1.3 Mourning, depression, sorrow and grief

Mourning, depression, sorrow and grief refer to unhappiness that is experienced by parents of children with disabilities. Parents mourn because something

precious has been lost to them, the healthy child is "dead" or lost to them and instead they have a "sick" child. This implies that parents suffer from double mourning: they mourn for the child who ought to be non-disabled and also mourn because the one who is alive has a disability (Van der Merwe 1989:42; Lansdown 1980:7; Tizard 1974:1).

This type of mourning has negative effects on parents. It may cause them to withdraw, have less energy, become irritable, lose their appetite and suffer from insomnia and anger. Their relationship with their child with a disability becomes affected and the child may be spoilt. Such a state of affairs affects the role of parents in the education of a child with a disability. Like shock, mourning may recur during the various stages of the child's development (Shea & Bauer 1985:30-31; Levitz 1991:94). When reactions in the primary phase subside and cease parents move on to the second phase.

4.4.2 Secondary phase

4.4.2.1 Anger and hostility

Anger may take the form of striking out at something. The parents may direct their anger at the child with a disability and it is usually an indication that the child has disrupted their life. Other targets of parents' anger may be doctors, nurses, social workers, teachers, the siblings, spouses, relatives and neighbours. Parents may also direct anger towards themselves or towards God. Anger increases as parents realise how much time, physical strength and money they spend caring for the child with a disability (Sillipp 1987:86; Levitz 1991:97; Gargiulo 1985:28).

Anger has negative effects on children with disabilities and their education and it brings about an unhappy atmosphere in the family. In some cases the children, owing to parental anger, may have tantrums or outbursts of rage when they are older. When anger is projected towards experts by parents, it tends to generate distrust in parents and the parents and the children with disabilities may be prevented from receiving the necessary medical and educational assistance (Chinn et al 1979:21; Hegeman 1984:67). In some parents other feelings such as guilt, self blame and shame may be found.

4.4.2.2 Guilt, self blame and shame

Guilt refers to the person's feeling of self-reproach and self-condemnation. Guilt is mostly directed towards self. Shame includes ridicule and criticism of oneself and of others. Guilt, self blame and shame are felt especially when one has done something wrong (Telford & Sawrey 1967:81; Ingalls 1978:318).

Guilt feelings usually result when the disability is caused by hereditary conditions where parents feel that they did not take the necessary precautions. Some mothers smoke, take drugs and liquor and may, therefore, feel that they have caused their children to be cerebral palsied. In other cases parents feel guilty if they delayed seeking medical and therapeutic assistance when they realised that something was wrong with the child. Other parents may feel they did not do their best for their children medically, educationally and socially (Van der Merwe 1989:44).

Guilt feelings in parents are detrimental for although they cannot remove the disability they undermine the parents' positive self-concept and cause parents to be very difficult to work with. Some parents' guilt feelings may cause them to lead a life of martyrdom while in others embarrassment, fear, confusion and frustration may result (Telford & Sawrey 1967:81; Chinn et al 1979:22; Gargiulo 1985:26-27).

4.4.2.3 Embarrassment, fear, confusion and frustration

Embarrassment refers to the feelings of bewilderment and puzzlement (Laird 1974:136). Sometimes parents may feel embarrassed if people stare at them, ask questions or even comment on their child with a disability. Fear arises when they feel uneasy or helpless and fear leads, for example, to their treating the child with a disability disrespectfully (Shea & Bauer 1985:33).

The intensity of fear is increased by anxiety, emotional conflict, lack of proper information and guidance. Sometimes various newspapers increase the fear in parents by providing incomplete or even incorrect information and parents become confused and frustrated. Frustration increases if parents cannot find services for their children with disabilities or when they realise that those who provide services are not sufficiently trained or do not understand their parental problems (Chinn et al 1979:25; Shea & Bauer 1985:33).

The result of embarrassment, fear, confusion and frustration is the loss of parental self-esteem and then parents tend to identify themselves with their children with disabilities. Moreover, these feelings affect the

relationship between the parents and their children with disabilities. This is revealed when parents do not educate their children adequately or when they are indifferent to their educational needs. Embarrassment can even cause parents to isolate themselves from other people in the community. Another factor that causes these emotions in parents is the realisation that they will be bound to take care of the child with a disability as long as the child lives (Shea & Bauer 1985:33-34; Levitz 1991:100-101). Another reaction that may be shown by parents is ambivalence.

4.4.2.4 Ambivalence

Ambivalence implies that a person has two kinds of contrasting feelings towards an object. These ambivalent feelings are shown, for example, when parents love and accept their child with a disability but simultaneously reject and dislike him or her. Parental feelings of ambivalence cause the child to feel insecure and display inconsistent behaviour. Inconsistency in behaviour is caused by parents who correct the behaviour of a child with a disability and on other similar occasions do not do so. The children then become confused for there are no fixed rules and guidelines to assist them (Telford & Sawrey 1967:80; Levitz 1991:95). Some parents, especially when they have not yet reached the stage of accepting their child with a disability fully, may continue with these responses and enter the tertiary stage.

4.4.3 Tertiary phase

4.4.3.1 Bargaining

One of the final stages that parents experience before adjusting to having a child with a disability is bargaining. Bargaining is a personal act which other people do not notice. Gargiulo (1985:29) is of the opinion that it "... is a strategy whereby parents hope to 'strike a deal' with God, science or any one who promises to make their child normal". Bargaining is a final attempt that parents make to cure their child.

Bargaining may have negative effects on the education of the child. The parents, for instance, waste valuable time bargaining instead of addressing the problem in hand. The parent, as Levitz (1991:100) states, represents society and has the function of teaching the child social rules, norms and relations. The mother in particular plays a major role in shaping the child during its early formative years. Levitz is of the opinion that "during the process of bargaining, the parent may be labouring under a misconception about the child's educative needs which could be disadvantageous for the child's eventual becoming". (Levitz 1991:101). When bargaining does not assist the parent, he or she moves on to adaptation and reorganisation.

4.4.3.2 Adaptation and reorganisation

Adaptation is a gradual process in the life of parents. The feelings of anxiety and other emotions are reduced and the parents start feeling at ease and are able to

exercise their parental skills. Reduced tension and feeling at ease enable parents to interact freely with their child with a disability and this is called a period of reorganisation. Included in parental reorganisation is the ability of parents to take up their responsibilities for the problems of their child with a disability. During this reorganisation period parents can work together or become estranged (Gargiulo 1985:30). During this reorganisation period parents pass through a number of phases.

The first phase parents usually pass through is the labelling phase. They try to explain away the problem by giving an acceptable explanation of the child's problems. For instance, instead of explaining that the child has a motor problem or simply explaining that the child is suffering from cerebral palsy they label the child as a late walker. For the parents this type of explanation is less offensive. If the doctor tells them the truth about their child's condition, they may feel highly offended. The parents can also change their views about the child and this is then referred to as "renegotiating". If they still cannot cope, they pass on to the normalisation phase (Cruickshank 1976:462).

During the normalisation phase parents regard the child's disability as normal and not affecting the relationships in the family. Parents give the community the impression that all is well in the family and they also try not to isolate themselves (Cruickshank 1976:462).

If this pretence is not effective they pass on to the mobilisation phase. In this phase members of the family may take on new roles. For example, the father takes on

some of the wife's duties so that she can spend more time with the child with a disability. If the shifting of roles is not effective parents pass on to the revisionist phase (Levitz 1991:102).

The revisionist phase implies that parents remain in the same house but interact as little as possible with each other, yet they are trying to give the impression of unity in the family. If unity is not created in the family through less interaction they try to discover the root of the cause of the disunity and if they find the reason, this assists them to be more at ease with each other. The discovery of the cause of the disunity places the parents in the polarisation phase.

The last phase which follows the polarisation phase is the elimination phase. The attainment of this phase shows that the polarisation phase has not been successful. At this stage parents try to eliminate or get rid of the child with a disability by placing him or her in an institution. They are trying, in this manner, to normalise family life (Cruickshank 1976:462). Some parents may also show some positive responses such as the acceptance of their child with a disability.

4.4.3.3 Acceptance and adjustment

As parents pass through various stages they learn more about other people and about themselves. The knowledge they gain does not completely wipe out their negative feelings but it helps them to accept themselves with their own weaknesses and strengths. In order to be able to accept their child with a disability parents have to change, to adjust themselves to the situation.

Adjustment implies that action is taken by parents (Shea & Bauer 1985:35; Seligman 1979:61).

The result of parental acceptance of the child with a disability at home enables the child to learn and parents to educate. It also encourages the child to accept himself and other people. Without acceptance the child experiences educational problems because he does not feel secure. The result is that the child will not trust nor identify with his parents. The child will experience anxiety and uncertainties, feel threatened, rejected and deserted. Such feelings are bound to affect the whole personality of the child and cause numerous hardships. Unlike the insecure child the secure one ventures out into the environment, explores the world and learns to be self-reliant (Levitz 1991:105). There are a number of other parental responses that are not categorised into specific phases.

4.4.4 Other aspects of parental reactions

Parents can also suffer from other responses such as "shopping behaviour" (see 4.4.4.2), parental rejection (see 4.4.4.4) and compensation (see 4.4.4.5). These responses are not placed under any particular heading owing to the fact that they fit into the primary, secondary and tertiary phases. Such aspects are often noticed by experts when working with parents of children with disabilities (Gargiulo 1985:30-31).

4.4.4.1 Chronic sorrow

Chronic sorrow is the result of the daily dependence of the child with a disability on parents. Sorrow is

referred to as chronic when it persists in parents and may last as long as the child lives. This type of sorrow "waxes" and "wanes" when the child does not attain the expected milestones or when parents notice that the non-disabled children or younger siblings overtake the child or when the child with a disability is placed in a special school. Chronic sorrow is also experienced when parents have to face problems that are related to the child's disability such as unacceptable behaviour, ill health or social problems. Chronic sorrow is related to mourning, depression, sorrow and grief (see 4.4.1.3). The difference is that parents pass through the stages of mourning and grief while chronic sorrow remains in them (Shea & Bauer 1985:31; Gargiulo 1985:31).

Like other parental responses chronic sorrow has detrimental effects on the education, learning and upbringing of child with a disability. It prevents parents from promoting the abilities of their children and they thus neglect his or her education. Because of chronic sorrow parents may also show aggression towards the experts who are helping the child. The parents may also be aggressive towards the child with a disability or either reject the child or over-protect it (Levitz 1991:107). Some parents engage in shopping behaviour.

4.4.4.2 Shopping behaviour

Shopping behaviour may be described as frequent visits to various experts by parents who cannot accept the diagnosis and are trying to obtain a cure for their child with a disability. These visits may be draining the parents financially or wasting their time. They also disrupt family life and have other negative influences

on the child with a disability. Shopping behaviour is caused by the guilt feelings of the parents. They then try to get rid of such feelings by attempting to prove that experts are wrong and are responsible for their child's disability (Gargiulo 1985:33; Chinn et al 1979:29).

Shopping behaviour may also affect the education of the child with a disability. The main concern of the parents is the perceived stigma attached to the child and themselves and they then try to erase the stigma by shopping around instead of concentrating on the child's educational needs (Levitz 1991:108).

4.4.4.3 Over-protection

Over-protecting children means that parents do everything for their child with a disability instead of training the child to be independent and do things for himself. Over-protection is the result of parental feeling such as dislike, resentment of the child with a disability, guilt, the needs of the dependent child and parental impatience if the child with a disability takes a long time to "heal" (Ingalls 1978:319; Wright 1960:315-316). To overcome such feelings parents indulge in excessive protection of the child with a disability.

Over-protection has negative effects. Besides depriving the child with a disability of the opportunity to be independent, it also hampers social and emotional development. The child may become spoilt, not learn to cope with life's problems and not explore the environment. Thus the child's physical and intellectual development may also be affected (Lowenfeld 1971:109;

Van Niekerk 1982:18). Other negative attitudes that may be exposed by parents are rejection and avoidance.

4.4.4.4 Rejection and avoidance

Rejection means avoiding any contact with the child with a disability. Parents may find themselves unable to feed, clothe or play with the child with a disability. Some parents may deny that the child is theirs or they may abuse the child physically or psychologically (Shea & Bauer 1985:31).

Parents show rejection by underestimating the abilities of their child with a disability. They may regard the child as useless or ignore and belittle its achievements. The child may then copy the parental under-expectations and act accordingly. Another type of rejection is shown when parents set unrealistically high goals for the child with a disability which the child cannot attain. They then see this as justification for their having negative feelings when the child does not reach these goals. Another type of rejection is escape. Parents abandon the child by placing it in a far away boarding school even when there are boarding schools nearby that provide the same facilities. Some parents escape from a child with a disability by becoming involved in other duties which prevent them from having much contact with their child (Gargiulo 1985:35).

The last type of rejection is reaction formation. Parents in public pretend to accept the child with a disability while at home they reject him (Lowenfeld 1971:109). Parental rejection causes the child with a disability to feel threatened and insecure. Such

children do not enjoy their childhood days and they may avoid contact with their parents and other people. They may strive for acceptance and attention by engaging in unacceptable behaviour which in turn may annoy other people and create tension. Tension affects the education of the child with a disability for it lessens the bond between the child and the parents. Rejection also destroys the identification of the child with a disability with other people around him or her (Levitz 1991:110-111; Van Niekerk 1982:17). Parents of children with disabilities may also try compensation.

4.4.4.5 Compensation

Compensation results when acceptance and rejection are combined in a parent. Parents show compensation, for example, by letting a child have instruction and training in the hope that he or she will acquire abilities. Children of such parents tend to be anxious, tense and fear their parents. Such feelings in the child with a disability prevent him or her from progressing in therapy given to him or her and their school work is also affected. The child may also reveal antisocial behaviour. Compensation, therefore, affects the education and the attainment of adulthood (Bryant 1971:327; Gargiulo 1985:36). In some cases parents may also feel rejected.

4.4.4.6 Feeling rejected as parent

Some parents may feel rejected because of being the parents of a child with a disability. Such feelings may also be due to a lack of understanding of parents' needs by experts and professionals. Some experts may neglect

to include parents when assisting their child with a disability at school or at home and also exclude them in the discussions about their child's needs. Other experts regard parents as lacking the understanding and ability to train their child in daily life activities. Some experts may not even assist the parents in their struggle to adjust to the disability of their child but may solve the problem by separating the child from its parents and the community to which the child belongs. Some parents may become hostile and reject advice and experts when they receive unsympathetic treatment from them. Such feelings may also be the result of parents' feeling worthless, useless and frustrated when they realise that they stand alone (Van der Merwe 1989:45; Hegeman 1984:17; Tizard 1974:1).

When parents feel that they are rejected they tend to neglect their duty of educating the child. The reason may be that the parents find themselves lacking in knowledge and experience and they may feel insecure. The feeling of rejection in parents continues as parents pass through various stages in their life cycle (Levitz 1991:113). Some responses arise as parents experience certain events in their family life cycle.

4.5 Life cycle events and parental reactions

There are certain stages in the family life cycle which tend to be more critical and traumatic for parents. The first may be when parents learn or even suspect that their child has a disability and then begin to suffer from various reactions. The second stage is experienced when parents take the child with a disability to school. They meet the professionals for

the first time and it may also be that the parents encounter special education for the first time. Problems resulting from such encounters may intensify and aggravate parental attitudes (Sillipp 1987:91).

The third stage is reached when the child with a disability reaches adolescence. The parents become more concerned as to whether their child with a disability will be able to be independent, be able to marry or whether he or she will be able to progress academically. At this stage the child with a disability may be experiencing more problems than his or her parents and, neither the parents nor the child may be able to solve the problems. The fourth stage is reached when parents become old and can no longer care for the child. They worry about who will take care of the child with a disability when they are dead or may place the burden of taking care of the child on siblings (Byrne & Cunningham 1984:853; Seligman 1979:65). Another serious problem that parents may face is the financial problem brought about by the expenses of caring for a child with a disability.

4.6 Financial problems

All children need to be cared for, which involves expenses. A child with a disability causes additional financial strain on parents because of medical or therapeutic needs. The financial burden is felt more in families with a low income. If the father is the only breadwinner he may be compelled to work after hours in order to supplement their income. They may then experience tension if they are accused of neglecting the family. Tension resulting from financial problems may

adversely affect the education of a child with a disability (Lansdown 1980:8; Shea & Bauer 1985:38-39; Van der Merwe 1989:58-59). Sometimes problems experienced by parents financially and otherwise may eventually isolate them from community activities.

4.7 Problems of parents in the community

The problem of parents of children with disabilities may cause non-participation in community activities. The fact is that they withdraw from their former friends. The reason may be that the friends are fearful and imagine that by associating with parents having children with disabilities they may produce similar children. Some parents regard the care of their children with disabilities as their first priority and they may then not have sufficient time left to spend with members of the community (Shea & Bauer 1985:40; Van der Merwe 1989:60).

Other parents withdraw from social activities if they are made to feel that they bear a stigma or when they feel guilty about or responsible for the disabilities of their children. Sometimes parents isolate themselves and their children in order to protect their children with disabilities from ridicule and remarks as well as from public curiosity, negative sympathy, social rejection and social avoidance (Hegeman 1984:70; Lansdown 1980:25).

The parents' isolation from community activities tends to hamper the children's socialisation. The children find it difficult to attain adulthood because of regarding themselves as incapable persons and unacceptable. In this manner the withdrawal of parents socially,

negatively affects the children's education and attainment of adulthood. Parental marital relationships may also be affected owing to a number of causes already discussed.

4.8 Marital relationships in the family

The family as a system is concerned with the needs of each member and each individual has specific roles which do not clash with those of other members. This organisation results in a certain equilibrium in the family system. It becomes, evident therefore, that children with disabilities in families may disrupt and disturb the balance in the family and affect the marital relationships of parents (Ross 1972:8-9; Lansdown 1980:16).

Any disturbance in marital relationships may cause the spouses to blame each other for the disabilities in the children. In some cases marital problems resulting from having a child with a disability may lead to divorce, suicide or even alcoholism. In other families the disabilities may be a binding force in the marriage of the parents who were up to then experiencing unhappy marriages (Gargiulo 1985:47). Conflict in the marriage may also hamper the education of the children with disabilities. Besides parents, other family members may also be affected by the children's disabilities.

4.9 Effects of the birth of a cerebral palsied child on various family members

Literature reveals that a child with a disability may be the cause of conflict in the family (Williams 1989:23).

It also reveals that these attitudes differ in nature and intensity from one member of the family to the other.

4.9.1 The reactions of the mother

During pregnancy a mother may have fears about the baby she is expecting. She may think that the child in utero will not be normal. If the baby at birth does not move its limbs, is premature or has severe jaundice, the mother may suffer from severe shock. Shock may generate anxiety, guilt, a sense of inadequacy or even depression. She may start blaming herself or her husband or the hospital for the disability of her child. Some wives cling to their husbands for support while others desert their husbands, thus ending the marriage and causing more developmental and educational problems for the child with a disability (Bowley & Gardner 1980:231; Byrne & Cunningham 1985:848-849).

Sometimes a newborn baby may be placed in an incubator and cannot suckle. Separation of the baby from the mother may have detrimental effects on the mother-child relationship. It affects the emotional bond which eventually enables the mother to help and educate the child. Overworked mothers may also suffer from severe stress. Stress may lead to conflict in the family and conflict may cause the child to be restless and aggressive. If the child is placed in a boarding school early in its life it may become more attached to the hostel mother than to its biological mother. The biological mother may then become confused in her educative tasks because the training her child receives at the special school may differ from the one the child receives at home. The child may also become uncertain

and confused as to which mother it should learn from and by whom it should be guided (Levitz 1991:122-125; Sillipp 1987:95). Although a mother may have a number of problems, the father may also fall prey to the negative effects related to the child with a disability.

4.9.2 The reactions of the father

The father of a child with a disability is also affected by the birth of such a child into the family. The fact may be that men are more inclined to assert control in the family than females. If they realise that they have no control over the disabilities of their children they may feel powerless. Some men may feel guilty and to lessen the guilt they may start drinking excessively or performing other duties that may keep them away from their child with disabilities. Some fathers desert their families altogether (Trout 1983:333-334; McAnaney 1989: 28-33).

Parental negative attitudes are likely to affect the education of children with disabilities. If, for instance, the father has deserted the family, the boy with a disability may feel insecure, uncertain and even confused as to how to behave or act as a male. The future of the acceptance of authority by the boy and the performance of his manly roles may be affected. If the husband happens to remain in the family he may leave the duty of training the boy to the mother, especially if the father rejects the son with a disability. In the case of a girl who is rejected by the father she may be affected in the choice of a marriage partner. She may also suffer from insecurity and other feelings that disrupt and disturb her in her learning and education

(Levitz 1991:125-129). The child with a disability may also have brothers and sisters in the family who may be affected by a cerebral palsied sibling.

4.9.3 The impact on siblings

Siblings may be strongly affected by children with disabilities in the family. Their attitudes are mostly modelled on those of their parents and they are also influenced by the sex of a child with a disability or by whether the child is in an institution or at home. Siblings reveal different responses which depend also on how parents treat them in relation to the child with a disability (Seligman 1979:69; Gargiulo 1985:51; Telford & Sawrey 1967:84).

Some siblings may resent taking care of the child with a disability. This resentment originates from the siblings' anger about having a brother or sister with a disability. They may also resent the child with a disability for receiving more parental attention. This can lead to jealousy and the siblings may compete for parental attention and affection. In order to receive sufficient attention from parents siblings may even go so far as to display behavioural problems or telling lies, or even by not performing well at school (Chinn et al 1979:429 Gargiulo 1985:51; Robinson & Robinson 1976:429).

Feelings of jealousy in siblings may cause them to be hostile to the child with a disability. They may blame their brother or sister with a disability for the problems they experience. They may even physically assault the child with a disability or harass or

ridicule him. Some siblings may respond by being disobedient to parents. Others suffer from guilt feelings especially if they ill-treat their brother or sister with a disability. Some siblings suffer from grief and from feelings of sorrow for the child with a disability (Trout 1983:345).

Some siblings may experience fear. They fear that they also will become crippled or that their future children will be disabled. Siblings may fear that they will be expected to take care of the child with a disability when the parents are no longer alive or when parents are old. They may also suffer from shame and embarrassment and prefer not to be seen in public with the child with a disability. Shame and embarrassment in siblings can cause them to reject the child with a disability in the family (Lansdown 1980:13; Sillipp 1987:97).

The attitudes of siblings differ. Girls often show weaker responses because of the female roles they play in the family. Boys may be more affected because of their male roles and they then show stronger responses. In this manner the males tend to be more susceptible to stress than females especially because, like their fathers, they may be inclined to control other siblings in the family (Murphy 1979:357; Breslau 1983:300).

It can be assumed that the attitudes of siblings may threaten the family unit and even affect the education of the child with a disability in the family (Levitz 1991:131). The attitudes of the parents discussed above show that parents may differ in the way they respond. The following paragraphs discuss the shortcomings which impede categorising parents into particular phases.

4.10 Sortcomings of categorizing parents into particular phases

Parental attitudes discussed in this chapter do not necessarily make the prediction of parental responses to their children with disabilities easy. There are a number of factors that may hinder exact predictions. Each family is unique. For example, families differ from one another even if they have numerous characteristics in common. Each family also experiences different unique situations and circumstances that are related to their children's disability. This implies that for each family the disability may have different meanings. Moreover, the family as a system functions as a whole and its members strive for a common goal. The presence of a child with a disability affects the family's structure, function and development differently. Each family may try to adjust to the child's disability in its own way and in the adjustment process certain unique factors may determine the effects of the children's disability on each family. To predict which factors will affect the family's responses at a certain time is not possible (Gargiulo 1985:42-43; Van der Merwe 1989:35).

Prediction may also be affected by the fact that parents of children with disabilities do not experience the disabilities of their children in the same way. Each parent is unique and cannot be stereotyped according to certain behavioural patterns. Stereotyping of parents can even lead to experts' misunderstanding or mishandling of parents of children with disabilities (Levitz 1991:88).

Another factor that prevents accurate prediction is that certain aspects of each phase apply more strongly to certain parents than to others. Parents may pass through the primary (see 4.4.1), secondary (see 4.4.2) and tertiary (see 4.4.3) phases and may either react by over-protection (see 4.4.4.3) or rejection (see 4.4.4.4) or feeling guilty (see 4.4.2.2) depending on the personal characteristics of each parent.

Other aspects that may influence parental attitudes may be the family size (see 4.2.1.2), the sex of the child (see 4.2.1.4) or socio-economic (see 4.2.1.3) factors. Such factors determine the intensity of the responses of each parent (Levitz 1991:147-148).

Prediction can also be affected by the fact that while some parents pass through the phases very rapidly and other parents may remain longer in a certain phase. For example, some parents do not progress beyond hurt or anger (see 4.4.2.1) while others accept and adjust (see 4.4.3.3) themselves to the disabilities of the child very quickly. It can also be added that parents do not progress together through these phases because each parent has his or her own way of responding. This difference means that one parent may be deeply involved in caring for the child during various phases while the other parent may escape responsibility (Gargiulo 1985:21).

It can be concluded that parents of children with disabilities cannot be categorised into various phases merely because they are parents of a child with a disability. The stated phases provide only some assistance in the understanding and study of parental attitudes to the birth of a cerebral palsied child.

4.11 Summary

This chapter tried to expose certain factors which may influence parental responses to the birth of a child with a disability. Some of these factors include, the influences exerted by the cultural groups on the parents of children with disabilities, the number of family members and whether the family is a two parent, single parent or remarried family. The sex of child with a disability, the geographical location of the home, the religious belief, the degree of the disability, and the personal characteristics of parents, are also shown as playing major roles in influencing parental attitudes.

It was shown in this chapter that these factors may also be related to a cerebral palsied child and may also affect parents and that parents protect themselves by employing various defence mechanisms. In order to survive the effects of the disabilities parents unconsciously adapt to the situation, passing through primary, secondary and tertiary phases. Parents are also shown as being affected by certain events in the family cycle such as the time when parents realise for the first time that their child is disabled, or when they take their child with a disability to school and meet the professionals for the first time or when parents realise that their child is reaching adulthood or when, owing to old age, they can no longer take care of their child with a disability.

Some of the additional factors that are reflected include the financial burdens on parents caused by raising a cerebral palsied child, the problems parents have to face in the community because of having a child

with a disability, the effects of disabilities on the marital life of parents and the effects of the disabilities on other members of the family. All these factors are exposed as intensifying the responses of parents and also as disrupting the parents in the tasks of bringing up and educating the child with a disability. This chapter also reveals that it is not possible to categorise parents' attitudes into various phases owing to the fact that individual parents and families differ and that certain factors do not have the same impact on all parents.

The research in this chapter takes into account all parents, universally. As this dissertation actually concerns the Xhosa parent, there is, therefore, a need to undertake an investigation to discover what the position is in the Transkei with Xhosa parents and their children with disabilities. This research will be reported in Chapter five.

CHAPTER 5EDUCATION OF XHOSA CHILDREN WITH SPECIAL REFERENCE TO CHILDREN WITH DISABILITIES5.1 Introduction

A child is usually brought up within a family context. It is within the family that the child first comes into contact with other people, acquires the characteristic attitudes of the community, internalises its customs "and so becomes acquainted with the specific way of life which is unique to the child's cultural group" (Levitz 1991:1).

Universally parents appear to suffer from various responses (see chapter 4) and these attitudes emerge as a result of disabilities in their children. Responses may continue as long as the child lives and the education of the child may thus be affected. Parents therefore often struggle to adjust to the disabilities of their children.

Among the Xhosa, the parents' educative role in the life of a cerebral palsied child does not differ fundamentally from that of any other parent. The importance of a child in a Xhosa family is that a child is a sign that parents are fulfilling tribal expectations of producing children and increasing the nation. The child is also a source of income for when he or she starts working the money is sent to the parents. Some parents also gain through the lobola of their daughters. A cerebral palsied child may be a sign to the

parents that he or she will neither marry nor work. Parents may then respond negatively to such a cerebral palsied child.

The intention in this chapter is to investigate the education of Xhosa children. Tribal aims and educational methods will be discussed. With regard to the urban setting, the dual task of parents, that of being workers and parents, will be discussed with reference to how it affects the education of the child.

Historical attitudes will also be studied because they form the foundation for contemporary attitudes. Some factors influencing parents in the education of their disabled children will be investigated. These include the influence of tribal doctors, parental illiteracy, family poverty and the organisation of the school system. The present attitudes of Xhosa parents will also form part of this chapter.

5.2 Education of Xhosa children

5.2.1 Tribal education

It has been stated (see 1.2.8.) that most of the Xhosa reside in rural area in the Transkei. Most of the Xhosa are, to some extent, conservative and follow the path of their ancestors by obeying taboos, rituals and customs. All these tribal values are instilled in children through tribal education (Levitas 1983:105). All adults of both sexes are expected to educate Xhosa children. Among these teachers are self elected and tribally approved educators, namely, the parents (see 1.2.9). They educate their children with specific aims in mind.

5.2.1.1 Aims of tribal education

The general aim of education is to lead the child towards adulthood (see 3.2.2.2). Among the Xhosa the aim is the same for they train their children to acquire adulthood skills that will make them fit into the tribe. Children are also trained to behave in an appropriate manner towards all members of the tribe. The children are trained to know the geographical environment such as soils, mountains, rivers and plants which are useful in the life of the tribe (Ngubentombi 1984:32). To attain these aims educators use specific methods.

5.2.1.2 Educators and teaching methods

The home, which is the initial educational setting (see 3.2.2.4), enables the parents to carry out their educative tasks. The main educator at home is the mother. Other educators are the grandmother, the siblings, especially the eldest sister, and some relatives living in the family. All these educators train the child informally and use methods such as imitation, observation and examples (Levitas 1983:105).

The education of the child commences when the child is born (see 3.2.2.1). Learning by the child is possible because the mother and the child are in close physical contact. This relationship is shown by the fact that the African child sleeps with the mother and the mother carries the infant on her back. This type of contact creates an intense bond between the mother and the child. Good attachment makes the child feel secure.

develop self-control and be curious. All these characteristics contribute towards social development (Mwamwenda 1989:19,21-22). Social development is further taught in the family by introducing the child into the ways of greeting, addressing elders, receiving gifts, dancing, clapping hands and doing domestic duties (Levitas 1983:105). Simultaneously the child is taught language and bodily movements early in childhood. Such activities result in precocity in children. Precocity refers to the attainment of milestones before the expected time (Mwamwenda 1989:23).

The above-mentioned activities also encourage the child to develop physically. The mother, to enable the child to grow, breast or bottle feeds the child and later introduces solid food. To reduce childhood diseases and dangers the child is given special treatment and protection and these are in the form of tribal medicines and amulets (Van der Vliet 1974:218; Ngubentombi 1984:33-34).

During these early years the child receives lenient and patient treatment until the weaning stage when, at about two to three years, the child is made to be less dependent on the mother and other family members. The gradual gaining of independence by the child is encouraged by the mobility of the child and the weakening of the bond between mother and child (Levitas 1983:105; Mwamwenda 1989:14).

The Xhosa child demonstrates his or her semi-independence by doing things on his or her own, exercising his or her skills, refusing to be controlled and managed, exploring the environment and starting

to form relationships with other people outside the family such as with the peer group. This stage is problematic for parents and other family members as they strive to exercise control over the child by imposing harsher measures. The aim of the stricter type of discipline is to teach the child to control his or her behaviour and emotions (Levitas 1983:105).

Among the Xhosa few men stay with their families (see 1.3.1). The role of the man with regard to children in the family is to be an identification figure, to exercise control over the children and to discipline, guide and be an authority (see 3.2.2.6). Unfortunately, most of the families in the Transkei lack fathers for the fathers stay with them briefly because of migratory labour practices, divorce or desertion. It may also be added that some mothers never marry (Burman & Reynolds 1986:144). Such marital status may affect the education of Xhosa children.

Another area that the family develops in the child is his or her cognition. They teach him or her to perform certain intellectual duties such as the ability to listen to tribal stories and to be able to relate them. Siblings widen the child's knowledge by taking him or her to the playgrounds where he or she learns more about other people outside the family circle. Peer play also increases his or her knowledge. Learning is also possible because the child feels safe since the siblings protect him or her from peer harm. In the family there may be a lot of competition for parental love and attention. Competition has its own negative results on the child but positively it encourages the spirit of sharing and self-esteem.

In some families the grandmother stays with the family and her influence is vast. Her influence over the child occurs in two ways: by indirectly influencing the attitudes and feelings of the parents towards the child or by directly influencing the child. Outside the family the peer group also plays a role in the education of the child by disciplining him or her. In this manner the child learns to perceive the needs and responses of others and to respond to them accordingly. The responses may be positive or the child may show acquired negative attitudes such as envy and rivalry. The peer group also instils other values in the child such as leadership skills, courage and how to be a follower. Among the boys stick fights are tests for leadership and courage while among girls the criterion is the ability to sing, clap and dance (Du Preez 1980:12; Mwamwenda 1989:34; Levitas 1983:106).

Adulthood duties are also taught to children. Boys learn to tend stock in the kraal and to herd them in the tribal lands. While out in the veld they learn the names of the plants and the wild animals. Such knowledge is essential for it teaches them the plants that are useful and those that are harmful. They also learn hunting skills and stick fighting for self-defence. The acquired pastoral knowledge enables the boys to learn the social, economic and religious values of cattle.

Young girls learn domestic duties and become acquainted with agricultural work (Katiya 1973:12; Mwamwenda 1989:299). The Xhosa child is not considered a full member of the family and the tribe before circumcision (for boys) and intonjane (circumcision for girls).

A child must at least reach puberty stage and children differ for they do not reach this stage at the same time. Circumcision and intonjane ceremonies enable the adolescents to be regarded as adults.

5.2.2 Home education of the urban Xhosa child

The bringing up of Xhosa children in urban areas is different from that of children in rural areas. The reason is that the parents no longer adhere to tribal taboos, rituals, customs or expectations. The marital status of the parents may be similar to that found in rural areas (see 5.2.1.2; 4.9.1). In families where there is no father, the mother plays dual roles: she becomes the breadwinner and brings up the children. Such a mother, after giving birth, is often compelled to return to the labour market without delay. The infant is usually taken care of by the aged and infirm grandmother, or by older children whose education has been disrupted by various factors, or in some cases, by ill equipped and inexperienced caretakers (Burman & Reynolds 1986:68; Pauw 1973:127-140). Such mothers are, therefore, struggling for their own survival and that of their children and the education of their children is affected.

Such a situation is in contrast to the well accepted idea and expectation, among the Xhosa, that a mother after giving birth should withdraw from society and devote her time to the infant. It is evident that for a working mother withdrawal is impossible and in most cases breast feeding is supplemented by bottle feeding. A number of infants are likely to suffer from malnutrition because they are weaned too early. The natural bond between the mother and the child is also

disrupted early in the life of the child. Moreover, the absence of the mother during the day may weaken discipline in the family (Burman & Reynolds 1986:69; Pauw 1973:106). The result is that mothers having double roles to play are likely to suffer from fatigue, tension, conflict and being overworked. All these maternal physical and psychological conditions affect the education of the children.

Some of the parents in both the rural and urban settings may have illegitimate children. Such children may be unwanted and resented. The parents may regard an illegitimate child as a "nuisance, an embarrassment, a liability, a calamity and a mistake that refuses to be erased" (Burman & Reynolds 1986:144). Such attitudes affect the education of illegitimate children.

Amongst rural and urban legitimate and illegitimate children there may be those who have disabilities. It is also essential to look into the education of Xhosa children with disabilities for they form part of the Xhosa tribe and society. Historical attitudes towards children with disabilities will now be discussed for they form the basis of contemporary attitudes.

5.3 The Xhosa child with disabilities

5.3.1 Historical attitudes

Literature reveals that in the past Xhosa parents produced children with disabilities. For a Xhosa, a child with disabilities is recognised by certain signs that indicate that the child differs from others. In the past the tendency was to respond differently to various

disabilities. Mental disability was tolerated because it was attributed to a slow growth process in children. The result was that the mentally disabled were accepted by the tribe (Tacke 1989:13-14). Acceptance was due to the fact that the mental disability was, in some cases, not conspicuous in a "plain" lifestyle. Acceptance may also have been based on the condition that the mentally disabled were not physically disabled as well.

Some children suffered from epilepsy and from illnesses such as catatonia or stupor. Catatonia (schizophrenia) is a kind of insanity where thoughts, feelings and actions are not connected. The general belief was that the children were bewitched. Other children feared them and did not want to associate with them. It can be surmised that children suffering from epilepsy and psychiatric illnesses were not accepted for the attitudes towards them were negative (Tacke 1989:13-14).

Negative attitudes towards children suffering from epilepsy and mental illnesses were deemed justifiable among the Xhosa. The reasons were that the well being of the tribe was more important than that of the individual. Moreover, the Xhosa could not tolerate or even accommodate anything that was unusual or different. Other cases that were considered as unusual were the birth of twins and physically deformed children. Such children were killed at birth. The reason was that they were regarded as a bad omen or as an indication of the wrath of the ancestors. This implies that reasons for killing children were based on religious and tribal beliefs (Tacke 1989:13). It may be assumed that attitudes towards twins and the physically deformed were extreme and most violent.

The contemporary Xhosa will also be investigated in order to find out whether they retain the same historical attitudes or not. The discussion will first focus on the specific factors that influence parents to react.

5.3.2 Some complicating factors

5.3.2.1 Tribal doctors

The continuing presence of tribal doctors among the Xhosa in the Transkei can be attributed to the fact that they play an influential role in the life of the tribe which none of the modern influences have, so far, been able to fill. For most rural parents modern medical services are remote and, moreover, they differ from traditional medical services. Modern scientific teaching that explains causes of diseases, disabilities and economic life is too new for them. Parents who may benefit from such services and knowledge may be those who stay in urban areas. Tribal doctors such as diviners are, therefore, likely to remain with the Xhosa for some time.

Tribal doctors, for Xhosa parents, provide answers to their questions and problems. They are consulted for, sicknesses, epidemics, lost property, failure of crops, calamity, fertility, ancestral favours and sudden deaths that cannot be accounted for (Lamla 1975:201; Pauw 1973:56). Such strong influences might affect parents in their responses to children with disabilities and in turn affect the education of such children. Another factor is illiteracy.

5.3.2.2 Illiteracy

Some traditional Xhosa parents are illiterate. This implies that they cannot derive essential information from newspapers or magazines on disabilities. Such parents may be referred to as being isolated and the term isolation is used to mean lack of education, remoteness and being out of contact, to some extent, with the scientific world. Remoteness and illiteracy also prevent parents from influencing the state on the selection of teachers who are suitable to teach their children. This fact directly indicates that Xhosa parents are not involved in the education of their children at school (Mpungu 1988:5; Chambers 1983:113; Sohn 1985:4; Verwey 1979:44). Most of these rural illiterate parents are poor.

5.3.2.3 Poverty

A family among the Xhosa is rated as being poor if it has few commodities, namely, a hut or two, scarcity of tools, few or no cattle and small stock (hens, goats, sheep and a pig). In very poor families the mother is forced to borrow from neighbours, relatives or traders. The result is short-term or long-term debts. In the Transkei the stock, food and cash might be very low, unreliable, seasonal and insufficient, hence the departure of some rural parents from rural poverty and debts, which they cannot meet, and their preference to settle in urban areas (Chambers 1983:109).

Poverty in the family often leads to starvation and under-nourishment. Poverty may also prevent parents and their children from visiting medical centres, hence the

consultation of the tribal doctors (see 5.3.2.1). The women in the absence of men are the ones who feel the brunt of poverty and disasters such as droughts, accidents and tribal fines. To meet such predicaments parents become poorer for they are compelled to sell the little they possess. (Chambers 1983:109).

Poverty also restricts parents in their educational functions for it prevents some of the parents from sending their children to school. The result is the increase in the number of illiterate children in rural areas. Some parents might be unable to visit the child at school owing to their inability to meet the travelling expenses. It can therefore be assumed that poverty causes lack of parental participation in schools as this discussion indicates. It can also be assumed that a child with disabilities might cause further expenses in the family and parents' attitudes to such a child might then be severe (see 4.6).

5.3.2.4 Organisation of the school system

Schools in the Transkei are structured in such a manner that the education of the children is possible. A school has a principal who is in control and teaching staff who assists him or her. In a special school owing to the needs of a child with a disability, an inter disciplinary team exists (see 3.5.2). Parents do not form part of the school management. According to the Transkei Education Act No. 35 of 1986 (1986:154,172) provision is made for parental participation at school level only. The parents are allowed to act as advisors only when they are members of the Governing Council or School Committee. The formation of parent-teacher associations with the

aim of encouraging participation in the education of their children is also suggested (Du Preez 1980:65-66).

The present situation at school is that parent-teacher associations have not yet succeeded in enticing parents to take part in the education of their children. There is still a wide gap between the home and the school. Parents also have the tendency to send their children to school, pay the school fees and then depart, leaving the teachers with the children, never to return during the course of the year. Such withdrawals are not conducive to the education of the Xhosa child (Betela s.a.:264).

It is evident that lack of participation in the education of Xhosa children is due to a number of factors that are linked to the home life. With regard to school, some of the repelling factors may be the type of treatment parents receive from the teaching staff; for instance, the teachers may not allow the parents to take part in classroom activities. The reason may be that parents are regarded as interfering or knowing next to nothing about school educational matters (see 3.5.3). Another factor is the type of the curricula that are offered to children at school. They are mostly based on the western type of education. These types of curricula do not relate to the tribal life of the Xhosa, hence the withdrawal of parents from school participation (Du Preez 1980:66).

5.3.3 Contemporary attitudes

The discussion above reveals that in general Xhosa parents lack interest in school matters. The study

focuses in particular, however, on parental attitudes towards their cerebral palsied children's education. With regard to the education of children with disabilities contemporary parents' attitudes are based on the historical attitudes of the tribe towards such children (see 5.3.1). Children with disabilities are regarded as a punishment from the supernatural (God and ancestors). Such an idea has no scientific foundation and is based on assumption and superstition. Such an attitude makes the child with a disability bear an everlasting stigma. The effects of rejection will not be different from those discussed in (4.4.4.4). The cause of rejection among the Xhosa is the fact that a disability is a constant reminder to them that "life is tragic, and their bodies too are mortal" (Tacke 1989:57).

Owing to the restrictions of the law, children with disabilities are no longer killed (see 5.3.1). Instead they suffer not only from rejection but also from being avoided by other people and the result is isolation. Isolated disabled children are unable to learn (see 3.2.2.4). Moreover, parents are influenced by tribal attitudes towards such children and may act negatively towards them.

5.4 Summary

The chapter has looked into the education of Xhosa children in both rural and urban environments. The findings are that the general aim of education for these children is not different from the general aim of education. Certain specific aims exist in the home education of the Xhosa child and these aims are meant

to prepare the child to fit into the tribe and to know his or her surroundings and use what is found there for the child's growth, development and survival. All adult members act as educators.

The chapter has also shown that the urban Xhosa do not strictly adhere to traditional practices with regard to the home education of their children. They also appear to be facing more problems owing to dual roles to play, those of being the worker and those working or single mothers also bringing up children. The result is that parents suffer from stress and other responses and the education of their children is affected. The children in such families do not receive sufficient discipline which is necessary for a growing child, to mould its personality.

In both rural and urban areas some families have illegitimate children. Some of these children may have disabilities and this implies that they suffer doubly: for the disabilities and for being illegitimate. Such children are not likely to receive the education they need.

It also appears that existing Xhosa attitudes towards individuals with disabilities are influenced by historical tribal attitudes. Historical attitudes to various disabilities appear to differ. The mentally disabled were accepted on condition that they were not also physically disabled. Responses towards epileptics and mentally ill were negative. With regard to twins and the physically deformed responses were severe and

they were usually killed. Parents, in order to feel accepted in the tribe, might also adopt the existing attitudes towards their children with disabilities. Home and school education of these children will then be affected.

These findings are theoretical for they are derived from a literature survey. There was, therefore, a need to interview parents and other people who educate children with disabilities. The aim was to find out whether Xhosa parents do have such attitudes towards children with disabilities. This empirical data will be discussed in Chapter six.

CHAPTER 6

DESIGN AND FINDINGS OF AN EMPIRICAL INVESTIGATION INTO XHOSA PARENTAL ATTITUDES TOWARD CEREBRAL PALSIED CHILDREN

6.1 Introduction

This chapter reports on the design and findings of an empirical investigation into parental attitudes towards cerebral palsied children within the Xhosa community in the Transkei. Certain issues arose from the literature study and they indicated that cerebral palsy in children causes parental attitudes which may disrupt the education of cerebral palsied children. The questions that need to be answered are the following:

- * How prevalent are cerebral palsied children in the Transkei?
- * How do Xhosa parents respond towards such children?
- * Do attitudes of parents have an impact on the education of cerebral palsied children in the Transkei?

In order to provide answers to the above-mentioned questions, empirical research was necessary. The aim was to ascertain whether literature findings also applied to the Transkei.

6.2 Research method

The survey consisted of two phases, namely:

- * A study of school records and
- * Structured interviews with twenty parents,

supplemented by interviews with five teachers, seven social workers and four hostel mothers.

The reason for having two phases was that the schools' records formed the foundation for the survey. The records also clearly indicated where the respondents were located.

6.3 Findings from school records

Records of two special schools in the Transkei were studied; namely, Ikhwezi Lokusa and Vukuzenzele, the former being in Umtata and the latter at Bizana. The choice of the schools was based on the fact that they were the best schools in providing specialised education for cerebral palsied children in the Transkei. The records of the total number of cerebral palsied children were studied (N=65). The following data were extracted from the schools' records.

6.3.1 Diagnosis

Spasticity	:	48 children
Athetosis	:	9 children
Ataxia	:	2 children
Mixed types	:	6 children
Sub-total	:	65 children.

6.3.2 Causes of cerebral palsy

Prenatally	:	old age, maternal accident, prematurity, heredity, unknown causes.
Sub-total	:	37 children.

Perinatally : anoxia, jaundice, Caesarean section,
forceps, prolonged labour, low birth
weight.

Sub-total : 27 children

Postnatally : accident.

Sub-total : 1 child.

Total : 65 children.

6.3.3 Marital status of parents

Single parents : 19 children

Married couples

staying together : 35 children

Deserted father/
mother

: 11 children

Total : 65 children

6.3.4 Age and standard of children

8 children were in the preschool, 10 in Sub A, 10 in Sub B, 6 were in Std. 1, 10 in Std. 2, 6 in Std. 3, 4 in Std. 4, 4 in Std. 5, 4 in Std. 6 and 3 were in Std. 7. The ages of the children ranged from 6 to 20.

Total : 65 children.

6.3.5 Siblings

Only child in the family : 10

One to six children in

the family : 55

Total : 65 children

6.3.6 Summary

Findings from the study of the schools' records confirmed that cerebral palsied children are prevalent in the Transkei (see 6.3.1). Cerebral palsy resulted from prenatal, perinatal and postnatal factors as revealed in 6.3.2. The marital status of parents shows that fifty percent of the children had both the father and the mother. The rest of the children had single parents owing to desertion by one parent, either the father or the mother.

6.4 Design of the qualitative study

6.4.1 Respondents

- The schools' records served as a resource for the choice of respondents. From the records 20 parents were chosen as respondents on the ground that they could be interviewed. The aim was to investigate whether Xhosa parents' attitudes really affected the education of their cerebral palsied children.

The selection of the respondents was based on the number of young cerebral palsied children in the two special schools. Children were to be ten years old or younger. Twenty children met this criterion and the decision was to interview the parents of these children.

The data from parents had to be verified. Additional information from secondary sources, such as teachers (N=5), social workers (N=7) and hostel mothers (N=4), was used to supplement and verify parental information.

Teachers were selected on the basis that they taught the cerebral palsied children and were likely to meet their parents and could, therefore, know parental reactions. Moreover, most teachers in special schools took a diploma in special education and the knowledge gained from such a course would supply the information sought on the attitudes of Xhosa parents towards the education of their cerebral palsied children.

The selection of social workers was based on the fact that they came into contact with parents by visiting them at home or meeting them in their offices. They were likely to know parents of the cerebral palsied children and how they reacted to such children.

The hostel mothers also acted in "loco parentis" and were likely to meet parents when they brought their children to the hostel or when they escorted home children not fetched by parents when schools closed. Hostel mothers were selected on the grounds that they knew the parents and would notice how parents interacted with their children when they visited them.

6.4.2 Interviews with parents

In order to obtain data from the parents a questionnaire was constructed (see appendix B). Interviews were used for the following reasons:

- * Some parents were illiterate and needed personal contact with the researcher who could explain questions to them. Such contact would ensure that parents understood questions in their proper context.

* The problem to be investigated demanded that rapport and empathy be established if suitable and sought after information was to be obtained. The interview questions were intended to discover what caused parents to react to the cerebral palsy of their children, why they reacted and how their responses were hampering the education of their cerebral palsied children. The interview questions were grouped under various categories/headings.

* The questionnaire was structured as follows:

Part A : Background information on parents

Questions were intended to determine the age of the respondent, the level of education, the family members and how they were related to the cerebral palsied child.

Part B : Birth history

Questions were concerned with the birth history of the cerebral palsied child.

Part C : Initial concern

The questions were aimed at determining the initial cause for the concern of the parents.

Part D : Developmental activities

Questions were concerned with developmental activities, that is, the attainment of the milestones.

Part E : Information about cerebral palsy

The questions aimed at obtaining facts about cerebral palsy.

Part F : Family relationships

Questions were concerned with family relationships.

Part G : Community relationships

Questions were intended to provide information on the relationships between the family and community members.

Part H : School life of the cerebral palsied child

The questions were intended to elicit information on the role parents play in the school life of their child.

Part I : Additional information

Additional information was requested to gain insight into the parents' attitudes towards their cerebral palsied child.

6.4.3 Interview with other respondents

The interview with teachers, social workers and hostel mothers were conducted orally. Questions asked were similar to that of the questionnaire drawn up for the parents. Only additional information to that of the parents' survey was reported.

6.5 Findings from the qualitative survey

The findings of the empirical investigation are as follows:

(N=20)

N = Number of respondents

NR = No responses

6.5.1 A. Background information on parents

1. What is your

i) age?

24 years	1
25 to 35 years	3
36 to 45 years	7
46 to 55 years	3
56 to 65 years	1
66 to 75 years	4
76 to 85 years	<u>1</u>
Total :	20

ii) Standard passed?

Never attended school	10
Sub A to Std. 3	1
Std. 4 to Std. 8	6
Std. 9 to Std. 10	3
Tertiary education	<u>0</u>
Total :	20

iii) Occupation?

Unemployed	12
Self-employed	3
Shop assistant	3
Clerk	1
Bus driver	1
Other careers	<u>0</u>
Total	: 20

2. Are you living together with your husband/wife?

i) Yes	7
ii) No	<u>13</u>
Total	: 20

If no, why not?

i) never married	3
ii) widowed	5
iii) husband/wife deserted	5
iv) NR	<u>7</u>
Total	: 20

3. Besides the cerebral palsied child how many other children do you have?

i) None	3
ii) One	4
iii) Two	3
iv) Three	6
v) Four	0
vi) Five	3
vii) Six	<u>1</u>
Total	: 20

Do any of these children suffer from cerebral palsy?

i) Yes	2
ii) No	<u>18</u>
Total :	20

If so, how many?

i) Boys	2
ii) Girls	0
Total :	2
(18 were not affected)	

6.5.1.1 Summary

Findings from the background information on parents (grandparents) showed that the ages of parents ranged from twenty four to eighty five years. Fifty percent of the parents were illiterate and the standard passed ranged from Sub.A to standard ten. Sixty percent of the parents were unemployed while the rest were doing various jobs as 6.5.1 indicates. Sixty five percent of the parents were single owing to never marrying, being widowed or being deserted by the partner. The number of siblings in families ranged from nought to six and only two male siblings of cerebral palsied children in the selected group were also found to suffer from cerebral palsy.

6.5.2 B. Birth history

4. Did the mother experience problems during pregnancy?

i) Yes	4
ii) No	15
iii) NR	1
Total :	20

5. Was the mother worried during pregnancy?

i) Yes	4
ii) No	15
iii) NR	<u>1</u>
Total	: 20

If so, why?

i) Because of car accident during pregnancy	1
ii) Owing to taking of drugs	1
iii) Owing to haemorrhage during pregnancy	<u>1</u>
iv) Because of maternal illnesses	1
v) Unknown causes	<u>16</u>
Total	: 20

6. What kind of delivery did the mother have?

i) Normal vertex/breech delivery	15
ii) Caesarean section	4
iii) Transverse	0
iv) NR	<u>1</u>
Total	: 20

7. Where was the baby delivered?

i) At home	8
ii) Hospital/clinic	11
iii) NR	<u>1</u>
Total	: 20

Who helped during delivery?

i) Nobody (the mother was alone)	0
ii) Relatives/neighbours	8

iii) Medical doctors/nurses at clinic/hospital	10
iv) NR	<u>2</u>
Total	: 20

6.5.2.1 Summary

The findings on the birth history showed that seventy percent of parents did not experience any problems during pregnancy and were not concerned about their pregnancy. Seventy five percent of the children were delivered in the normal way at home or hospital/clinic. During delivery the mothers were assisted by either relatives/neighbours or by doctors/nurses.

6.5.3 C. Initial concern

8. When was the disability first noticed?

i) 0 to 2 months	4
ii) 3 to 5 months	2
iii) 6 to 8 months	3
iv) 9 to 11 months	10
v) 12 to 14 months	1
vi) 15 to 24 months	<u>0</u>
Total	: 20

8a) How was the disability acquired?

i) Prenatal factors	5
ii) Perinatal factors	3
iii) Postnatal factors	<u>12</u>
Total	: 20

8b)	How did you feel about it?	
	i) Worried	11
	ii) Sad and depressed	7
	iii) Shocked	<u>2</u>
	Total	: 20

9.	Did your husband/wife also notice that something was wrong?	
	i) Yes	9
	ii) No	<u>11</u>
	Total	: 20

10.	After noticing that something was wrong with the child to whom did you take the child?	
	i) Medical doctors	2
	ii) Medical and tribal doctors	6
	iii) Tribal doctors	9
	iv) Social workers	2
	v) Nurses	0
	vi) School staff	<u>1</u>
	Total	: 20

11.	Who explained the child's disability to you?	
	i) Medical doctors	3
	ii) Tribal doctors	12
	iii) Social workers	0
	iv) Nurses	0
	v) School staff	0
	vi) Neighbours	0
	vii) Nobody	<u>5</u>
	Total	: 20

12. When were you informed about the child's disability

i)	During consultation	3
ii)	After child's assessment by the school staff	1
iii)	Never informed	<u>16</u>
	Total	: 20

13. What were you told concerning the causes of your child's disability?

i)	Caused by maternal illnesses	1
ii)	Caesarean section	1
iii)	Forceps	2
iv)	Anoxia	1
v)	Bewitched/ anger of the ancestors	12
vi)	Prolonged labour	1
vii)	Heredity	2
viii)	Prematurity	0
viii)	Accident	<u>0</u>
	Total	: 20

14. How did you feel when you were told about the cause of the child's disability?

i)	Hurt	1
ii)	Angry	2
iii)	Guilty/self blame	3
iv)	Blamed others	3
v)	Increased sorrow	2
vi)	Confused	7
vii)	Acceptance	<u>2</u>
	Total	: 20

15. Did your husband/wife accept what you were told?

1) Yes	9
ii) No	<u>11</u>
Total	: 20

6.5.3.1 Summary

The main findings with regard to the initial concern were that the disability in a child was discovered with in the period immediately after birth up to early childhood. The tendency of the parents was to react as soon as the disability was noticed and reactions differed in type and intensity. Another finding was that parents tried to assist the child with a disability by consulting various doctors. Parents who consulted tribal doctors were told that the disability in their child was the result of witchcraft or the anger of the ancestors.

6.5.4 D. Developmental activities

16. What are your views on teaching the child to:

dress

i) Difficult	20
ii) Not difficult	<u>0</u>
Total	: 20

wash

i) Difficult	20
ii) Not difficult	<u>0</u>
Total	: 20

. feed

i) Difficult	20
ii) Not difficult	<u>0</u>
Total	: 20

17. Did your husband/wife help you in the training of the child in these activities?

i) Yes	4
ii) No	<u>16</u>
Total	: 20

If not, why not?

i) Working in South Africa	0
ii) Working in a rural shop	2
iii) Deserted by him/her	7
iv) He regarded the training of the child as the function of a wife	1
v) Owing to his or her illness	1
vi) Widowed	5
vii) NR	<u>4</u>
Total	: 20

18. Did your other children help in taking care of the child?

i) Yes	18
ii) No	<u>2</u>
Total	: 20

19. How did they feel about having a brother/sister with a disability?

i)	Accept him/her for they never complain about his/her disability	18
ii)	Reacted negatively towards him/her	<u>2</u>
	Total	: 20

20. What are your views about disciplining the child with a disability?

i)	Should receive lenient treatment	19
ii)	Should be disciplined like other children in the family	<u>1</u>
	Total	: 20

6.5.4.1 Summary

The findings were that cerebral palsy in children caused parents to encounter difficulties when training the child to perform certain activities. The effect of difficulties was that they influenced parents to adopt certain attitudes towards such children. Moreover, the tendency of the siblings not to comment about the disability in their brother/sister was judged by parents to mean that they had positive reactions towards such children. The fact was that the siblings were hiding their true negative feelings owing to their upbringing. Another finding was that lenient treatment of the cerebral palsied children tended to spoil such children and was affecting the growth of independence in them.

6.5.5 E Information about cerebral palsy

21. Were you ever told about:

Causes of cerebral palsy?

i) Yes	0
ii) No	<u>20</u>
Total	: 20

Results of cerebral palsy?

i) Yes	0
ii) No	<u>20</u>
Total	: 20

Sub-types of cerebral palsy?

i) Yes	0
ii) No	<u>20</u>
Total	: 20

The degree of the child's disability?

i) Yes	0
ii) No	<u>20</u>
Total	: 20

Other associated disabilities?

i) Yes	0
ii) No	<u>20</u>
Total	: 20

The physical and medical treatment of the child?

i) Yes	0
ii) No	<u>20</u>
Total	: 20

How cerebral palsy may be prevented?

i) Yes	0
ii) No	<u>20</u>
Total	: 20

22. Who informed you?

i) Doctors	0
ii) Nurses	0
iii) Social workers	0
iv) School staff	0
v) Nobody	<u>20</u>
Total	: 20

23. When were you informed?

i) During consultation	0
ii) After consultation	0
iii) When the child was accepted at the special school	0
iv) Never informed	<u>20</u>
Total	: 20

24. How did you feel when you eventually found out your child had cerebral palsy?

i) Hurt	1
ii) Angry	2
iii) Sad	8
iv) Guilty	1
v) Blamed others	<u>8</u>
Total	: 20

25. Despite what other people told you, what do you think is the possible cause of your child's disability?

i) Caesarean section	1
ii) Forceps	2
iii) Anoxia	1
iv) Drugs	1
v) Haemorrhage	1
vi) Accident	2
vii) Prolonged labour	2
viii) Heredity	4
ix) Witchcraft/anger of the ancestors	<u>6</u>
Total	: 20

6.5.5.1 Summary

The main finding was that none of the parents were informed about cerebral palsy. The parents, therefore, supplemented lack of information on cerebral palsy by forming their own opinions about the causes of cerebral palsy in children.

6.5.6 Family relationships

26. Do you think the cerebral palsied child causes financial problems in the family?

i) Yes	18
ii) No	<u>2</u>
Total	: 20

27. Do you think the child's disability is affecting your marriage?

i) Yes	11
ii) No	<u>9</u>
Total	: 20

28. Is the cerebral palsied child happy in the family?

i) Yes	18
ii) No	<u>2</u>
Total	: 20

Explain your answer. The child

i) is liked by all family members and feels accepted	17
ii) often cries and is not happy	2
iii) is happy and helpful	<u>1</u>
Total	: 20

29. Do you think the cerebral palsied child fits into your family?

i) Yes	20
ii) No	<u>0</u>
Total	: 20

Explain your answer. The child

i) is accepted	20
ii) is not accepted	<u>0</u>
Total	: 20

6.5.6.1 Summary

The findings on family relationships were that a cerebral palsied child caused a considerable strain on family relationships. Negative attitudes to the child were possible because of the financial burden the family had to endure. Eleven parents stated that cerebral palsy

in the child affected their marriage. Despite these adverse effects, on the whole cerebral palsied children were accepted in their families.

6.5.7 G Community relationships

30. In spite of having a cerebral palsied child are you able to take part in community activities?

i) Yes	12
ii) No	<u>8</u>
Total	: 20

31. Do you think other people accept your child?

i) Yes	19
ii) No	<u>1</u>
Total	: 20

Explain your answer

i) Neighbours and relatives visit and inquire after the child	19
ii) All people in the locality are interested in the family	0
iii) Neighbours and other members of the tribe utter hurting remarks	<u>1</u>
Total	: 20

32. Besides neighbours, relatives and people in the locality, are there other people who are interested in your family?

i) Teachers	0
ii) Social workers	0
iii) Nurses	0
iv) Ministers of religion	1
v) Red Cross and other philanthropic bodies	1
vi) Nobody	<u>18</u>
Total	: 20

33. Do you ever take the child along when going for shopping or visiting?

i) Yes	6
ii) No	<u>14</u>
Total	: 20

6.5.7.1 Summary

The main finding was that fourteen cerebral palsied children were not exposed to the wider environment's influences. Teachers, social workers and nurses also shun families with cerebral palsied children. Such findings were in agreement with literature findings, especially with regard to the intensification of parental responses owing to lack of support from other people and professionals.

6.5.8 H. School life of the cerebral palsied child

34. Who took care of the child before it started attending school?

i) Biological mother	4
ii) Biological mother and the family helper	3
iii) Grandmother	12

iv) Step-father/step-mother	1
v) One of the siblings	<u>0</u>
Total	: 20

35. To which school did you initially send your child?

i) Mainstream of education	7
ii) Special school	<u>13</u>
Total	: 20

36. When did the child go to a special school?

i) 3 to 5 years	0
ii) 6 to 8 years	9
iii) 9 to 10 years	<u>11</u>
Total	: 20

37. Why was the child sent to a special school?

i) Complaints of teachers in the mainstream about the slow progress and the hampering of progress of other children in class	15
ii) Referred to a special school	2
iii) Told by other people about the special school	<u>3</u>
Total	: 20

38. How do you feel about:

special school

i) Satisfied	20
ii) Dissatisfied	<u>0</u>
Total	: 20

teaching

i) Satisfied	20
ii) Dissatisfied	<u>0</u>
Total	: 20

therapy

i) Satisfied	20
ii) Dissatisfied	<u>0</u>
Total	: 20

parents meetings at school

i) Satisfied	20
ii) Dissatisfied	<u>0</u>
Total	: 20

39. Do you think the teachers like your child?

i) Yes	20
ii) No	<u>0</u>
Total	: 20

40. How often do you visit the school?

i) 1 to 2 times a month	3
ii) More than twice a month	1
iii) Never visit	<u>16</u>
Total	: 20

41. How do you foresee the future of your child?

i) He/she will be a clerk.	7
ii) He/she will be a social worker.	1

iii) He/she will never be educated and will never be independent.	1
iv) I cannot envisage the type of life he/she will lead.	11
Total	: 20

6.5.8.1 Summary

The findings were that the grandmothers also played a major role in the upbringing and education of cerebral palsied children. The cerebral palsied children did not, for specific reasons, fit into the mainstream of education and had to be transferred to special schools. The parents were satisfied with the type of education that special schools provided but took no part in the school education of their cerebral palsied children. The education of eleven cerebral palsied children was found to be negatively affected by the fact that parents did not know what type of work their children would do, nor what kind of life such children would lead. Such findings were in line with literature findings.

6.5.9 I. Additional information

42. Do you have any suggestions as to what might be included in this study to make the researcher understand your situation better?

Question no. 42 needed parents, teachers, social workers and hostel mothers to make suggestions and these are presented below. The suggestions are given at random.

6.5.9.1 Suggestions from parents

- * The illiteracy of parents in the Transkei needs to be addressed for it is one of the factors that causes parents lack of involvement in the school education of their cerebral palsied children.
- * The schools for the mainstream of education can be used after school hours for the education of those parents who dropped out of school or who never attended school. The upgrading of the standard of parents might be helpful towards the education of cerebral palsied children.
- * In some families children with disabilities were not liked. Such children tended to be lonely for they isolated themselves from other members of the family.
- * The law should force runaway fathers to support financially the families they deserted.
- * Negative relationships, such as children disliking their parents and parents being impatient with their cerebral palsied children, need to be corrected.
- * Parents should stop spoiling their children by being lenient in their disciplinary methods. They should also not treat such children as babies, especially if they are already at a special school. Such treatment disrupts the efforts of the school.
- * The abuse of cerebral palsied children at home should be stopped. Children are sexually abused when parents are absent or parents themselves use them as sources of income in the family; for instance, they allow the child

to beg and keep the child at home so as to obtain a disability grant.

- * Children with disabilities should not be left alone in the hut, as some parents do. Such a practice is harmful to children who suffer from convulsions for they can sustain additional injuries and feel unwanted and rejected.
- * Grandmothers, single and widowed mothers must receive a special fund for the needs of the cerebral palsied children they are taking care of.
- * Grandmothers need to be assured about who will take care of their cerebral palsied children when they are deceased.
- * The reason why parents keep away from special schools is that they fear to be scolded by the school staff, they are ashamed of their cerebral palsied children or the special schools are too far.
- * Xhosa communities should be informed about problems experienced by parents of cerebral palsied children. They should also be informed about the effects of hurtful remarks directed at the parents or at the cerebral palsied children.
- * Tribal members need to be informed about the danger of mixing hospital/clinic medicines with those of the tribal doctors. Such medicines tend to be too strong for young children, especially for the foetus, and may cause harm.

- * Headmen should see to it that migrant fathers receive information on disabilities. The birth of a child with a disability during the absence of the father causes the father to be suspicious, quarrels result, divorce or desertion of the family by the father or mother.
- * Social workers should visit homes of parents with cerebral palsied children for parents have problems that need the attention of social workers. Ministers of religion should also visit such families.
- * Boreholes should be sunk in areas where the river is the only source of water. During droughts people and animals compete for the often stagnant and polluted river water. Polluted water may cause illnesses and disabilities in children.
- * Clinics should be built in rural areas especially those that are very remote from towns. In such remote areas women become pregnant and also need to be monitored and given advice, if disabilities are to be reduced.
- * In families where the father has absconded, the mother should be trained to do certain jobs so that she can support the family and not depend on the pension fund of the grandmother/grandfather.

6.5.9.2 Suggestions from teachers

- * Teachers should encourage parental participation in the education of their cerebral palsied children in the following ways:
 - Writing letters that invite parents to visit the school.
 - Arranging class outings where parents are invited to

take part.

- Contacting parents after school meetings and taking them to their classes.
 - Visiting the families. Parents may copy the example of teachers and start visiting the school.
-
- * Special schools should supply free transport for children whose parents neither fetch nor bring them to school.
 - * Parent-teacher associations should be established for they do not exist in schools for cerebral palsied children. Such associations may encourage parental participation at schools.
 - * Parent-teacher-hostel mother associations may even be more effective in encouraging parental participation at schools.
 - * It should be the duty of the special schools to train cerebral palsied children for their future jobs because parents are not professionals and not able to train the children even if they participate in the education of the children.
 - * Where possible, children with disabilities should attend school but reside at home. This enables the children to receive the care and love they need for their growth and development.
 - * Every parent should be encouraged to visit the school. This should be one of the conditions of the acceptance of cerebral palsied children at special schools.

- * Special schools' meetings should be arranged more than twice a year. The more the parents visit, the better the relationship will be between them and the school staff.
- * Parents who cannot afford to pay a visit to their children should at least write letters to them. The children will then not feel unwanted and rejected.
- * Parents should report when taking their children home for holidays and when bringing them back. Parents should not allow very young cerebral palsied children to travel back to school alone.
- * Other people, such as the siblings, friends of the family, relatives and neighbours should also visit the cerebral palsied child at school.
- * Parents should be taught the therapy started at school so that they can continue it at home. Such instruction might help them to realise the need, for the child, of wearing walking appliances at home.
- * Organisations such as the Red Cross should be responsible for the education of cerebral palsied children where parents have no means of educating them.

6.5.9.3 Suggestions from social workers

Suggestions from social workers were mostly similar to those suggested by parents.

6.5.9.4 Suggestions from hostel mothers

- * Certain localities are not suitable for the upbringing and education of cerebral palsied children; for

instance, the municipality dumping area where some parents stayed and had built shacks. The schools should be responsible for removing the children from such areas and finding a more suitable place for them.

- * Parents should take care of their cerebral palsied children by washing them when they are on holiday at home. Children remain unwashed because during droughts the only source of water is the river and it is usually far. Another reason is that the grandmothers who are very old do not have energy for washing their cerebral palsied children.

6.6 Synthesis of main findings

6.6.1 Findings on the causes of cerebral palsy

- * The findings were that children are born with or acquire cerebral palsy prenatally, perinatally and postnatally.
- * Factors causing cerebral palsy in other countries were also responsible for causing cerebral palsy in children in the Transkei.
- * Cerebral palsy was often accompanied by additional disabilities in a child. The disabilities, together with cerebral palsy, affected the learning and education of the child.

6.6.2 Finding and awareness of the problem

- * The majority of parents in Transkei were ill-informed about cerebral palsy. In fact, all parents interviewed did not know what cerebral palsy was. They then formed

their own opinions as to what might have caused the disabilities in children.

- * Parents were not aware that cerebral palsy affected the education of cerebral palsied children. This ignorance caused them to use methods that were not suitable for the upbringing of such children.
- * The awareness of the physical deformity caused the parents to experience difficulties with regard to the visualisation of the future vocational life of cerebral palsied children.
- * Awareness of the disabilities in children also caused parents to yearn to be informed about the disabilities.

6.6.3 Findings on the attitudes of parents toward the education of the child with cerebral palsy

6.6.3.1 Caring for the child at home

- * The empirical investigation revealed that the distancing of parents from their cerebral palsied children caused the child to be physically neglected. The cause was that the grandmothers were very old and lacked the strength needed for caring for the child with a disability. Some mothers were working and had no time to care for the child. Physical neglect caused other aspects of development in the child to be neglected as well. Such neglect affects the education of the child.

6.6.3.2 Educational problems

- * The empirical investigation revealed that mobility problems of the child caused frustrations in parents

especially when trying to train the child in a certain activity such as dressing, washing or feeding himself or herself.

- * Parents revealed different degrees in the intensity of their reactions. Some parents, for instance, felt relieved when the child was at the special school and would not even attempt to visit the child at school.
- * The negative home atmosphere caused by the cerebral palsied child had an effect on the education of such a child. In some families the disability of the child caused more co-operation between the father and the mother especially with regard to assisting the child. Such parents were able to cope.
- * In the literature study, sibling rivalry for parental love and attention was found to exist. In the empirical investigation the Xhosa children were mostly found not to compete with the cerebral palsied child. The fact was that the children had negative reactions but they kept them under control in the presence of adults. Hidden responses were also affecting the education of the cerebral palsied child by siblings.

6.6.3.3 The school education of cerebral palsied children

- * The reactions of some of the parents to the cerebral palsy of their children were so strong that they refrained from visiting special schools and their cerebral palsied children.
- * In most special schools no parent-teacher associations exist. Parent-teacher associations were supposed to encourage more parental participation in schools.

- * The majority of Xhosa parents were found to lack interest in the school education of their children. Neither the teachers, the parents nor the community made an effort to narrow the widening gap between the school and the home.

6.7 Conclusion

The primary aim of the empirical investigation was to substantiate or refute the findings established by means of the essential analysis of the literature.

In this regard it is safe to assume that the empirical investigation findings not only verify, but also clarify many of the conclusions which are found in the literature. The findings from section 6.5.9.1 to 6.5.9.4 are of particular relevance and interest for the successful education of cerebral palsied children, not only in the former Transkei, but also in Africa as a whole.

Chapter seven will focus on a resume of the study with appropriate recommendations that could improve the education of cerebral palsied children both in the former Transkei and in general.

CHAPTER 7

SUMMARY AND RECOMMENDATIONS OF THE INVESTIGATION

7.1 Introduction

The attainment of adulthood by a cerebral palsied child depends to a large extent on the type of care, love and acceptance the child receives from parents. The literature study and the empirical investigation findings showed that the learning of such a child is influenced by parental attitudes in environments such as the home, school and the community.

7.2 Research problem: background and statement

Before parents of cerebral palsied children can become educated in the true sense of the word, they have to have an accurate and realistic understanding of the problems experienced by their children. They can only lead the child to adulthood if they (the parents) are fully knowledgeable about cerebral palsy and the far reaching consequences thereof for the child and the family as a whole. The degree of success of parents guiding their children is usually influenced by, among other things, geographical, demographic, economic and educational factors (see 1.3). The problem this study investigated was: What are the attitudes of Xhosa parents towards the education of their cerebral palsied children?

7.3 Aims of the study

The general aim of the study was to investigate the attitudes of Xhosa parents towards the education of

their cerebral palsied children.

The specific aims were to:

- * study cerebral palsy and how it affected the development of such children (see Chapter 2),
- * study the education of cerebral palsied children (see Chapter 3),
- * investigate the influence of cerebral palsy on parents of the children(see Chapter 4),
- * study how Xhosa parents educate their children with disabilities (see Chapter 5).

7.4 Method of study

In order to obtain a deeper understanding of the problem relevant overseas and South African literature was studied. A literature study was essential, for it formed the framework of reference. Owing to a certain need to verify or supplement literature findings, a limited empirical investigation had to be carried out and interview schedules were used for the collection of data (see 1.6).

7.5 Summary of findings

7.5.1 Findings from the literature survey

7.5.1.1 Cerebral palsied children

- * Children in some families suffer from cerebral palsy (see 2.1).

- * Cerebral palsied children (see 1.2.7) tend to suffer from additional disabilities related to cerebral palsy. In this manner cerebral palsy becomes a complex phenomenon (see 2.6).
- * Cerebral palsy is caused by numerous factors prenatally, perinatally and postnatally (see 2.5).
- * In some western countries (see 2.2) the incidence figures have been lowered while in South Africa and the Transkei success has not yet been attained and the number is increasing (see 2.2.4; 2.2.5).
- * Various steps may be taken to prevent the incidence of cerebral palsy (see 2.7).

7.5.1.2 Education of cerebral palsied children

- * Cerebral palsy causes problems in the education of cerebral palsied children. The disability affects the structure of education (see 3.2.2) and the role played by educators of cerebral palsied children, such as parents.
- * Team members must put the interests of the child before all other considerations (see 3.5.2). This common commitment where the welfare of the child is of primary importance tends to wield the team together into a therapeutic team.

7.5.1.3 Parents of cerebral palsied children

- * Cerebral palsy affects parents attitudes towards their cerebral palsied children. Some of the attitudes are

ambivalence (see 4.4.2.4), bargaining (see 4.4.3.1), acceptance, reorganisation (see 4.4.3.2) and compensation (see 4.4.4.5).

- * Parents are differently affected by the disability of their child (see 4.10).

7.5.1.4 Education of Xhosa children with special reference to children with disabilities

- * All adult members are educators of Xhosa children especially with regard to traditional education (see Chapter 5).
- * The adult members are affected by children with disabilities and the attitudes towards such children are influenced by various factors (see 5.3).
- * Xhosa parents hardly participate in the school education of their children and various factors influence their lack of participation (see 5.3.2.4).

7.5.2 Findings from the empirical survey

7.5.2.1 Background information on parents

- * Parents of cerebral palsied children ranged from illiterate to literate.
- * Most of the parents were unemployed. Such parents were, therefore, poor.
- * The marital status showed that parents were either married or single. Being single was due to the situation

of one parent absconding, widowhood or the person never marrying (see 6.3.6).

7.5.2.2 Birth history

- * During delivery mothers were assisted by relatives/neighbours or by doctors/nurses (see 6.5.2.1).

7.5.2.3 Initial concern

- * Parents tried to "cure" their children by consulting various doctors, predominantly tribal doctors. The fact is that tribal doctors are ignorant, for they do not know a person's anatomy or brain structure and the effects of cerebral palsy on the child, parents, community and the education of such children, yet they give parents health advice (see 5.3.2.1).

7.5.2.4 Developmental activities

- * All parents encountered problems when training their cerebral palsied child, for instance, to wash, dress or feed himself or herself.
- * Parents treated their children leniently. Leniency hindered the development of independence in cerebral palsied children (see 6.5.4.1).

7.5.2.5 Information on cerebral palsy

- * None of the parents were informed about what cerebral palsy was.
- * Lack of knowledge about cerebral palsy caused parents to form their own ideas about causes of cerebral palsy,

namely, the supernatural powers (ancestors and witchcraft). Such unscientific perceptions are rooted in superstition and this is a factor that can influence parental attitudes towards cerebral palsied children negatively.

- * The unscientific perceptions also show that parents have not yet been enlightened about causes and results of cerebral palsy.

7.5.2.6 Family relationships

- * The presence of a cerebral palsied child affects the marital relationships of parents. Some parents, for example, absconded. In other families the couple's marriage was not affected and the disability strengthened the relationship of parents.
- * A cerebral palsied child causes additional costs in a family. Such costs influenced parents to have negative attitudes towards their cerebral palsied children.
- * In most families cerebral palsied children were accepted.
- * Siblings in the family were found to assist and to make no comments about their brother or sister with a disability.
- * Parents interpreted the lack of comments as meaning that siblings liked and accepted such children. In fact the siblings were hiding their real negative feelings because of their upbringing.

7.5.2.7 Community relationships

- * In the traditional upbringing of non-disabled boys and girls there is a total involvement of the community in this type of education (see 5.2).

- * Although parents could take part in the community activities and indicated that other people accepted their cerebral palsied children, the researcher found out through talking with teachers that negative relationships did in fact exist.

- * In the light of normal community relationships, the isolation of the cerebral palsied children was even more marked. The parents did not take their children with them when going shopping. Reasons for isolating their children were, among other things, that parents were ashamed of their children and that the community members were intolerant of children with disabilities. One explanation that can be offered for this intolerance is that modern people want efficiency, productivity and material progress. Those who fall short of such competency, such as the cerebral palsied individuals, are rejected (see 5.3.3).

- * Another finding was that the isolation of cerebral palsied children had specific results. Such children were denied the socialisation process through being excluded from being educated by community members. Exclusion is, therefore, a severe social disability. Such a state of affairs is bad for parents for they must deal alone with cerebral palsied children.

7.5.2.8 School life of the cerebral palsied child

- * It was found that cerebral palsied children often had to be removed from ordinary schools and placed in special schools. Such a removal had effects on parents. It highlighted the fact that their child was different from others (non-disabled mainstream children), needed extra assistance and that they (parents) might have to take care of their dependent child for as long as he or she lived. Such revelations could discourage parents and cause them to avoid special schools and visiting the child. They might not be able to envisage the type of life the child could lead or the work he or she could do in future.

7.5.3 Additional information

7.5.3.1 Needs of parents of cerebral palsied children

- * Parents wanted to be educated (receive formal education using school buildings after school).
- * They also wanted clinics to be built where they could obtain medicines and receive information about disabilities.
- * Parents also needed money. They suggested that fathers who deserted the family be made to support the family financially, and that parents should receive a disability grant for their children with cerebral palsy.

7.5.3.2 Factors affecting parental participation in the school education of cerebral palsied children

Some factors that caused lack of parental interest in

the school education of their children were:

- * illiteracy,
- * long and expensive journeys to and from special schools,
- * being ashamed of their children and
- * fear of the schools' professionals.

7.5.3.3 Ways of encouraging parental participation

Methods that could be used, according to the teachers, to encourage parental participation include:

- * writing letters that invite the parents to visit the school,
- * having parents participating in the class outings of their children,
- * contacting parents after the school meetings,
- * visiting the families of the children they teach, and
- * starting parent-teacher associations and also parent-teacher-hostel mother associations.

7.6 Conclusions

The following conclusions can be drawn from the findings in this study:

7.6.1 There are no incidence figures regarding children with cerebral palsy in the Transkei

1. No known investigation has been conducted into the incidence figures of children with cerebral palsy.
2. The lack of actual incidence figures shows that the registration of births especially of children with

cerebral palsy is not strictly controlled.

3. Lack of actual numbers of children with disabilities is affecting effective planning of education for children with disabilities. Existing special schools cannot accommodate all children and some are not accepted. These children may miss out on education. Such a state of affairs affects parents who desire to educate their children. Moreover, no attempts are being made to locate such children and to educate them.
4. The incidence of cerebral palsied children can be reduced (see Chapter two). In the Transkei no attempts are made to counteract the cause and results of cerebral palsy, hence the rising number of cerebral palsied children.

7.6.2 The education of the cerebral palsied child

1. Cerebral palsy influences the attitudes of parents towards the education of their cerebral palsied children.
2. Parents who have negative attitudes towards such children will not be inclined to have close contact and positive relationships with their children.
3. The education of cerebral palsied children is costly.

7.6.3 Cerebral palsy causes parents (universally) to have certain attitudes toward their cerebral palsied children

1. Positive attitudes of parents show that they are also able to accept human differences and are thus able to allow cerebral palsied children to be full members of

their families and the community, if the community accepts them.

2. Negative attitudes indicate that parents cannot accept their cerebral palsied children especially when they are aware of their children's physical differences. In view of the negative attitudes revealed in this study there is a great need to encourage tolerance in parents of cerebral palsied children.
3. Parents' negative attitudes cause cerebral palsied children to be, among others things, isolated and rejected in their families. The result is that cerebral palsied children may internalise such attitudes and regard themselves as inferior and sub-normal. Such views have the consequence of worsening the situation of cerebral palsied children in their families and in the community.
4. Some parents in various families incorporate western and modern facets such as furniture, cars and television. Such aspects of modern life in the families of cerebral palsied children, tend to alienate individuals with disabilities who cannot participate fully in modern life. There is, therefore, a need to encourage parents to see to it that cerebral palsied children are given education and training that will allow them to contribute meaningfully to the family and the community in the modern world.
5. Negative parental attitudes need to be changed. It is unlikely that the attitudes of contemporary parents can be changed drastically. The solution is to change those of young children, using various methods such as instruction and contact with cerebral palsied children.

7.6.4 Cerebral palsy affects the role played by Xhosa parents in the education of their children

1. Among the Xhosa there is a strong belief in supernatural powers (ancestors and witchcraft) as causes of disabilities in children. Such beliefs affect the amount of contact, care, love and education parents give to their children with disabilities. In fact, such children either do not receive the traditional education given to their non-disabled counterparts or are hardly integrated into community education. There is, therefore, a need to convince parents of the necessity of giving their cerebral palsied children traditional education. They also need to be persuaded to have less belief in supernatural powers. Most of all they need to be informed about disabilities in their children.
2. Children with cerebral palsy are often deprived of the right to be socialised. The reason for such deprivation is that such children are physically different from other children or that they receive more attention or special treatment from parents. This treatment may cause such children to be over-conscious of their difference. Too much awareness may cause children to withdraw themselves from family and community members. Rejection directed at such children also isolates them. Such a situation indicates that there is little or no co-operation between parents and community members with regard to the education of children with cerebral palsy. Co-operation, therefore, needs to be fostered.
3. The influence of the tribal doctors in the life of the rural Xhosa is very strong. The reason could be that such doctors existed throughout the history of the Xhosa and that they are still trusted and consulted.

4. Medical doctors, especially the non-Xhosa speaking ones, are not understood by parents. Such doctors use translators who may not fully convey the doctor's diagnosis to parents. Such doctors are avoided by parents. The problem is that there are no equivalent Xhosa terms for English medical terms such as cerebral palsy. There is, therefore, a need to ensure that medical doctors serving in the Eastern Cape Province, learn Xhosa and to coin new Xhosa terminology for various disabilities.
5. Xhosa parents have little or no interest in the school education of their children with disabilities. Different reasons account for lack of interest and participation. Methods used in ordinary schools, such as parent-teacher associations are just not effective in encouraging involvement. It would, therefore, be better when starting such associations in special schools to devise additional methods that will assist in attracting parents to visit such schools.

7.7 Recommendations

7.7.1 The incidence of cerebral palsy

Recommendation

The Department of Health should promote an active programme in determining the number of cerebral palsied children in various districts or regions of the Eastern Cape Province (Transkei).

Motivation

The incidence of children with cerebral palsy has not yet been accurately established in the Eastern Cape Province (Transkei). It is essential that the numbers be known, so that there can be effective planning of education for such children.

7.7.2 Central register on children with cerebral palsy**Recommendation**

A central register should be kept in each district where all the names of cerebral palsied children are recorded.

Motivation

A central register would enable nurses and social workers to trace "hidden away" cerebral palsied children and to take note of children in special schools and in the mainstream of education who are suffering from various degrees of cerebral palsy.

7.7.3 Parent guidance and counselling**Recommendation**

Parent guidance and counselling should form part of the task of the school. This should include guidance during initial admission procedures, as well as throughout the child's stay at a special school. This goal may be achieved by means of regular parent-teacher meetings, group discussions and the establishment of supportive mums-groups.

Motivation

Parents have special needs with regard to educating a cerebral palsied child. No adequate guidance is given to parents of cerebral palsied children in the Transkei. The guidance programme should be planned in such a manner that it includes all the stages of the child's development. The programme must also ensure that illiterate, semi-literate and literate parents benefit. To enhance parental knowledge, discussions and workshops should form part of the guidance programme.

7.7.4 Attitudes toward children with disabilities**Recommendations**

Efforts should be made to change negative attitudes concerning children with disabilities, especially cerebral palsied children. Close co-operation should be strongly encouraged between regular schools and schools for special education.

Motivation

Negative attitudes towards cerebral palsied children tend to isolate such children socially. The attitudes of non-disabled children towards cerebral palsied children also need to be changed.

7.7.5 The dissemination of information regarding cerebral palsied children**Recommendations**

Deliberate efforts should be made to disseminate

information and spread information on cerebral palsy to inhabitants of the Eastern Cape. This should include adequate use of local radio stations, as well as television coverage.

Motivation

This investigation has indicated that very little information regarding cerebral palsied children exists, especially in the rural areas of the Eastern Cape. The majority of the parents were unaware of what cerebral palsy is, and also of the causes of cerebral palsy, the abilities and possible achievements of cerebral palsied children, how to act towards them, the particular needs of such children and job opportunities for them. By giving parents and the community reliable information concerning cerebral palsy, it is hoped that the negative attitudes towards such children will be eliminated, and that they will not be regarded as worthless and hidden away by being kept at home.

7.7.6 The role played by special schools and parental participation

Recommendation

Parental participation should be strongly encouraged and facilitated by schools in the Eastern Cape catering for cerebral palsied children. This commitment could be achieved by amongst other things, the following:

- * A school bus should be sent to the rural areas to collect parents who have no means of transport or who cannot afford it.

- * Grandmothers should be involved in as many school meetings or activities as possible.
- * Contact with parents can be achieved by the principal of the school writing individual letters to parents encouraging them to come to the school.
- * A positive atmosphere should be created at school in which parent participation is encouraged.
- * Any successful parent participation is dependent on the positive role played by the principal in encouraging parents to participate in the education of the cerebral palsied child. This success could be achieved by the principal holding initial discussions with parents when they enrol the child. It should be the principal's responsibility to encourage his or her teachers to show respect towards the parents and regard them as partners in the education of their children.
- * As the school hostel plays an integral role in the education of cerebral palsied children, hostel mothers should also be encouraged to have a meaningful discussion with the parents when they bring or collect their children at the beginning and end of each term.
- * The school should try to establish mother support groups where mothers can discuss common or similar problems experienced by families with a cerebral palsied child.

Motivation

The special school plays an essential role in the education of children with disabilities. This is also true in the field of special education for cerebral

palsied children. This investigation has revealed that the majority of parents play a very insignificant role in school participation. Active participation is very important in the development of a cerebral palsied child. Furthermore, this investigation has highlighted the importance of grandparents in Xhosa culture, as an extension of the parental role.

7.7.7 Associations and organisations

Recommendation

- * The Cerebral Palsy Division of the National Council for the Physically Disabled in South Africa should become actively involved in the Eastern Cape Region by establishing a regional office where interested parties could be brought together by means of an annual conference or the holding of workshops in the area to discuss the needs of parents, teachers, social workers, as well as those of other paramedical staff working with cerebral palsied children.
- * Parent-teacher associations should be started in special schools for cerebral palsied children in the Eastern Cape.
- * Parent-teacher-hostel mother associations should also be formed, especially in the rural areas of the Eastern Cape where active participation by all role players should be encouraged.

Motivation

This research has indicated that in the Eastern Cape there exist very few associations and organisations

actively involved in catering specifically for parents of cerebral palsied children. This is specifically true in the rural areas of the country.

7.7.8 The role of the medical and tribal doctors

Recommendation

- * The training of medical doctors should include a section on the emotional trauma of parents of children with disabilities such as cerebral palsy.
- * When discussing problems with parents, doctors who do not speak Xhosa should employ interpreters to explain carefully to parents in layman's terms what the doctor is trying to convey.
- * Tribal doctors should be made aware of the causes and consequences of cerebral palsy.
- * Tribal doctors should be invited to attend gatherings where discussions on cerebral palsy are taking place. These doctors should be encouraged to join the newly formed medical-herbalists associations where they could interchange ideas with medical doctors and vice-versa.

Motivation

The empirical investigation revealed that medical doctors do not give due acknowledgement to the emotional trauma which parents experience, and they often use medical jargon which is incomprehensible to parents. Parents in the Eastern Cape also consult tribal doctors, who often do not know the causes or consequences of cerebral palsy.

7.8 Future research

The following research topics are recommended:

1. An investigation into the attitudes of Xhosa parents toward the education of their cerebral palsied children could be done on a larger scale.
2. An investigation into the mainstreaming of cerebral palsied children.
3. An investigation into the training of traditional doctors incorporating modern western technological advances without losing sight of the "traditional powers" of such doctors.

7.9 Closing remark

Cerebral palsy is a phenomenon that exists throughout the world. Children suffering from cerebral palsy, like other non-disabled children, have a right to receive education. To enable a cerebral palsied child to develop towards adulthood parents must accept the child not as a problem child but as a child with a problem.

BIBLIOGRAPHY

- Achenbach, T.M. 1982. Developmental psychology. Toronto: Wiley & Sons.
- African National Congress Education Department. 1994. A policy framework for education and training. Braamfontein: ANC.
- Arens, L.J. 1984. Cerebral palsy. Continuing Medical Education, 2 (May): 52-56.
- Arens, L.J., Molteno, C.D., Marshall, S.R., Robertson, W.I. & Rabkin, J. 1978. Cerebral palsy in Cape Town. South African Medical Journal, 53 (August): 319-324.
- Ayim, E., Bion, J., Farman, J., Prior, F., Bewes, P., Cory, C. & Kisia, A. 1986. Primary anaesthesia. London: Oxford University Press.
- Barsh, R.H. 1968. The parents of the handicapped child. Springfield, Illinois: Charles C. Thomas.
- Battle, C.U. 1974. Disruptions in the socialisation of a young, severely handicapped child. Rehabilitation Literature, 35 (5):130-140.
- Behr, A.L., Cherian, V.I., Mwamwenda, T.S., Ndaba, E.P. & Ramphal, A. 1986. An educational psychology for schools in Africa. Durban: Butterworths.
- Berger, K.S. 1983. The developing person through the lifespan. New York: Worth Publishers.

- Berkov, R. (ed.) 1982. The Merck Manual. 14th edition. Rahway, New York: Merck & Company.
- Betela, T.M. S.a. Primary education in Transkei with emphasis on efficiency. D.Ed. Unpublished thesis. University of Orange Free State, Bloemfontein.
- Biehler, R.F. & Hudson, L.M. 1986. Developmental psychology, an introduction. 3rd edition. Boston: Houghton Mifflin Company.
- Blacha, S. 1982. The application of Bobath philosophy of treatment to the practice of occupational therapy. South African Journal of Neurodevelopment therapy, 6 (2): 15-21.
- Bleck, E.E. & Nagel, D.A. 1982. Physically handicapped children: a medical atlas for teachers. New York: Grune & Stratton.
- Bobath, K. 1980. A neurological basis for the treatment of cerebral palsy. London: William Heinemann Medical Books.
- Bolton, P.J. 1983. Drug abuse, in: Drugs and pregnancy: human teratogenesis and related problems, edited by D.F. Hawkins. New York: Longman Group:128-147.
- Boone, D.R. 1972. Cerebral palsy. New York: The Bobbs-Merrill Company.

- Botha, P.N. 1989. Cerebral Palsy, in: Children with problems: an orthopedagogical perspective, edited by J.A. Kapp. Pretoria: Serva : 233-298.
- Bowley, A.H. & Gardner, L. 1980. The handicapped child. 4th edition. Edinburg: Churchill Livingstone.
- Bowley, A.H. & Gardner, L. 1972. The handicapped child. 3rd edition. Edinburg: Churchill Livingstone.
- Breslau, N. 1983. Family care: effects on siblings and mothers, in: Comprehensive management of cerebral palsy, edited by H. Thompson. New York: Grune & Stratton :
- Byrne, E.A. & Cunningham, C.C. 1984. The effects of mentally handicapped children on families- a conceptual review. The Journal of Child Psychology, 26(6): 847-864.
- Bryant, J.E. 1971. Parent child relationships: their effects on rehabilitation. Journal of Learning Disabilities, 4(1): 325-329.
- Burman, S. & Reynolds, P. 1986. Growing up in a divided society: the contexts of childhood in South Africa. Johannesburg: Ravan Press.
- Cavalli-Sforza, L.L. 1977. Elements of human genetics. Menlo Park, California: W.A. Benjamin.
- Chambers, R. 1983. Rural development: putting the last first. New York: John Wiley & Sons.

- Champion, H. 1976. The New Transkei. Sandton: Valiant Publishers.
- Chinn, P.C., Winn, J. & Walters, R.H. 1978. Two way talking with parents of special children. St. Louis: C.V. Mosby.
- Chinn, P.C., Drew, C.J. & Logan, D.R. 1979. Mental retardation: a life cycle approach. St. Louis: C.V. Mosby.
- Coovadia, H.M. & Loening, W.E.K. 1988. Paediatrics and child health. Cape Town: Oxford University Press.
- Crowley, P. 1983. Premature labour, in: Drugs and pregnancy, edited by D.F. Hawkins. New York: Longman Group: 155-157.
- Cruickshank, W.M. 1976. Cerebral palsy. 3rd edition. Syracuse University.
- Cruickshank, W.M. & Johnson, G.O. 1975. Education of exceptional children and youth. Englewood Cliffs, New Jersey: Prentice-Hall.
- Cunningham, C. & Davis, H. 1985. Working with parents of exceptional children: a framework for collaboration. Philadelphia: Open University Press.
- DeLoach, C. & Greer, B.G. 1981. Adjustment to severe physical disability: a metamorphosis. New York: McGraw-Hill.

- Delventhol, M. 1991. This is my story-this is my song, in: Young Children. 46(September): 16-18.
- Derbyshire, E.J. 1989. Learning disabilities, in: Children with problems: an orthopedagogical perspective, edited by J.A. Kapp. Pretoria: Serva: 445-496.
- Diamond, J.L. & Jaudes, P.K. 1983. Child abuse in a cerebral palsied population. Developmental medicine and child neurology. 25(2): 169-174.
- Donald, D. 1992. Specialised educational needs in education reconstruction: central or peripheral? Address delivered at the Conference on Specialised Education, held by the Department of Education and culture, Directorate: Psychology, guidance and special education, May 1992, 7-9.
- Duminy, P.A. & Steyn, P.D.G. 1983. Education: a course in didactics and method. Cape Town: Maskew Miller Longman.
- Du Plooy, J.L. & Kilian, C.J.G. 1981. Introduction to fundamental pedagogics. Pretoria: HAUM.
- Du Preez, J.N. 1980. The education system of the Transkei. Unpublished M.Ed. dissertation. University of the Orange Free State, Bloemfontein.
- Du Toit, L. 1989. The child with problems, in: Children with problems: an orthopedagogical perspective, edited by J.A. Kapp. Pretoria: Serva:23-34.

- Du Toit, L. 1989a. Orthopedagogical aid, in: Children with problems: an orthopedagogical perspective, edited by J.A. Kapp, Pretoria: Serva: 55-87.
- Eastern Cape Regional Welfare Board. 1982. People as the most important resources in community development. Alice: University of Fort Hare.
- Edge, W.E.B. 1986. Encyclopaedia for child care for Southern Africa: from birth to adolescence. Cape Town: David Phillip.
- Education Affairs Act (House of Assembly), No. 70. 1988. Pretoria: Government Printer.
- Finnie, R.F. 1974. Handling the young cerebral palsied child at home. London: William Heinemann Medical books.
- Gargiulo, R.M. 1985. Working with parents of exceptional children: a guide for professionals. Boston: Houghton Mifflin.
- Glenting, P. 1970. Etiology of congenital spastic cerebral palsy. Kobenhavn: F.A.D.L.S. Forlag.
- Grabe, R.P. 1985. Cerebral palsy, in: The South African Journal of Continuing Medical Education. 3(8): 115-123.
- Griffiths, M. & Russell, P.C. (eds). 1985. Working together with handicapped children, guidelines for parents and professionals. London: Souvernir.

- Gunter, C.F.G. 1978. Aspects of educational theory. Stellenbosch: University Publishers & Booksellers.
- Harmse, H.J. & Kirsten, P.P. 1979. Pedagogiek deel 1. Durban : Butterworths.
- Harris, P. & Mawdsley, C. (eds) 1974. Epilepsy. Proceedings of the Haus Berger Centenary Symposium. (1974:135).
- Haskell, S. 1964. Some speculation on the effects of sensory deprivation upon cerebral palsied infants and adults, in: Learning problems of the cerebrally palsied. Report of the Study Group. London: The Spastics Society: 51-56.
- Hegeman, M.T. 1984. Developmental disability, a family challenge. New York: Paulist Press Ramsey.
- Heward, W.L. & Orlansky, M.D. 1980. Exceptional children. Columbus, Ohio: Merrill:
- Hewett, S., Newson, J. & Newson, E. 1970. The family and the handicapped child. London: Allen & Unwin.
- Hildebrand, V. 1981. Parenting and teaching young children. New York: Webster/ McGraw-Hill.
- Hilt, N.E. & Cogburn, S.B. 1980. Manual of orthopedics. St. Louis: C.V. Mosby Company.
- Human Sciences Research Council. 1981. The Report of the Work Committee. No. 8. Education for children with special educational needs. Pretoria:HERC.

- Human Sciences Research Council. 1987. The Report of the Work Committee. No. 10. Education for the black disabled. Pretoria: HSRC.
- Ingalls, R.P. 1978. Mental retardation: the changing outlook. New York: John Wiley & Sons.
- Jelliffe, D.B. 1985. Child health in the tropics. London: Edward Arnold.
- Kapp, J.A. 1989. The education of the handicapped child, in: Children with problems, an orthopedagogical perspective, edited by J.A. Kapp. Pretoria: Serva:541-559.
- Katiya, N. 1973. The development of Bantu rural secondary education in Ciskei, 1949-1968. A History survey. Alice: University of Fort Hare.
- Keats, S. 1965. Cerebral palsy. Springfield: Charles C. Thomas.
- Kephart, N.C. 1971. The slow learner in the classroom. 2nd edition. Columbus, Ohio: Charles E. Merrill.
- Kretch, D. & Crutchfield, R.S. 1960. Elements of psychology. New York: Alfred A. Knopf.
- Lamla, C.M. 1975. Present-day diviners (amagqira) in the Transkei. Unpublished M.A. dissertation. University of Fort Hare, Alice.
- Lamont, R.F. 1982. Drugs in pregnancy and neonatal jaundice, in: Drugs in pregnancy: human teratogenesis and related problems, edited by D.F. Hawkins. New York: Longman Group:185-191.

- Laird, C. 1974. Websters' New World Thesaurus. New York: Warmer Books.
- Lansdown, R. 1980. More than sympathy. London: Tavistock Publishers.
- Leary, M. S.a. Understanding epilepsy in childhood. Cape Town: University of Cape Town.
- Lerner, J. Mardell Czudnowski, C. & Goldenberg, D. 1987. Special education for early childhood years. Englewood Cliffs, New Jersey: Prentice-Hall.
- Lessel, S. & Van Dalen, J.T.W. 1988. Neuro-ophthalmology. Chicago: Year Book Medical Publishers.
- Levitas, B. 1983. Ethnology: an introduction to the peoples and cultures of Southern Africa. Cape Town: Oxford University Press.
- Levitz A. 1982. The significance of a team approach in the educational milieu of the hearing impaired child. Unpublished M.Ed. dissertation. University of Pretoria, Pretoria.
- Levitz A. 1991. A parent guidance programme for the education of deaf children. Unpublished D.Ed. thesis. University of South Africa, Pretoria.
- Livneh, H. 1982. On the origins of negative attitudes toward people with disabilities. Rehabilitation Literature, 43(November-December): 338-347.
- Low, N.L. & Carter, S. 1987. Static encephalopathies, in: Pediatrics, edited by A.M. Rudolf, J. Hoffman. Connecticut: Prentice-Hall.

- Lowenfeld, B. 1971. Our blind children, growing and learning with them. Springfield, Illinois: Charles C. Thomas.
- McAnaney, K.D. 1989. Single parenting. Exceptional parent. 19(July-August): 28-33.
- McDonald, E.T. & Chance, B. 1964. Cerebral palsy. Englewood Cliffs, New Jersey: Prentice-Hall.
- McFadyen, I.R. 1985. Smoking, in: Progress in obstetrics and gynaecology. edited by J. Studd. Edinburg: Longman group: 62.
- Mpungu, J.D. 1988. Investment opportunities in Transkei. Umtata: University of Transkei.
- Muller, C.F.J. 1977. Five hundred years. A history of South Africa. Pretoria: University of South Africa.
- Murphy, A.T. 1979. The families of handicapped children. The Volta Review. 81(5): 265-278.
- Mwamwenda, T.S. 1989. Educational psychology: an African perspective. Durban: Butterworths.
- Mwamwenda, T.S. 1995. Educational psychology: an African perspective. 2nd edition. Durban: Butterworths.
- Naidoo, A. 1993. Rehabilitation International Congress seminar/feedback. Decade of disabled persons. A strategy for the future. Disability: awareness in action. Durban: Spes Nova School.

- National Cerebral Palsy Division of the National Council for the care of Cripples in South Africa. S.a. Cerebral palsy. Johannesburg: National Cerebral Palsy Division.
- National Council for the Care of Cripples in South Africa. 1973. Information pamphlet of the National Cerebral Palsy Division. Johannesburg.
- Ngubentombi, S.V.S. 1977. Critical analysis of the policies underlying education development in the Transkei. Unpublished M.Ed. dissertation. University of Fort Hare, Alice.
- Ngubentombi, S.V.S. 1984. Teacher education in Transkei. A critical and comparative study of the evolution of selected aspects of its administration, curricular and course structures as an indicator of future policy and planning in the provision of teachers. Unpublished D.Ed. thesis. University of Natal, Pietermaritzburg.
- Pauw, B.A. 1973. The second generation: a study of the family among the urbanised Bantu in East London. 2nd edition. Cape Town: Oxford University Press.
- Pauw, B.A. 1975. Christianity and Xhosa tradition. Cape Town: Oxford University Press.
- Peterson, N.L. 1987. Early intervention for handicapped children and at-risk-children. Denver: Love Publishing Company.

- Poonsamy, P. 1984. An investigation into attempts made by various institutions in Athlone in educating the cerebral palsied child with special reference to the Eros Cerebral Palsy School. Unpublished M.Ed. dissertation. University of the Western Cape, Cape Town.
- Powell, M. 1986. Orthopaedic nursing and rehabilitation. 9th edition. Edinburg: Churchill Livingstone.
- Republic of Transkei. 1985. Annual Report on Education. Umtata: Government Printer.
- Republic of Transkei. 1992. Annua Report on Education. Umtata: Government Printer.
- Riccardi, V.M. 1977. The genetic approach to human diseases. New York: Oxford University Press.
- Robinson, A. 1980. Principles and practices of teaching. London: George Allen & Unwin.
- Robinson, H.B. & Robinson, N.M. 1976. The mentally retarded child: a psychological approach. 2nd edition. New York: McGraw-Hill.
- Ross, A.O. 1972. The exceptional child in the family. helping parents of exceptional children. New York: Grune & Stratton.
- Rudolf, A.H. & Hoffman, J. 1987. Pediatrics. Connecticut: Prentice-Hall.
- Samilson, R.L. (ed.) 1975. Orthopaedic aspects of cerebral palsy. London: William Heinemann Medical Books.

- Sarkin, T.L. 1989. Seven paths to orthopaedics. Cape Town: Maskew Miller.
- Schell, G.C. 1981. The young handicapped child: a family perspective. Topics in early childhood - special education, 1(3 October):21-27.
- Scherzer, A.L. & Tscharnuter, I. 1982. Early diagnosis and therapy in cerebral palsy. New York: Marcel Dekker.
- Schreir, A.R. 1991. Illness from the parent and child perspective, in: Child health for all: a manual for Southern Africa, edited by M.A. Kibel & L.A. Wagstaff. Cape Town: Oxford University Press.
- Seifert, K. 1983. Educational psychology. Boston: Houghton Mifflin Company.
- Sieffert, A. 1978. Parents' initial reactions to having a mentally retarded child: a concept and model for social workers, in: Clinical Social Work Journal, 6(1):33-43.
- Selfde, L. & Stow, L. 1981. Children with handicaps. London: Hodder & Stoughton.
- Seligman, M. 1979. Strategies for helping parents of exceptional children. London: The Free Press.
- Shaffer, D.R. 1985. Developmental psychology: theory, research and applications. Monterey, California: Brooks/Cole Publishing Company.

- Shea, T.M. & Bauer, A.M. 1985. Parents and teachers of exceptional students: a handbook for involvement. Boston: Allen & Bacon.
- Sillipp, C.A. 1985. Assessment and remediation on mental retarded cerebral palsied children based on an age-norm development scale. Unpublished M.Ed. dissertation. Rand Afrikaans University, Johannesburg.
- Sillipp, C.A. 1987. Interaction patterns in families having a child with cerebral palsy or specific learning disabilities. Unpublished D. Lit. & Phil. thesis. University of South Africa, Pretoria.
- Smith, R.M., Neisworth, J.T. & Hunt, F.M. 1983. The exceptional child: a functional approach. 2nd edition. New York: McGraw-Hill.
- Soga, T.B. 1974. Intlalo ka Xhosa. Alice: Lovedale Press.
- Sohn, F.A. 1985. Education reforms to accelerate black economic advance. Address delivered on the occasion of NAFCOC'S 21st Annual Congress at Sun City. 7th August. Mabatho: NAFCOC.
- Stanfield, W.D. 1983. Schaum's outline series of theory and problems of genetics. 2nd edition. New York: McGraw-Hill.
- Stocker, J.T. & Dehner, L.P. 1992. Pediatric pathology. Chicago: Year Book Medical Publishers.

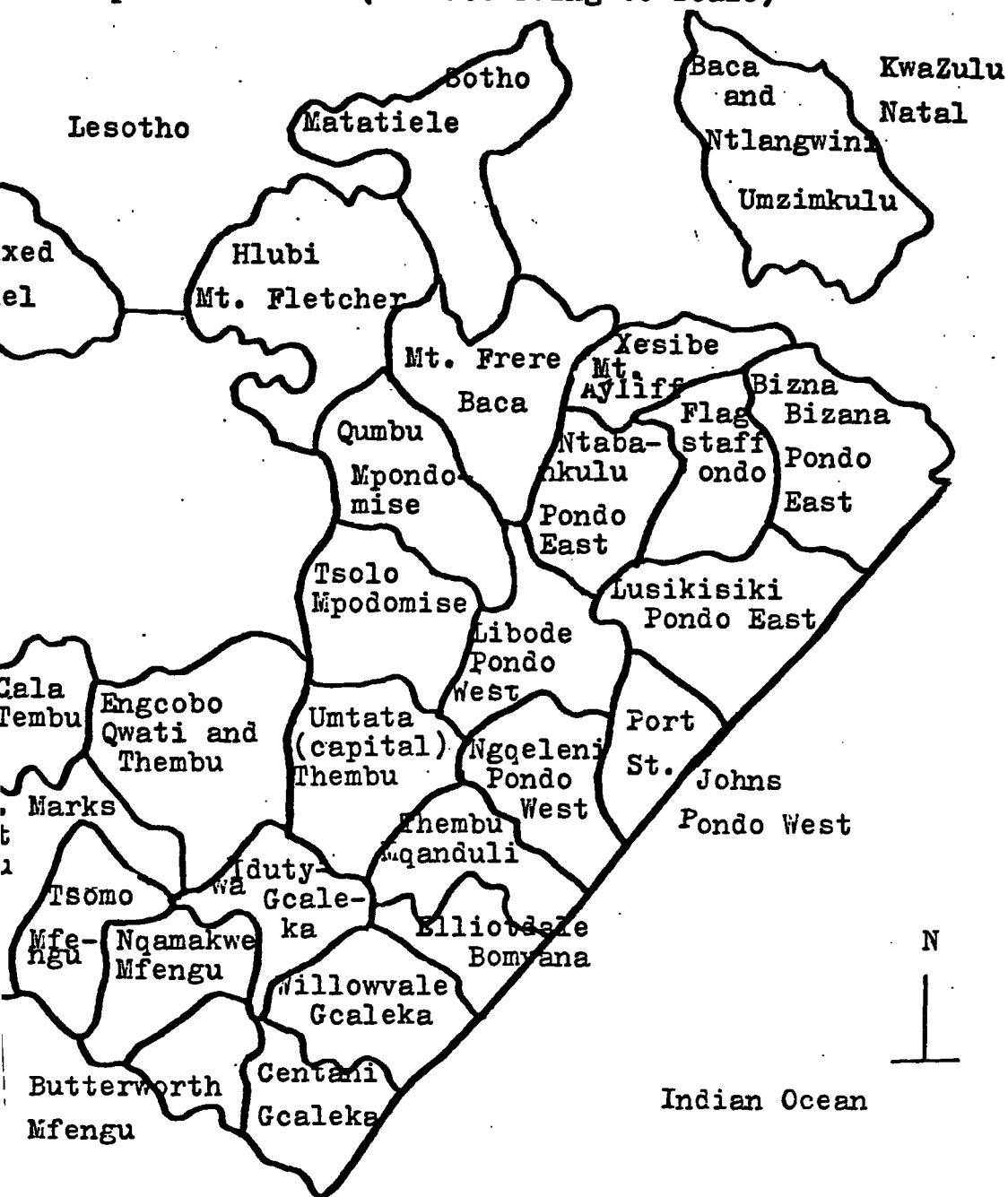
- Stuart, J.F., Van Niekerk, L.J., McDonald, M.E.W. & De Klerk, D. 1987. Didactics, an orientation for first year students. Johannesburg: Southern Book Publishers.
- Tacke, M.J. 1989. A study of University of Transkei students' perceptions of the handicapped. Diploma in Adult Education. University of Transkei, Umtata.
- Telford, C.W. & Sawrey, J.M. 1967. The exceptional individual: psychological and educational aspects. New Jersey: Prentice-Hall.
- Tizard, J. 1974. Mental retardation: concepts of education and research. London: Oxford University Press.
- Transkei Education Act. National Assembly. 1977. Debates of the National Assembly. Umtata: Government Printer.
- Transkei Education Act. No. 35. 1986. Umtata: Government Printer.
- Trout, M.D. 1983. Birth of a sick or handicapped infant: impact on the family. Child Welfare League of America. LX11 (4 July-August): 337-341.
- Turnbull, A.P. & Turnbull, H.R. 1986. Families, professionals and exceptionality, a special partnership. Ohio: Merrill.

- Urbani, G. 1980. Die belewensproblematiek rondom kinders met genetiese gestremdhede. RGN verslag 0-109. Pretoria: RGN.
- Urdang, L. 1991. The Oxford Thesaurus. London: Clarendon Press.
- Van der Merwe, J.M. 1989. Ouerbetrokkenheid in die onderwys van verstandelik erg gestremde kinders. Ongepubliseerde M.Ed. verhandeling. Universiteit van Suid Afrika, Pretoria.
- Van der Vliet, V. 1974. Growing up in traditional society, in: The Bantu speaking peoples of Southern Africa. edited by W.D Hammond-Tooke. London: Routledge & Kegan Paul: 211-245.
- Van Niekerk, P.A. 1982. The teacher and the child in educational distress. Stellenbosch/Grahamstown: University Publishers and Booksellers.
- Van Rensburg, C.J.J. & Landman, W.A. 1988. Notes on fundamental pedagogics contents - an introduction and orientation. Pretoria: NG Kerkboekhandel.
- Van Zyl, P. 1973. Opvoedkunde. Deel 1. Johannesburg: De Jong.
- Verwey, C.T. 1979. The economic activity and level of education of the Xhosa with special reference to the Transkei. Bloemfontein: University of the Orange Free State.
- Viljoen, T.A. & Pienaar, J.J. 1971. Fundamental pedagogics. Durban: Butterworths.

- Wallis, J. 1989. This is Transkei. Umtata: Marketing Division TDC.
- Walshe, F. & Walshe, J. 1970. Diseases of the nervous system. Baltimore : The Williams & Williams Company.
- Williams, P. 1989. Family problems. London Oxford University Press.
- Wood, P.C. & Van Schoor, A.M. 1976. The agricultural potential in the Transkei. Pretoria: Department of Bantu Administration and development.
- Wright, B.A. 1960. Physical disability: a psychological approach. New York: Harper & Row.

Appendix A

Map of Transkei (not according to scale)



- 1: Shows the Transkei the country that was selected for the study. The Transkei is in the Eastern Cape Province and is bounded by Lesotho, KwaZulu/Natal, the India Ocean and South Africa. In the centre is Umtata where the main study was conducted. The map also shows the three main units that formed the former Transkei, various districts and tribes.

APPENDIX B

INTERVIEW SCHEDULE

6.5.1 A. Background information

1. What is your

i) age?

- 24 years
- 25 to 35 years
- 36 to 45 years
- 46 to 55 years
- 56 to 65 years
- 66 to 75 years
- 76 to 85 years

ii) standard passed?

- Never attended school
- Sub A to Std 3
- Std 4 to Std 8
- Std 9 to Std 10
- Tertiary education

iii) Occupation

- Unemployed
- Self-employed
- Shop assitant
- Clerk
- Bus driver
- Other careers

2. Are you living together with your husband/wife?

- i) Yes
- ii) No

If no, why not?

- i) Never married
- ii) Widowed
- iii) Husband/wife deserted
- iv) NR

3. Besides the cerebral palsied child how many other children do you have?

- i) None
- ii) One
- iii) Two
- iv) Three
- v) Four
- vi) Five
- vii) Six

Do any of these children suffer from cerebral palsy?

- i) Yes
- ii) No

If so, how many

- i) Boys?
- ii) Girls?

6.5.2 B.

Birth history

4. Did the mother experience problems during pregnancy?

- i) Yes
- ii) No
- iii) NR

5. Was the mother concerned about her pregnancy?

- i) Yes
- ii) No
- iii) NR

If so, why?

- i) Because of car accident during pregnancy
- ii) Owing to taking of drugs
- iii) Owing to haemorrhage during pregnancy
- iv) Because of maternal illnesses
- v) Unknown causes

6. What kind of delivery did the mother have?

- i) Normal vertex/breech delivery
- ii) Caesarean section
- iii) Transverse
- iv) NR

7. Where was the baby delivered?

- i) At home
- ii) Hospital/clinic
- iii) NR

Who help during delivery?

- i) Nobody (the mother was alone)
- ii) Relatives/neighbours
- iii) Medical doctors/nurses at the clinic/hospital
- iv) NR

6.5.3 C. Initial concern

8. When was the disability first noticed?

- i) 0 to 2 months
- ii) 3 to 5 months
- iii) 6 to 8 months
- iv) 9 to 11 months
- v) 12 to 14 months
- vi) 15 to 24 months

8a) How was the disability acquired?

- i) Prenatal factors
- ii) Perinatal factors
- iii) Postnatal factors

8b) How did you feel about it?

- i) Worried
- ii) Sad and depressed
- iii) Shocked

9. Did your husband/wife also noticed that something was wrong?

- i) Yes
- ii) No

10. After noticing that something was wrong with the child to whom did you take the child?
- i) Medical doctors
 - ii) Medical and tribal doctors
 - iii) Tribal doctors
 - iv) Social workers
 - v) Nurses
 - vi) School staff
11. Who explained the child's disability to you?
- i) Medical doctors
 - ii) Tribal doctors
 - iii) Social workers
 - iv) Nurses
 - v) School staff
 - vi) Neighbours
 - vii) Nobody
12. When were you informed about the child's disability?
- i) During consultation
 - ii) After child's assessment by school staff
 - iii) Never informed
13. What were you told concerning the cause of your child's disability?
- i) Caused by maternal illnesses
 - ii) Caesarean section
 - iii) Forceps
 - iv) Anoxia
 - v) Bewitched/anger of the ancestors

- vi) Prolonged labour
- vii) Prematurity
- viii) Accident

14. How did you feel when you were told about the cause of the child's disability?

- i) Hurt
- ii) Angry
- iii) Guilty/self blame
- iv) Blamed others
- v) Increased sorrow
- vi) Confused
- vii) Acceptance

15. Did your husband/wife accept what you were told?

- i) Yes
- ii) No

6.5.4 D. Developmental activities

16. What are your views, in teaching the child to:

dress

- i) Difficult
- ii) Not difficult

wash

- i) Difficult
- ii) Not difficult

feed

- i) Difficult
- ii) Not difficult

17. Did your husband/wife help you in the training of the child in these activities?

- i) Yes
- ii) No

If not, why not?

- i) Working in South Africa
- ii) Working in a rural shop
- iii) Deserted by him/her
- iv) He regarded the training of the child as the function of a wife
- v) Owing to his/her illness
- vi) Widowed
- vii) NR

18. Did your other children help in taking care of the child?

- i) Yes
- ii) No

19. How did they feel about having a brother/sister with a disability?

- i) Accepted him/her for they never complain about his/her disability
- ii) Reacted negatively towards him/her

20. What are your views about disciplining the child with a disability?

- i) Should receive lenient treatment
- ii) Should be disciplined like other children in the family

6.5.5 E.

Information about cerebral palsy

21. Were you ever told about:

Causes of cerebral palsy?

- i) Yes
- ii) No

Results of cerebral palsy?

- i) Yes
- ii) No

Sub-types of cerebral palsy?

- i) Yes
- ii) No

The degree of the child's disability?

- i) Yes
- ii) No

Other associated disabilities?

- i) Yes
- ii) No

The physical and medical treatment of the child?

- i) Yes
- ii) No

How cerebral palsy may be prevented?

- i) Yes
- ii) No

22. Who informed you?

- i) Doctors
- ii) Nurses
- iii) Social workers
- iv) School staff
- v) Nobody

23. When were you informed?

- i) During consultation
- ii) After consultation
- iii) When the child was accepted at the special school
- iv) Never informed

24. How did you feel when you eventually found out your child had cerebral palsy?

- i) Hurt
- ii) Angry
- iii) Sad
- iv) Guilty
- v) Blamed others

25. Despite what other people told you, what do you think is the possible cause of your child's disability?
- i) Caesarean section
 - ii) Forceps
 - iii) Anoxia
 - iv) Drugs
 - v) Haemorrhage
 - vi) Accident
 - vii) Prolonged labour
 - viii) Heredity
 - ix) Witchcraft and anger of the ancestors

6.5.6 F. Family relationships

26. Do you think the cerebral palsied child causes financial problems in the family?
- i) Yes
 - ii) No
27. Do you think the child's disability is affecting your marriage?
- i) Yes
 - ii) No
28. Is the cerebral palsied child happy in the family?
- i) Yes
 - ii) No

Explain your answer. The child

- i) is liked by all family members and feels accepted
- ii) often cries and is not happy
- iii) is happy and helpful

29. Do you think the cerebral palsied child fits in your family?

- i) Yes
- ii) No

Explain your answer. The child

- i) is accepted
- ii) not accepted

6.5.7 G.

Community relationships

30. In spite of having a cerebral palsied child are you able to take part in community activities?

- i) Yes
- ii) No

31. Do you think other people accept your child?

- i) Yes
- ii) No

Explain your answer

- i) Neighbours and relatives visit and inquire after the child

- ii) All people in the locality are interested in the family
- iii) Neighbours and other members of the tribe utter hurting remarks

32. Besides neighbours, relatives and members of the community, are there other people who are interested in your family?

- i) Teachers
- ii) Social workers
- iii) Nurses
- iv) Ministers of religion
- v) Red Cross and other philanthropic bodies
- vi) Nobody

33. Do you ever take the child along when going for shopping or visiting?

- i) Yes
- ii) No

6.5.8 H. School life of the cerebral palsied child

34. Who took care of the child before it started attending school?

- i) Biological mother
- ii) Biological mother and the family helper
- iii) Grandmother
- iv) Step-father/step-mother
- v) One of the siblings

35. To which school did you initially send the child?
- i) Mainstream of education
 - ii) Special school
36. When did the child go to a special school?
- i) 3 to 5 years
 - ii) 6 to 8 years
 - iii) 9 to 10 years
37. Why was the child sent to a special school?
- i) Complaints of teachers in the mainstream of education about the slow progress and the hampering of progress of other children in class
 - ii) Referred to a special school
 - iii) Told by other people about the special school
38. How do you feel about:
- special school
- i) Satisfied
 - ii) Dissatisfied
- teaching
- i) Satisfied
 - ii) Dissatisfied

therapy

- i) Satisfied
- ii) Dissatisfied

parents' meetings at school

- i) Satisfied
- ii) Dissatisfied

39. Do you think teachers like your child?

- i) Yes
- ii) No

40. How often do you visit the school?

- i) 1 to 2 times a month
- ii) More than twice a month
- iii) Never visit

41. How do you foresee the future of your child?

- i) He/she will be a clerk
- ii) He/she will be a social worker
- iii) He/she will never be educated and never be independent
- ix) I cannot envisage the type of life he/she will lead

6.5.9 I.

Additional information

42. Do you have any suggestions as to what might be included in this study to make the researcher understand your situation better?