

***THE LIFE-WORLD OF INDIAN PARENTS' WITH A
DOWN'S SYNDROME CHILD***

by

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DECLARATION

" I declare that this dissertation '*The life-world of Indian Parents' with a Down's syndrome child*' represents my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references".

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DEDICATION

**This dissertation is dedicated to my parents who exemplify the belief
that with knowledge comes wisdom**

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APPENDIX A Questionnaire

SUMMARY

The aim of this investigation was to examine the life-world of Indian parents' with a Down's syndrome child.

Down's syndrome is the most commonly occurring form of mental retardation that is known to be caused by a genetic defect. It is also known as Mongolism because of the Eastern (Mongoloid) slant of the eyes or as Trisomy - 21 because it is caused by the presence of an extra (third) chromosome on the twenty-first pair of chromosomes. Although a Down's syndrome child can result from any pregnancy the incidence thereof increases with the age of the mother - the older the mother the higher the risk. One out of every 640 babies born has Down's syndrome.

The Down's syndrome child's experience of his impairment was described in terms of his relationship with himself, others, objects and ideas, and God. Meaningful and active acceptance of his impairment by the child seems to be possible if parents unconditionally accept the child and share his experiences by rendering sustained and responsible assistance and support.

Parents of Down's syndrome children experience their parenthood in a different way from the parents of normal children for the simple reason that they are parents of children with special needs. Their initial reaction after discovering the child has Down's syndrome is shock and disbelief followed by anger, disappointment, denial and often guilt feelings. In general, parents with disabled children are unable to accept and/or assimilate in a responsible way their unusual experience of parenthood without professional support. Parents need adequate support right from the very birth of a disabled child.

For the purpose of the empirical investigation a self-structured questionnaire was utilized. An analysis was done of the questionnaires completed by the parents of Down's syndrome children in the Durban area. The data thus obtained was processed and interpreted by means of descriptive statistics.

In conclusion, a summary and findings emanating from the literature study, and the descriptive statistics were presented. Based on these findings, the following recommendations were made:

- Genetic services of the Department of Health must be made better known and more available to the general public.
- From the initial diagnosis of a Down's syndrome child support should be rendered to the parents to meet the special needs brought about by a disabled child.
- Existing information concerning the care and education of Down's syndrome children must be utilised in the compiling of counselling programs for parents.

OPSOMMING

Hierdie ondersoek was daarop gerig om die leefwêreld van Indiër ouers wat kinders met Down se sindroom het, te ondersoek.

Down se sindroom is een van die bekendste vorme van verstandelike gestremdheid. Dit staan ook bekend as Mongolisme as gevolg van die Oosterse (Mongoolse) trek om die oë of as Trisomie - 21 omdat dit veroorsaak word deur die aanwesigheid van 'n derde 21ste chromosoom. Alhoewel enige vrou geboorte kan gee aan 'n kind met Down se sindroom hou dit direkte verband met die moeder se ouderdom - hoe ouer die moeder hoe groter word die moontlikheid van Down se sindroom. Een uit elke 640 babas word met Down se sindroom gebore.

Die kind met Down se sindroom se belewing van sy gestremdheid is beskryf aan die hand van sy verhouding met homself, met ander, met dinge en idees, en met God. Dit blyk dat die sinvolle en aktiewe aanvaarding van sy gestremdheid deur die kind wel moontlik is indien die ouers tot die kind se beleweniswêreld toetree en volgehoue verantwoordbare hulp en steun aan die kind verleen.

Ouers van kinders met Down se sindroom beleef hulle ouerskap anders as dié van ouers met normale kinders omrede hulle die ouers is van kinders met spesiale behoeftes. Meeste ouers reageer met skok en ongeloof op die nuus dat hulle kind met Down se sindroom gebore is. Hierna volg gewoonlik gevoelens van woede, teleurstelling en selfs ontkenning. Ouers van gestremde kinders kan oor die algemeen nie die belewing van hulle ouerskap sonder die hulp van ander met verantwoordelikheid verwerk en/of aanvaar nie. Dié ouers het reeds vanaf die geboorte van die gestremde kind behoefte aan ondersteuning.

In die empiriese ondersoek is van 'n selfgestruktureerde vraelys as meetinstrument gebruik gemaak. Die vraelys is deur die ouers van kinders met Down se sindroom voltooi. 'n Ontleding is van die voltooide vraelyste gedoen en die gegewens wat daaruit verkry is, is verwerk en geïnterpreteer aan die hand van beskrywende statistiek.

Ten slotte is 'n opsomming en sekere bevindings voortspruitend uit die literatuurstudie en die beskrywende statistiek aangebied. Na aanleiding van hierdie bevindings is die volgende aanbevelings gemaak:

- Genetiese dienste van die Departement Gesondheid moet beter bekendgestel word.
- Ondersteuning moet reeds vanaf die eerste diagnose van Down se sindroom aan die ouers gegee word ten einde die anderse behoeftes van ouers met 'n gestremde kind te ontmoet.
- Bestaande inligting rakende die versorging en opvoeding van kinders met Down se sindroom moet deur kundiges aangewend word om ondersteuningsprogramme te ontwerp vir ouers met dié gestremde kinders.

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CHAPTER 1

ORIENTATION

1.1 INTRODUCTION

It is commonly recognised that disability results from physical, environmental or biological factors which prevents an individual from functioning effectively without specialist intervention or modification of the environment (Mitchell & Brown, 1991:1). No one is immune to birth defects, yet not everyone is equally susceptible. Specific defects occur in varying proportions in different national, racial, religious and socio-economic groups. Each group has a unique set of values, meanings and life-style that constitute its culture and is learned by individual members of the group from the time they are young. Values toward disability are learned in the same way as other aspects of a culture (Bondo, 1980:23). An understanding of the meanings and values attached to birth defects in any given group, then becomes important in understanding the effects of a birth defect on the individual (Darling & Darling, 1982:1). Indian parents will therefore experience their disabled child differently to parents of other cultures.

The crisis of giving birth to a Down's syndrome child makes the life-world of the parent different from those of other parents. Suran and Rizzo (1989:403) say that learning that one's child is "not normal" is a lonely experience - having such a child tends to thrust the parents outside the mainstream of help, comfort and advice. Uncommon problems cannot be shared with next-door neighbours and friends and relatives feel, and often are, ill qualified to advise or assist. The usual sources of professional help may seem inappropriate and parents may feel some alienation from the "normal" lives others appear to

live. Seligman and Darling (1989:6) state that when a disabled child is born the family also has to confront its beliefs about people who have disabilities.

Parents play a vital role in caring for and rearing their children - even more so if it is a child with Down's syndrome. Parents react differently to their child's impairment. Gallagher (1989: 163) says some parents will accept the impairment more easily than others and will carry out the task of caring for the child more cheerfully and with greater devotion. However, others will feel isolated and distressed and may experience chronic sorrow. Steenkamp and Steenkamp (1992:12) state that there is no typical reaction to the birth of a disabled child. The extent of acceptance is determined by the parent's disposition, temperament, values, faith and even intelligence. The higher the intelligence of the parent, the wider the gap will be between their expectations and the child's potential, and the sharper the contrast between the disabled child and normal children. Their disappointment will be greater, but the possibility of a more realistic acceptance and approach will also be correspondingly greater.

When the disability is not very severe there is a moderate adjustment to the life-style of the family. More severe cases of Down's syndrome, however, demand greater adjustment and responsibility which places a heavier burden on the parents. The changes parents make will depend on how they perceive the condition and their understanding of what is wrong with the child (Shepperdson, 1988:68; Thomas, 1982:45). Without the active involvement of parents the developmental progress made by disabled children will be greatly reduced (Mitchell & Brown, 1991:206).

1.2 ANALYSIS OF THE PROBLEM

Most parents look forward to the birth of their baby and with happy anticipation. Suran and Rizzo (1989:399) say that while awaiting the birth of a child, prospective parents experience a wide range of emotions. In most cases there is eager anticipation and excitement as parents plan for the child's birth. Although some parents may have fears about the health of their unborn child, these fears are generally neutralised by friend, relatives and physicians (Darling & Darling, 1982:112). When the baby is born with a defect that is immediately apparent to the delivery room staff, as in the case of Down's syndrome, parents experience feelings of shock, powerlessness and sadness. Macheith (Freude, 1991:121) states that the birth of a Down's syndrome baby is likely to invoke feelings of reproductive inadequacy.

Babies are normally shown off with pride and parents seek to identify with the infant, to claim it by pointing to a particular parental feature in the baby's appearance (Kauffman & Hallahan, 1981:23). Parents are also congratulated and a big fuss is made with producing a fine baby. Therefore, to give birth to a baby that is "not normal", is to "fail", and many parents faced with such a misfortune experience a sense of failure and humiliation (Gallagher, 1989:400).

The first need of parents when they are told that they have a child with Down's syndrome, is to come to terms with the diagnosis (Lynch & Stalock, 1988:78). For some parents the decision will be whether or not to take the baby home while for others whether to pursue active medical treatment for any life threatening conditions. All parents, however, have to begin the process of constructing a framework in understanding what the diagnosis means for the child, themselves and the family. There is generally no

framework to help them anticipate the immediate and long term consequences of the diagnosis. This creates uncertainty about how they will cope, what they should do and how to make sense of what is happening (Glenn, 1985:347; Tulani & Power, 1993:948).

Parents differ in their ability to stand up to stress and the capacity to engage in various coping strategies. Freude (1991:103-105) states that parents differ in how they judge their problems and in their ability and willingness to think constructively about how they will contend with practical demands. Some concern themselves mainly with immediate matters, where as others focus on the longer-term future for the child and the family. Some parents persist in denying the extent of the problem they face. There are also parents who insist unrealistically that there has been a mistaken diagnosis or that the child will "grow out of is" and develop normally. Selikowitz (1990:20) says that some parents actively resist adjustment to the situation, and vigorously maintain their anguish, refusing to acknowledge that life may yet prove to be bearable. They are reluctant to "make the best" of the situation and appear to feel that accepting the Down's syndrome child, would be to submit too easily to a monstrous rage. They are loath to resign themselves to what they may view as a life sentence of hardship, distress and disappointment (Nadler, Lewinstein & Rahav, 1991: 21).

According to Op't Hof (1985:9,15) parents withdraw from society and social life as a form of protest and self-pity or in order to avoid "disgrace". Situations where the child may be compared to other children are avoided. Research has shown that disabled persons are viewed negatively by the general public (Seligman and Darling, 1989:91). Data regarding marital dissatisfaction and divorce in families with disabled children are contradictory. Schippers (Seligman & Darling, 1989:94) has found that a large number of

marriages are under stress because of the presence of a disabled child, parents are unable to cope - a number of marriages simply fails. In families who had serious personal and/or financial problems prior to the birth of their Down's syndrome child, the child often becomes "the last straw that broke the camels back". Gallagher (1983:11-12) regards it as a myth that a Down's syndrome child, or any child for that matter, can bring a troubled marriage together.

Wyne and O'Conner (1982:408) say that along with the mental stress of coping with a Down's syndrome child are likely to come various practical problems which creates additional stress. If local resources are inadequate for disabled children, mothers are unable to pursue a career since there is a full-time commitment to care for the child. The loss of the mother's income may mean a possible financial strain on the family because in most cases extra money is needed for special food, special equipment, medical care and other necessary professional services. In order to ease the financial hardship fathers may take a second job, leaving the mother even more isolated (Selfe & Stow, 1981:208; Thomas, 1982:102).

1.3 STATEMENT OF THE PROBLEM

The problem that will be investigated in this study pertains to the special needs and problems, difficulties, uncertainties, and adjustments that are created for parents, and the family with the birth of a Down's syndrome child. The disabled child has a remarkable influence on the parent's life-world and the normal functioning of the family. Initially parents experience a wide range of emotions - shock, confusion, resentment, rejection, sorrow, powerlessness, etcetera. Therefore, their immediate need will be to begin the process of constructing a framework of understanding and assistance. Parents

with Down's syndrome children experience their parenthood differently from those with normal children because the child has special needs.

The following are questions that require answers in order to assist parents with Down's syndrome children:

- . How do Indian parents experience their Down's syndrome child?
- . What do the parents know about their child's condition and what is essential in this regard?
- . What are the needs of the parents with a Down's syndrome child and how can these needs be adequately met?
- . Is sufficient professional support available to assist Indian parents to cope with the child's disabilities?
- . How does the Down's syndrome child experience his impairment?

1.4 ELUCIDATION OF CONCEPTS

1.4.1 Life-world

According to Van den Aardweg and Van den Aardweg (1988:141) every person lives in his or her own unique life-world. A person's life-world includes everything that has meaning for him or her. Not only the persons geographical world, but all relationships with objects, ideas, people, the self

and God. Vrey (1990:15) says the Gestalt of meaningful relationships constitutes a person's life-world. These relationships may be interdependent and interactive; they are also dynamic and ever increasing and changing. A persons behaviour and actions should be interpreted within the context of his or her life-world - all to which a person has attributed significance and therefore understands.

1.4.2 Family

The term "family" implies the smallest most basic unit in society, united by blood relationship, marriage or adoption (Le Roux (ed.), 1992:9). The composition of a family is often determined culturally and can include uncles, aunts and grandparents besides the nuclear family. Van den Aardweg and Van den Aardweg (1988:89) describe the extended family as consisting of more members than just mother, father and siblings. Other members may include grandparents, both maternal and paternal, aunts, uncles, sons-in-law, daughters-in-law and so on. Today in many cultures, also the Indian culture, the extended family is gradually becoming a thing of the past and is replaced by the nuclear family. This is caused largely by social and economic pressures on families and movement to the urban areas.

1.4.3 Impairment

An impairment is a physical or psychological abnormality which is clearly recognizable, such as an amputated or defective limb, or a disease affecting some organ mechanism or system of the body (Davies, 1982:1). According to Suran and Rizo (1988:109) the term disability is a defect in physical make up or functioning that can be specified and described objectively. Davies (1982:1) says the term disability refers to "an interference in function" and is

therefore the commonly used term that indicates what the individual cannot do. It may be absolute, for example blindness, or partial like stiffness and pains in joints following arthritis. Disabilities may be congenital or acquired. From the above it becomes clear that the definitions of "impairment" and "disability" overlap and a clear distinction between the two terms is not possible.

A disability inevitably produces complications in the development of a child, but it is only when these complications *limit* the child's development that we can view the individual as handicapped (Suran & Rizzo, 1989:109). According to Kapp (ed.) (1991:27) a handicap refers to an identifiable deficiency in the child's given potential, such as sensory, neural, intellectual or physical deficiencies.

1.4.4 Chromosomes

Chromosomes are microscopically observable, rod-shaped, dark stained bodies, present in the nucleus of all human body cells and they become more distinct and visible during cell-division. The number of chromosomes for each normal human being is constant, 23 pairs or 46. Chromosomes contain the genes or hereditary factors of the human body (Clarke, 1986:28; Urbani, 1982:6).

1.4.5 Genes

The minute units comprising the chromosomes are called genes. Genes provide the laws or blueprint for the growth and development of the body. They determine the structural characteristics of a person, e.g. height, colour of eyes and hair, etc. (Kapp (ed.), 1991:234). Because each chromosome can

contain thousands of genes that may moreover occur in various combinations, one can imagine the limitless of possibilities. Gillham (1986:28) refers to the genes as the biological units of heredity that are located in a definite position on a particular chromosome.

1.4.6 Down's syndrome

Kapp (ed.) (1991:298) says that Down's syndrome is one of the best-known forms of severe mental handicap. It is also known as Mongolism because of the Eastern (Mongoloid) slant of the individual's eyes, or as Trisomy-21, because it is caused by the presence of an extra (third) 21st chromosome (normally there are only two). This will result in a total number of 47 chromosomes in a cell. There are actually three kinds of Down's syndrome. The three types are identified on the basis of the way in which the additional chromosome originated (Steenkamp & Steenkamp, 1992:131):

- **Trisomy 21** or true Down's syndrome. It is caused by an error during meiosis division of the mother's sex cells and is mostly found in older women. Every cell of the child's body therefore has a complete, additional 21st chromosome.
- **Mosaic-Down's syndrome.** In this case the sex cells were normal but the division error occurred in the early embryonic phase. The child then has both normal and abnormal body cells. The proportion in which the abnormal cells are present, determine the prominence of the Down's syndrome symptoms.
- **Translocation-Down's syndrome.** This is the genetic type. It occurs in cases where either parent or any other ancestor has

had a structural chromosome error which led to a portion of the 21st chromosome adhering to another chromosome. As soon as the additional 21st chromosome appears (i.e. the usual two chromosomes plus the attached piece), Down's syndrome is manifested by the child.

1.5 AIM OF THIS STUDY

The aims of this study are:

- To pursue a study of relevant literature in order to establish the nature of the life-world of the Indian parent with a Down's syndrome child.
- To undertake an empirical investigation into the life-world of the Indian parent with a Down's syndrome child.
- To provide certain recommendations and guidelines so that accountable support can be instituted in order to meet the special needs of parents' with a Down's syndrome child.

1.6 METHOD OF RESEARCH

Research with regard to this study will be conducted as follows:

- A literature study of available, relevant literature.
- An empirical survey comprising a structured questionnaire to be completed by Indian parents.
- Informal interviews with the parents of Down's syndrome children and professionals in this field.

1.7 FURTHER COURSE OF THE STUDY

Chapter 2 will deal with the incidence , clinical features, problems and development of Down's syndrome children.

The Down's syndrome child's experience of his impairment will be the topic of discussion in Chapter 3

Chapter 4 will focus on the parents' experience of their child with Down's syndrome.

In chapter 5 the planning of the research will be outlined.

The research data will be analyzed and interpreted in chapter 6

Chapter 7 will comprise of a summary and certain relevant recommendations.

CHAPTER 2

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CHAPTER 2

THE CHILD WITH DOWN'S SYNDROME

2.1 INTRODUCTION

Down's syndrome is the most commonly occurring form of mental retardation that is known to be due to a genetic defect. On average, one child in every 640 live births has Down's syndrome (Byrne & Cunningham, 1988:9). The condition can occur in any family, however, for young mothers the risk of having a child born with Down's syndrome is rather small, but increases with the age of the mother. The unusual patterning of physical characteristics that typifies children with Down's syndrome makes these children easily identifiable (Kapp (ed.), 1991:298). Although few of these children have *all* the characteristics typical of this syndrome, the following features are common: slanting of the eyes; speckling of the iris of the eye; abnormally thick eyelids; flat, broad face and nose; thickened tongue; short, broad neck; stubby fingers. The number of physical features bears no relationship to the degree of retardation in the child (Selikowitz, 1990:26). The range of mental retardation in Down's syndrome varies, but research has shown that the majority of these children are in the moderately retarded range (Gillham, 1986:5).

According to Gunn (1993:1) evidence of Down's syndrome dates back to the artifacts of the Olmecs in ancient Mexico, although the first detailed and systematic description of the syndrome by doctor Langdon Down, came much later, in 1866. He, however, did not understand the cause of the condition and referred to it as "mongolian idiocy". He assumed that the condition was a reversion to a primitive Mongolian ethnic race. His son Reginald, also a

doctor, repudiated this diagnosis. In 1932 research findings by De Waardenburg indicated that Down's syndrome might be caused by chromosomal abnormality. This was confirmed in 1959, ninety-three years after Down's original description of the syndrome, when Lejeune, Gautier and Turpin (Matson & Mulick, 1983:23) demonstrated that Down's syndrome was associated with an extra chromosome. This was confirmed in the same year (1959) by Ford (Edelstein, 1984:5) and today chromosome counts are standard practice for the identification of diagnosis of Down's syndrome.

In this chapter a brief explanation of the genetic background and incidence of Down's syndrome will be given, followed by a more detailed description of the three different types of Down's syndrome. The clinical features and problems associated with the syndrome will be discussed and the development of the child with Down's syndrome will be examined.

2.2 TYPES OF DOWN'S SYNDROME

2.2.1 Genetic background

The principal mechanisms of heredity are chromosomes and genes. Chromosomes are not the actual determiners of traits. Along the length of chromosomes exist about 20, 000 genes which are the determiners of traits. These gene-carrying chromosomes from the mother's and the father's side of the family unite to determine physical, and - to a much less understood extent - behavioural traits (Wyne & O'Connor, 1982:364). At the moment of conception both the sperm cell (male) and the egg cell (female) contains 23 chromosomes. A fertilized egg cell contains 46 chromosomes - 23 from the father and 23 from the mother. When the fertilized egg cell divides to form new cells, each of the new cells contains 46 chromosomes which is an exact

duplicate of the original cell. This process of cell division, called mitosis, is repeated over and over again as the fertilized egg cell grows and develops into a new human being (Gallagher, 1989:129).

In relative rare cases, and for reasons not totally understood by scientists, this process does not always work properly and chromosomal abnormalities occur. Selikowitz (1990:33) avers that sometimes chromosomes are damaged - broken or muddled in some way - so that from conception the biological programme for building the cells of the human body are faulty. Chromosome abnormality may be inherited, but it can also occur randomly and the risk increases as the mother ages. Chromosomal abnormalities account for a variety of developmental deviations in human beings (Carr, 1985:16).

Down's syndrome is caused by an abnormal chromosomal relationship that alters patterns of growth and development. Normally a person has 46 chromosomes - 23 matching pairs - in every body cell. A child with Down's syndrome typically has an extra chromosome in the twenty-first pair, creating a total of 47 chromosomes (Suran & Rizzo, 1989:218). The twenty-first pair of chromosomes then has 3 instead of 2 (one pair) chromosomes (cf. figure 1).

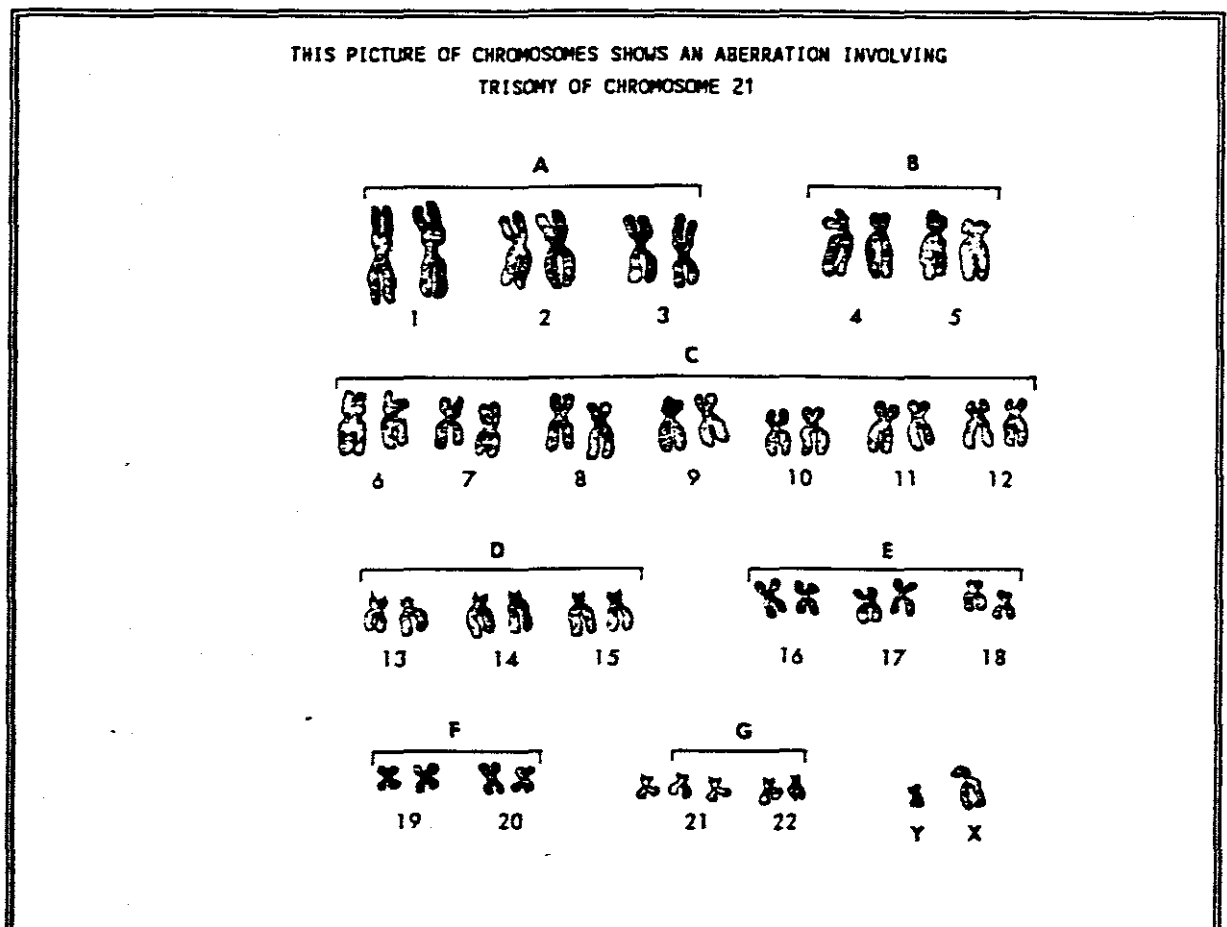
The development of a new diagnostic technique, amniocentesis, has opened the possibility of detecting chromosomal abnormalities before the birth of a child (Lynch & Stalock, 1988:77). Amniocentesis is a procedure for drawing some of the amniotic fluid from the pregnant women. Since cells from the fetus are found in the fluid, the cells can be analyzed for chromosomal abnormalities by karyotyping (Zaremba, 1985:88). Thus, high risk parents can know early in pregnancy that they will or will not have a disabled child.

All children with Down's syndrome have an extra critical portion of

chromosome 21 in their cells. There are actually three types of Down's syndrome which are identified on the basis of the way in which the additional chromosome has originated (Kapp (ed.), 1991:298). The three types, namely trisomy - 21, translocation and mosaic will be discussed in more detail.

2.2.2 Standard trisomy - 21

Trisomy - 21 (true Down's syndrome) results primarily from a genetic defect in sex cells (egg or sperm) which occurs prior to conception. According to Byrne and Gunn (1993:1) the vast majority of children (95%), with Down's syndrome have a complete, additional 21st chromosome in every cell of their body, and therefore have trisomy - 21 ("tri" means three and "somy" refers to chromosome). Although this chromosomal aberration is genetic, it is not generally hereditary because it results from cell division (meiosis), that in most cases is related to advanced maternal age (Selikowitz, 1990:35).



Trisomy - 21 is also referred to as "meiotic non-disjunction" because when the egg cell or sperm cell is formed during cell division (meiosis) in the sex organs, the chromosomes do not divide evenly - the 21st pair of chromosomes in the original cell does not separate or "disjunct". Normally, when eggs or sperm are formed, a cell in the ovary or testicles divide to form two new cells, each with half (23) the original number (46) of chromosomes (Zaremba, 1985: 27-29). It is from these cells that the eggs or sperm originate. In the case of trisomy this meiotic division is abnormal, and the egg or sperm receives an extra number 21 chromosome. Therefore, an egg or sperm cell may have 24 chromosomes, instead of the normal 23 chromosomes (Gunn, 1993:2). Normally after conception the nucleus of the fertilized egg cell contains 46 chromosomes (23 from the mother and 23 from the father) aligned in pairs (23 pairs). In the case of Down's syndrome the fertilized egg cell will contain 47 chromosomes (24 from the mother and 23 from the father, or vice versa). There is thus an abnormal alignment of the chromosomes with the extra chromosome attaching itself to the 21st pair.

Research has shown that the incidence of Down's syndrome increases significantly in children born to mothers older than 35 years (Gunn, 1993:2). According to current figures, over 50% of Down's syndrome children are born to mothers over 35 (Herman, 1994: 433). It should not be concluded, however, that the mother is the exclusive cause of the extra chromosome. The father contributes the extra chromosome in 20 to 25 percent of known cases (Dyson, 1987:19).

2.2.3 Translocation

Translocation Down's syndrome is also a genetic type but tends to follow the laws of inheritance. It occurs in cases where either parent or any other

ancestor has or had a *structural chromosome error* (Cunningham, 1982:76). Structural abnormalities occur when there are deviations in the chemical structure of one of the chromosomes, for example, a piece of a chromosome could break off and then be attached to the same or to another chromosome. This process of one chromosome sticking on to another is called translocation (Kapp (ed.), 1991:298). Down's syndrome is manifested when the small top portion of chromosome 21, and another chromosome breaks off, and the two remaining pieces adhere forming additional 21st chromosomal material - i.e. the usual two chromosomes plus the attached piece (Gunn, 1993:2). The fault will then be repeated in all subsequent processes of cell division. Parental age play no role in translocation Down's syndrome (Selikowitz, 1990:35).

Only certain chromosomes, namely 13, 14, 15 or 22 become involved in the translocation with chromosome 21, with 14 the most common one. All these chromosomes have small, genetically inactive tips which can easily break off and be lost without any ill effect (Zaremba, 1985:28).

Translocation Down's syndrome may be inherited from a parent, who is a "translocation carrier" - a parent with a translocation chromosome but the normal count of genes. Thus a translocation carrier is normal, because he or she has the usual 23 pairs of chromosomes (46). The only difference is that one of the 21st chromosome pair has joined on to one of the other chromosomes. This causes no problem to the carrier personally, but when egg or sperm cells are produced the number of chromosomes cannot divide evenly because of the two joined chromosomes. An egg or sperm cell will be formed with an abnormal number of chromosomes (24 because the joined one could not divide) which will result in a fertilized egg with 47 chromosomes. This abnormal number of chromosomal material then repeats itself billions of times as development of the fertilized egg continues (Op't Hof, 1984:49; Selikowitz, 1990:36). As well as been inherited, Down's

syndrome of the translocation type may be "sporadic" (when the parents have a normal chromosome structure). The inherited type account usually, but not always, for those instances where more than one member of a family has Down's syndrome. This type of Down's syndrome only accounts for about four percent of reported cases (Suran & Rizzo, 1989: 2, 218).

2.2.4 Mosaicism

In this type of Down's syndrome the egg and sperms cells are normal and fuse to form a normal fertilized egg cell. The division error in the number of chromosomes occurs in the early embryonic stage in certain cells. The child has an extra 21st chromosome in only a portion of his or her body cells. The rest of the cells have the normal number of chromosomes (Kapp (ed.), 1991:298). These Down's syndrome children are said to exhibit mosaicism, because the cells of their bodies are like a mosaic, made up of different cells, some normal with 46 chromosomes and some with an extra chromosome.

According to Steenkamp and Steenkamp (1992:131) mosaicism, as would be expected, is usually associated with less affected individuals, because of the counteracting effect of the normal cells. Children with mosaicism often have less prominent physical features typical of Down's syndrome. They also develop and function closer to the normal child. However, individuals with this type of Down's syndrome very rarely have normal intellectual abilities. Mosaicism accounts for only one percent of reported Down's syndrome children. It is still not known how and why the extra chromosome material affects the development and functioning of the human brain. That it does cannot be reasonably denied - cognitive and psychomotor deviance is pronounced in most individuals with Down's syndrome (Lane & Stratford, 1985:56).

2.3 INCIDENCE OF DOWN'S SYNDROME

Although a Down's syndrome child can result from any pregnancy, research has shown a definite relationship between the incidence of the condition and the age of the mother. The older the mother the higher the risk of giving birth to a child with Down's syndrome. The following chart is an indication of the relationship between maternal age and the risk factor (Gillham, 1986:4; Cusbelly & Gunn, 1993:86).

Chart 1 The relationship between maternal age and the incidence of Down's syndrome

| MATERNAL AGE | INCIDENCE |
|---------------|-------------------------|
| 20 - 24 years | 1 out of 2500 births |
| 20 - 29 years | 1 out of 1500 births |
| 30 - 34 years | 1 out of 750 births |
| 35 - 39 years | 1 out of 280 births |
| 40 - 44 years | 1 out of 100 births |
| over 45 | 1 out of 35 - 50 births |

If there is to be a goal of lessening the incidence of Down's syndrome, it will probably be realised through either primary or secondary prevention procedures. Cunningham (1982:88) and Ershow (1986:508) describes these procedures as follows:

Primary prevention which will necessitate a strong educational programme. Couples planning to have children must be made aware of the risks associated with advancing maternal age.

- Secondary prevention is also related to maternal age. Through a procedure called amniocentesis, it is possible to take a sample of the pregnant women's amniotic fluid usually between the 15th and 19th weeks of pregnancy. The cells can be tested and examined and if present, the chromosome abnormality leading to Down's syndrome can be identified. Theoretically it could lead to the complete elimination of most chromosomal aberrations if every pregnancy were to be tested.

2.4 CLINICAL FEATURES

As many as 120 features have been described in Down's syndrome children. However, most of the children with Down's syndrome have no more than six or seven of these distinguished features. With the exception of intellectual disability there is no other feature that is present in all individuals with Down's syndrome (Steenkamp & Steenkamp, 1992: 145).

Semperle (Mitchell & Brown, 1991:131), Edelstein (1984:14) and Emery and Tuer (Luster & Okagaki, 1993:123) identified the features associated with Down's syndrome as listed below:

- Hair is fine and straight.
- The skin is coarse
- Eyes slant upwards with a fold of skin at the inner corner(the epicanthal fold).
- The mouth is small
- The tongue which seems large in relation to the rest of the mouth. It often protrudes and is deeply fissured and becomes increasingly so with age.
- The top of the head is flatter than that of a normal child.

- The head is shorter from front to back.
- The nose is small with a low (flattened) bridge and the nostrils point forward.
- Teeth appear later than in normal children and are usually irregular.
- Ears tend to be small, are usually low set and lobes may be reduced or absent.
- Neck is short and broad.
- Hands are broad and stumpy with short fingers and just one horizontal palm fold (the Simian fold).
- The body is short.
- Voice is harsh with little variation in tone.
- Feet tend to be stubby and have a larger space than normal between the first and second toes (Sandal gap).

The limbs and neck of young children with Down's syndrome are usually floppy. This muscular floppiness is referred to as "hypotonic" which means they have a "low tone" and are flabby. Muscle tone is the resistance they give to being moved when they are relaxed. Tone is quite different from muscular strength which is the active contraction of the muscle. Muscle strength is usually normal in children with Down's syndrome. Their muscles may be hypotonic but they are not weak (Mitchell & Brown, 1991: 16).

Children with Down's syndrome usually weigh less than average at birth. During childhood they grow steadily, but at a slower than normal rate, and their ultimate adult height is generally shorter than would be expected for their family. Body height is usually close to the bottom of the normal range - approximately between 145 - 168 cm for men and 132 - 155 cm for women (Boer & Dunn, 1992:43).

2.5 PHYSICAL PROBLEMS PERTINENT TO DOWN SYNDROME

Children with Down's syndrome have a low resistance to infection, usually have heart defects, hearing problems and visual impairments. Therefore, these children need more medical care than the average normal child (Cusbelly & Gunn, 1993:523). However, since 1980, remarkable progress was made regarding the physical problems characteristic of these children that lead to a new generation of Down's syndrome children. Physical problems prevalent in Down's syndrome children will be examined in the following discussions.

2.5.1 Heart defects

According to Selikowitz (1990:89) the presence of heart diseases in Down's syndrome children can take a number of different forms of which the following are amongst the most common:

- **Atrio-ventricular septal defect (A-VSD)** which is the most common heart defect and is present in one out of every ten children. The child suffering from this defect has a hole between the two ventricles of the heart.
- **Patent ductus arterious (POA)** occurs in about one in fifty children. This condition of a patent (open) ductus arterious is present when the artery fails to close after birth.
- **Eisenmenger complex** is the name given to the complication that develops in children (and adults) with certain types of heart disease once the resistance to blood flow in the lung vessels has

become very high and the vessels have irreversibly narrowed.

Tetralogy of Fallot are found in approximately one in a hundred children with Down's syndrome. The term "tetralogy" describes four abnormalities which occur together. The two most important ones are a large hole in the ventricular septum and a narrowing of the blood vessels leading from the heart to the lungs.

Halliday-Smith (Lane & Stratford, 1985:68) states that both the life expectancy and the quality of life for the Down's syndrome child have improved dramatically over the last twenty years. This is the result of more and improved knowledge that lead to better medical care. In 1958 as many as 70% of all Down's syndrome children failed to survive the first ten years and 63% died in their first year. From 1960 to 1980 the mortality rate was reduced by nearly 60%. Although cardiac defects affect prognosis adversely, the clinical impression is strong that the situation has improved further since the last available statistical figures.

2.5.2 Hearing impairment

Gallagher (1983:143) reported finding an unusually high percentage of Down's syndrome children with mild hearing loss associated with a susceptibility to otitis media, an infection of the middle ear. According to Davies (1985:100) there is ample evidence from the small, but consistent body of research regarding the auditory function in Down's syndrome children and adults, that all individuals should have careful audiological supervision throughout their lives. This is necessary because children with hearing disabilities typically show no physical signs of impairment even though the consequences of the impairment may be quite extensive. When a child has

normal hearing abilities the acquisition of language occurs spontaneously and almost effortlessly, but the child with a hearing impairment must overcome obstacles in order to adequately master language as a communication medium (Suran & Rizzo, 1989:110).

Parents of Down's syndrome children should be informed about the likelihood of hearing deficits and be encouraged to ensure that this aspect of the child's development is carefully monitored and appropriate treatment given if necessary. Parents should refuse any opinion suggesting that "the child hears well enough for a child with Down's syndrome" (Lewis, 1987:69).

2.5.3 Visual impairment

Millis (Lane & Stratford, 1985:117) reports that visual impairment, to a greater or lesser extent, is a feature of the majority of Down's syndrome children. Generally both eyes are affected equally, although changes may occur earlier in only one of the eyes. The following are some of the most common eye defects as noted by Eyman, Call and White (1991:605) in Down's syndrome children:

- **Farsightedness (Hyperopia)** is a condition in which rays of light focus behind the retina of the eye, forming a blurred and unclear image of objects that are close by.

- **Nearsightedness (Myopia)** is a condition in which rays of light focus in front of the retina, forming blurred and unclear images of objects viewed seven or more meters distant. Deviations in the shape of the eyeball, the thickness and curvature of the lens or cornea, cause errors in light refraction and, in turn, problems with near (Hyperopia) and distance (Myopia) vision.

- **Squint (Strabismus)** or crossed eyes caused by a lack of coordination of the external eye muscles. The eyes do not simultaneously focus on the same object - can be constant or intermittent.
- **Nystagmus** is the quick, jerky involuntary movements of the eyeball due to muscular inadequacies, resulting in marked visual inefficiency.
- **Cataract** is a condition of the eye where a growth of film results in the crystalline lens becoming opaque with loss of visual acuity.

2.6 DEVELOPMENT OF CHILDREN WITH DOWN'S SYNDROME

Development is a gradual, perceptible change or unfolding which is empirically manifested as the child is able to accomplish more and more tasks on the road towards realization of the goal of becoming, which is adulthood (Van den Aardweg & Van den Aardweg, 1988:60). Development can be quantitative or qualitative and is a continuous complex process, unique to each child. Thus we can speak of, linguistic, cognitive, conative, social, moral, religious and physical development. Cunningham (1982:170) states that children with Down's syndrome will continue to learn new skills and acquire knowledge for most of their lives. This development is marked by periods of little apparent progress and periods of rapid progress. Wyne and O'Conner (1982:4-5), however, point out that these children are identified as exceptional because of measurable differences in their development and behaviour. Their development therefore requires special services and resources beyond those required by other children. Differences in academic

performance, social adjustment, physical capabilities, language, vision, hearing, and so on need some form of special education. For the purpose of this study the following developmental aspects of the Down's syndrome child will be discussed:

- . Physical development.
- . Cognitive development.
- . Social development.

2.6.1 Physical development

Physical development is simply the growth of the body which apparently follows a preordained course. Motor abilities, or the skills required to control and use muscles, are closely linked to physical development and are dependent on it (Van den Aardweg & Van den Aardweg, 1988:171). For a short period after birth (1 - 2 months), the physical and motor development of the child is relatively normal, but gradually slows down so that the child exhibits increasing retardation in relation to other children (Steenkamp & Steenkamp, 1992:132). According to Burn and Gunn (1993:5) crawling occurs on average at about 12 months compared with 7 - 8 months in normal children. A similar picture emerges with other motor skills as illustrated in the following chart:

Chart 2 The relationship between motor development in children with Down's syndrome and "normal children"

| MOTOR SKILL | DOWN'S SYNDROME CHILD | | "NORMAL CHILD" | |
|-------------------|-----------------------|-----------------|----------------|-----------------|
| | Average age | Age range | Average age | Age range |
| Smiling | 2 months | 1,5 to 4 months | 1 month | ½ to 3 months |
| Rolling over | 8 months | 4 to 22 months | 5 months | 2 to 10 months |
| Sitting alone | 10 months | 6 to 28 months | 7 months | 5 to 9 months |
| Crawling | 12 months | 7 to 21 months | 8 months | 6 to 11 months |
| Creeping | 15 months | 9 to 27 months | 10 months | 7 to 13 months |
| Standing | 20 months | 11 to 42 months | 11 months | 8 to 16 months |
| Walking | 24 months | 12 to 65 months | 13 months | 8 to 18 months |
| Talking words | 16 months | 9 to 31 months | 10 months | 6 to 14 months |
| Talking sentences | 28 months | 18 to 96 months | 21 months | 14 to 32 months |

Henderson (1986:92) reports the following three facts regarding the physical development of the Down's syndrome child:

- At most of the developmental stages the child functions less well than his or her normal peers.
- There are enormous differences between individuals within the syndrome.
- Down's syndrome individuals seem to fall further and further behind their normal peers as they grow older.

A child's motor skills depend largely on the maturation of the central nervous system. The centres that control and co-ordinate movement, develop along with the muscular system. Because of the slower maturation of the child with Down's syndrome muscle control and co-ordination will also be delayed (Steenkamp & Steenkamp, 1992:133).

Buhrmeister (Boer & Dunn, 1992:92) summarises as follows: "Although children and young people with Down's syndrome do not keep up with their peers in terms of motor development, changes in societal attitude and expectations, improved health and dietary control, as well as easier access to experimental opportunities are likely to influence positively each individual's development."

2.6.2 Cognitive development

Cognitive development is the continuous and cumulative development of the intellect and it proceeds at the individual's own tempo. Cognitive development concerns all that has to do with knowing - perception, conceptualization, insight, knowledge, imagination, intuition and is closely related to experience (Van den Aardweg & Van den Aardweg, 1988:39). Lovett & Harris (1987:355) state that the cognitive development of the Down's syndrome child must be thought of as different, in most respects, from that of a normal child. Kapp (ed.) (1991: 298) says research has shown that the children with Down's syndrome are mentally handicapped and therefore not as intelligent as normal children. This difference in intellectual ability is, however, not very obvious during the first two years, but as they grow older this intellectual "gap" seems to widen.

Down's syndrome children usually have IQs between 30 and 70. According to Carr (1985:177) most researchers have found that the IQ declines as the child grows older. The reason for this decline is still not known, but more important is the fact that it is not clear what remediation methods might be effective in combating this. Early intervention has succeeded in raising the level of the child's IQ but has not shown any

remarkable affect on the rate of decline (Ruskin, Mundy, Kasari & Sigman, 1994: 501).

It is to be expected that the child with a mental handicap (pathological brain condition) will experience problems with regard to cognitive development. Besides the slower rate and limited level of development Kapp (ed.) (1991:303) also identifies the following three aspects of cognitive development:

- **The rate of development** - It is generally accepted that the rate at which the child develops cognitively correlates directly with his intelligence. The child with an IQ of 75 progresses intellectually at about three quarters of the speed of a normal child (IQ 100), the child with an IQ of 50 at half the rate, and the child with an IQ of 25 at a quarter of the rate. A discrepancy develops between the child's actual age and his mental age and this difference increases as he grows older.
- **The levels reached** - Mildly mentally handicapped children (IQ 50-75) normally do not progress further than the concrete operational stage (mental capacity to relate an object or event to a total system of interrelated parts). Severely handicapped children (IQ 25-50) remain in the pre-operational phase (capable of visual, auditory and tactile exploration of environment).
- **Specific cognitive defects** - The mentally handicapped child's thinking remains rigid. On account of the inflexibility of his cognitive structures, the child does not think of new solutions. Closely associated with the characteristics of rigidity is an inability to form associations and a lack of creativity and ingenuity.

Cunningham (1982:134), however, warns against the general assumption regarding the cognitive development of Down's syndrome children. With effective guidance these children can be encouraged to take an active part in their learning, and in so doing help to improve their cognitive development in accordance to their abilities. Dykens and Hodapp (1994:581) mention the fact that with the aid of modern technology, people with Down's syndrome can learn new and often complex skills previously thought to be beyond their ability.

(1) Perception

Perception is the act of receiving information through the senses of sight, sound, touch, taste and smell or the result of a visual image. According to Steenkamp and Steenkamp (1992:31) perception includes becoming aware of the world around you by looking at things, listening to various sounds, tasting, touching and smelling. Perception is idiosyncratic in nature and is influenced by cultural background, upbringing and personality. The Down's syndrome child's visual and tactual abilities regarding perception are as follows (Lane & Stratford, 1985:153; Gunn, 1993:6):

- There seems to be no significant difference between the *manner* in which a Down's syndrome and a normal child perceive the environment visually - provided they are on a similar developmental level. They do, however, experience difficulty in recalling the visual information.
- The tactile ability of children with Down's syndrome is inferior to that of normal and other mentally handicapped children of the same developmental level. Down's syndrome children have difficulty either in discriminating objects tactually or in remembering tactual information.

(2) Communication

Communication is a sharing, verbally and non verbally, of experiences, happenings, knowledge, opinions and ideas. Studies from pre-speech to adulthood indicate that communication may be delayed in people with Down's syndrome in terms of the onset of vocalisation, the number of morphemes in early utterances and the complexity of later sentences (Matson & Mulick, 1983:68). There is therefore a considerable variability in the age at which children begin to use words and sentences, although some of this may be the result of variation in hearing loss (Ruskin *et al.*, 1994:502).

Steenkamp and Steenkamp (1992:132) mention the finding that expressive language (talking and vocabulary) is usually poorer than repetitive language (understanding what other people say). Dyken, Hodapp and Evans (1994:580-587) also found a weakness in communication in Down's syndrome children, relative to daily living and socialisation skills. Expressive language was significantly weaker than receptive skills in children over two years.

Poor articulation often makes it difficult for the listener to understand what the person is saying. In this regard Burn and Gunn (1993:80) quote as follows: "Because of my tongue, it's usually thick, it is very hard for my speech to come through clearly. Sometimes it sticks and I mumble. People don't understand me."

2.6.3 Social development

Social development is the development of relationships and associations with others. It is marked by mutual interaction, friendliness, geniality with the aim of enjoying the society or the companionship of others (Van den Aardweg & Van den Aardweg 1988:214).

Lane and Stratford's (1985:152) description of all Down's syndrome children as sociable, friendly, affectionate, cheerful and amusing, has almost become as synonymous to the syndrome as the mental handicap. However, individual differences are as common in Down's syndrome children as they are in normal children and stubbornness is often cited as a personal trait (Selikowitz, 1990:26). The generally accepted opinion that persons with Down's syndrome are being particularly sociable could be because other people have low expectations of them. Any social behaviour will therefore be over emphasized simply because it is not expected. Edelstein (1984:66) reasons as follows: "Possibly, this stereotype survives more strongly than the research data would justify, because we who work with the condition, value it."

Gillham (1986:153) maintains that researchers agree that social disabilities are part of the learning disabled child's life, and that this child finds it difficult to comply with the social demands of adulthood. The following factors can be seen as possible causes for the impediment in the child's social development (Ruskin et al., 1994:505; Kapp (ed.), 1991:397):

- Characteristics unique to the learning disabled child such as emotional lability, perceptual, motor, language and cognitive disabilities.
- The child's inability to process information from social situations and to integrate and react meaningfully to these.
- The child's inability to comprehend social situations, the interaction between people and his own position in such situations.
- The lack of social intelligence which involves aspects such as social interest (concern for others), social self-efficacy, empathy skills and social performance skills.

- The child is unable to adequately interpret stimuli in the social environment and appropriately relate such interpretations to the social situation.
- An inability to understand the perceptions of the total social field, perceptions of oneself in relation to the behaviour of others, as well as to events and circumstances that involve others.

2.7 SUMMARY

Down's syndrome is caused by an abnormal chromosomal relationship that alters patterns of growth and development in the child. A child with Down's syndrome typically has an extra chromosome in the twenty-first pair, creating a total of 47 chromosomes (normally 46). Since the twenty-first pair of chromosomes is actually 3 chromosomes instead of 2, the condition is also called trisomy 21. Two other types of Down's syndrome have also been identified, namely, translocation and mosaicism. Down's syndrome is the most widely known form of mental retardation that is known to be due to a genetic disorder, and on average one child in every 640 live births has Down's syndrome. The condition can occur in any family but the risk increases with the age of the mother. The unusual patterning of physical characteristics that typifies children with Down's syndrome makes these children easily identifiable. Typical features of the condition are slanting of the eyes; abnormally thick eyelids; flat, broad face and nose; thickened tongue; short, broad neck; stubby fingers. The number of physical features bears no relationship to the degree of mental retardation in the child.

Children with Down's syndrome have a greater incidence of heart defects, hearing problems and visual impairment. Both the life expectancy and the quality of life for the Down's syndrome child have improved dramatically over the last twenty years as a result of more and improved knowledge that lead to better medical care.

Children with Down's syndrome are identified as exceptional because of measurable differences in their development and behaviour. Differences in academic performance, social adjustment, physical capabilities, language, vision, hearing, and so on need some form of special education. During the first two months physical and motor development of the child is relatively normal, but gradually slows down so that the child exhibits increasing retardation in relation to other children as they grow older. The cognitive development of the Down's syndrome child must be thought of as different, in most respects, from that of a normal child because the child is intellectually impaired. This difference in intellectual ability is, however, not very obvious during the first two years, but as they grow older this intellectual "gap" seems to widen. Social disabilities are also part of the learning disabled child's life, and that therefore the child finds it difficult to comply with the social demands of adulthood.

In the following chapter attention will be given to the life-world of the Down's syndrome child.

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CHAPTER 3

THE LIFE-WORLD OF THE DOWN'S SYNDROME CHILD

3.1 INTRODUCTION

Every child lives in his or her own unique life-world. Just as each child is unique so the life-world of each child is unique. The child's life-world includes everything that has meaning for him or her, not only the geographical world but all the relationships with objects, ideas people and himself or herself (Van den Aardweg & Van den Aardweg, 1988:141; Du Toit & Kruger, 1991:15). These relationships may be interdependent and interactive, they are always dynamic and ever increasing and changing. Vrey (1990:21) says this Gestalt of meaningful relationships constitutes the child's life-world. All the child's behaviour and actions should be interpreted within the context of his life-world. From birth the child is actively constituting this life-world using his genetic potentials, aspirations, will and psychological abilities, within his particular cultural context, forming an ever-changing, increasing, interacting whole in which he is involved and to which he attributes meaning (Van Rensburg, Landman & Bodenstein, 1994: 435, 438).

The child is a person in a world of other people, objects, norms, values and ideas in which he orientates himself while becoming an adult (Vrey, 1990:60). The child's orientation is only possible with the help of adults as educators (parents or teachers). Educators unlock meanings to the child and this attribution of meaning enables the child to constitute a meaningful life-world by forming meaningful relationships (Du Toit & Kruger, 1991:13). Experiencing is an act of orientating oneself. The child learns that experiences have a denotative and connotative character which makes an

experience unique to the one who experiences (Nel & Urbani, 1990:95-96). The child with Down's syndrome must be led to meaningful experiences and acceptance of his disability - of the sorrow and crisis situation in which he finds himself. When the Down's syndrome child undergoes a certain experience, meanings are assigned and these meanings acquire the personal dimension of the child's disability (Thomas, 1982:53).

In this chapter attention will be given to the concept experience and the Down's syndrome child's experience of his impairment. The forming of relationships by the child with Down's syndrome will be addressed.

3.2 THE CHILD'S EXPERIENCE OF HIS IMPAIRMENT

3.2.1 The concept experience

Van Rensburg, Landman and Bodenstein (1994:383) say the term experience as derived from the German "erfahren" and the Afrikaans "ervaar" implies to be in motion and while being in motion to undergo or experience something. The verb "erfahren" implies the acquisition of knowledge, getting to know and becoming aware of something.

The child learn that experiences have a denotative (logical) and connotative (emotional) character which makes an experience so unique to the one who experiences. Gouws and Kruger (1994:6) noted in this regard: "What I know another may know, but what I experience is unique to me." An experience can be positive or negative, as seen in physical perceptions (pain, comfort, energy), social relationships (enjoyment, rejection, acceptance), with objects (frustration, success) and spiritual experiences (peace, solace, confusion) - all describe the individual's subjective experiences in terms of moods and

feelings. Urbani and Nel (1990: 106-107) assert that each experience is accompanied by feeling and willing, different in quality and intensity. Du Toit and Kruger (1991:19) state that experience is related to the emotional and affective dimension of being human and indicates an evaluation of a fluid situation in broad categories of pleasant and unpleasant. Examples of feelings experienced, such as excitement, disappointment, gaiety and frustration during involvement in a situation indicates how a person is emotionally effected by the situation. Experience never occurs in a vacuum, but is related to a person's situation. Van den Aardweg and Van den Aardweg (1988:83) and Vrey (1990:42) give the following essential components of experience:

- . Experience determines the quality of relationships.
- . Experience is emotional and is evaluated in terms of varying degrees of pleasantness and unpleasantness.
- . Experience stresses the uniqueness of each person's relationships.
- . Experiences, especially their intensity, determine the clarity and stability of the meanings assigned by a person.
- . Experiences inhibits or incites a person's involvement in every attribution of meaning.
- . Experience is a meaningful event, involving the total person who experiences certain feelings and also knows that he experiences them.

- An educator's praise or disapproval is a determining factor in the positive and negative intensity of the subjective experience.

Children with disabilities, like Down's syndrome, have more limitations on their experiences than their able-bodied peers.

3.2.2 Affective experience

Affective experience is concerned with those aspects pertaining to emotions, feelings, passions, moods, sentiments and whims (Du Toit & Kruger, 1991:54; Gouws & Kruger, 1994:94). Affectivity is basic to the behaviour of the child and determines his personality. Kapp (ed.) (1991:306-307) maintains that affective qualities accompany man's memory, thought, concepts, ways of thinking, responses, association of impressions and experiences are inseparable joined to every perception, conscious or unconscious, physical or intimately personal. The affective adds colour and variety to life, but unless it is detected and controlled it may leave lasting and devastating effects on the child (Lewis, 1987:67) .

In the exploration of his world the child with Down's syndrome experiences limitations as the result of his impairment. The child experiences things and situations which he cannot handle and may increase his anxiety (Vrey, 1990:69). This anxiety may manifest as moodiness, aggression, jealousy and excessive attention seeking (Steenkamp & Steenkamp, 1991:31). For example the child with an inadequate command of language expresses his emotions physically - crying, screaming, kicking or biting. Gallagher (1983:144) says in this regard that the Down's syndrome child's emotions are easily aroused and reaction may be in the form of temper tantrums, real fears and unreasonable manifestations of jealousy.

Social stress, not knowing how to act in social settings, is a primary source of anxiety (fear) and may result in shyness and withdrawal (Suran & Rizzo, 1989:220). With insufficient physical prowess the Down's syndrome child becomes angered and frustrated. If the cause of the frustration cannot be removed or anger cannot be vented against it, aggression may be vented elsewhere. Other common emotions expressed by the Down's syndrome child are joy and affection. The child enjoys being acknowledged, noticed and praised and such responses give him a feeling of well being as he is an affection seeking being (Shearer, 1981:35).

Physical defects and intellectual shortcomings disturb the child's emotional life if not assisted to accept unavoidable deficiencies and experience them as meaningful (Du Plooy, Griessel & Oberholzer, 1982:148). The acknowledgement and acceptance of his shortcomings by the child is only possible within a relationship of trust and confidence between adult and child (Van Niekerk (ed.), 1991:16). Consistent care, affection and support enable the child to anticipate both general and specific help and support. In order to actualise the possibilities of the child with Down's syndrome his educators should support and accompany him in such a way that he learns to control his emotions by his will (conative aspect) and his mind (cognitive aspect) (Vrey, 1990:23; Du Toit & Kruger, 1991:54).

3.2.3 Cognitive experience

According to Van Rensburg, Landman and Bodenstein (1994:339) the concept cognitive implies the life of knowing of the child, of which the outcome is knowledge. The cognitive experiencing of the child embraces facets of analysis, synthesis, abstraction, comparison and so forth and leads to objective judgements, pronouncements and knowledge. Education, amongst others,

implies cognitive guidance of the child towards achieving an intellectual grasp of the world. Van den Aardweg and Van den Aardweg (1988:39) maintain that cognitive development concerns all that has to do with knowing - perception, conceptualization, insight, knowledge, imagination, intuition and is closely allied to experience.

Research has shown that the child with Down's syndrome has limited mental (cognitive) capacity and therefore the cognitive development of the child is slow and limited (Gallagher, 1983:129; Suran & Rizzo, 1989:402). According to Kapp (ed.) (1991:298) the children with Down's syndrome are intellectually impaired and their IQs are usually between 30 and 70 (cf. 2.6.2). One of the most fundamental ways in which retardates differ from normal children of the same age lies in the slowness and inefficiency with which they acquire knowledge and skills (Steenkamp & Steenkamp, 1991:4). It is generally accepted that the rate at which the child develops cognitively correlates directly with his intelligence. The child with an IQ of 75 progress intellectually at about three-quarters of the speed of a normal child (IQ 100), the child with an IQ of 50 at half the rate (Kapp (ed.), 1991:303). The eight-year-old mentally handicapped child with a mental age of four is already four years behind, at sixteen his mental age will be a mere eight years, etcetera. Gallagher (1983:173), however, stresses the importance of the fact that researchers have found a substantial number of Down's syndrome children who fall in the educable or even higher range of measured intellectual performance. He formulates as follows:

- There is a possibility that the child could be educable on a psychometric base.
- A great deal of variability exists in Down's syndrome children's development.

- The limits of Down's syndrome children's educability are virtually unknown.

Besides the slower rate and the limited level of development, researchers have also found other specific defects in these children's cognition, namely rigidity and a lack of originality (Zigler and Balla, 1982:61). In practice it means that, on account of the inflexibility of his cognitive structures, the child is not in a position to think of new solutions or even form new associations (Wyne & O'Connor, 1982:402). He tends to continually repeat the old cognitive actions instead. Kapp (ed.) (1991:389-390), Van Niekerk (ed.) (1991:215) and Gerber (1985:167) identify the following characteristics of the learning disabled child:

- The inability to identify cause and effect, to interpret symbols and to use imitation successfully in the learning act.
- Some children find it difficult to move from the concrete level of cognitive functioning to the abstract level. They remain concretely bound in their thinking and need to see the material they are taught, hear it, touch it, smell it, feel it, be it.
- Children experience difficulty to retrace a matter to its original departure point.
- Children have problems both in integrating new information with existing information and in seeing relationships between aspects.

They are mostly passive learners who are unable to work independently and purposefully. They are often impulsive in their approach to problems and do not always understand instructions.

(1) Language development

The language of children with Down's syndrome show many defects. Language is acquired in the same way as normal children, but only more slowly and they remain longer in each of the various language stages (Thurman & Widerstrom, 1985:98). According to Kapp (ed.) (1991: 304) their expressive language also shows the specific defects, namely short telegram like sentences, simple sentence structure and limited vocabulary mainly consisting of concrete words. Concerning their receptive languages, Zigler & Hodapp (1986:37) established that the Down's syndrome child finds it difficult to understand complicated language. Zigler and Balla (1982:102) conclude as follows: "The child listens but he does not 'hear'. The child does not 'hear' because of a limited verbal comprehension. He understands very little of what is being said and just 'stops' listening." Even when he is listening and hears what is being said his inadequate intellectual (cognitive) ability prevents him from storing the information in a meaningful way. The child does not always make sense from what he hears and accordingly cannot react appropriately. Speech defects are also common amongst children with Down's syndrome and this may cause pronunciation to be unintelligible.

It is important to note that the language they do acquire is not effectively employed as a means of thought - their language assumes a disconnected role in their thinking (Vrey, 1990:133). The same disconnection is also apparent between their language and their actions. Gallagher (1983:144) found that the

language of the mentally handicapped regulated their actions to a far lesser extent than those of the normally gifted.

(2) Perceptual development

Children with Down's syndrome also experience problems in the field of perception (Suran & Rizzo, 1989:249). They tend to perceive more cursorily and superficially than normal children. Their ability to discriminate (auditorially, visually and tactually) also differs from other children. They do not easily distinguish between sounds that sound alike and do not easily see differences. Research by Zigler and Balla (1982:102) has shown another problem regarding the mentally handicapped child's perception, i.e. the child's preference for using the visual rather than the auditory modality. The fact that the auditory modality is neglected may possibly be one of the reasons for the child's inadequate language acquisition and for the fact that he does not allow language to serve as a means of regulating his actions.

The Down's syndrome child's sensory organs must be stimulated, his interest and attention must be attracted, he must be taught to observe, to compare and differentiate according to his ability (Steenkamp & Steenkamp, 1991:87). It is the task of the educator to make the child a more independent and responsible person. However, each individual child's intellectual potential must be borne in mind to avoid unnecessary emotional tension and frustration arising from activities in which the child will be incapable of making progress (Zigler & Hodapp, 1986:37).

(3) Attention

Attention is a mental process which focuses on a specific portion of the total motivation on a person. It involves the total direction of a person towards something (Van den Aardweg & Van den Aardweg, 1988:25). Attention is the action of giving heed, taking note of, taking interest in an event, topic, incident, person or situation. Paying attention is the essential starting point for any act of learning and should be maintained throughout the learning act (Vrey, 1990:263 -264).

Research has found that the majority of children with Down's syndrome have attention difficulties which usually manifest in non-listening, poor concentration, impulsivity, excessive shifting between activities and an inability to organize their work (Gallagher, 1983:144; Ingalls, 1988:261). These children's main problem with regard to attention is not that they are unable to solve a problem, but that they don't know how to start solving it. They do not easily grasp the importance or relevance of a particular aspect of the problem which confronts them. It takes them much longer than the normally gifted "to catch on", as Zeaman and House (Kapp (ed.), 1991:309) put it. The ability to discover the relevance of a particular matter (also called selective or discriminating attention) also correlates positively with intelligence. A further problem for these children is that they find it difficult to ignore irrelevant external conditions (stimuli) (Vrey, 1990:264).

Children with Down's syndrome also have a particularly short attention span (Hanko, 1985:32). They do not only have problems in selecting the important and disregarding the irrelevant, but in sustaining attention for any length of time. Gallagher (1983:135) ascribes the short attention span to the child's "meagre mental energy", and feels that the level of energy may be so low in

these children that their attention only lasts for a few minutes.

3.2.4 Physical experience

The child is physically (bodily) in the world. His body is both the centre and medium of his experiences. The range of a child's potentials and the level to which it can be developed are genetically determined and have a biological-neurological basis (Nel & Urbani, 1990:5-6). Physical development greatly effects the child's psychological development influencing his intellectual (cognitive) development, his relationship with others and his self-concept. The more able and active the child is physically, the better will he be able to explore his world and learn (Van den Aardweg & Van den Aardweg, 1988:169; Vrey, 1990:67).

The Down's syndrome child reaches the so-called developmental milestones (sitting, crawling, walking, running, etcetera) later than the normal child (Gallagher, 134-135). Specific defects that may occur are that their gross motor movements are less well co-ordinated and consequently they appear clumsy and awkward. These children move and act more slowly than the normal child - it is particularly noticeable when a quick motor response is expected from the child (Kapp (ed.), 1991:306). As a result of these problems the child's ability to investigate his life-world through exploration is limited, and thus also his opportunities to become adequately involved.

Van Zyl (Du Plooy, Griessel & Oberholzer, 1982:147) expounds that the education of disabled children make exceptionally exacting demands. These children must be supported in the acceptance of their own corporality, they have to be helped to accept their impairment. They do not demand compassion, which may give rise to their falling into self pity and bitterness,

but they ask for an opportunity to live meaningfully and propitiously inspite of their physical defects (Birenbaum & Cohen, 1993:151).

It is important to reiterate that each child responds differently to what may appear to be very similar disabilities and life experiences. Young people who perceives themselves to be given no independence (trust) as opposed to those people with such labilities, tend to be depressed, have a low self-esteem and display anti-social behaviour (Halliday, 1989:79).

The Down's syndrome child misses many of the normal physical experiences, which should assist his own development, as a result of inadequate awareness and motivation. The disabled child is not as agile as the normal child (Suran & Rizzo, 1989:218). He is frequently confused by the underlying interaction of various parts of his body, he has poor grasp of his own position in space and is thus uncertain of the distance between himself and the objects he sees, or even the direction in which he is looking. The child often has a lateral dominance (Wyne & O'Connor, 1982:452-453).

Effective physical development of the child can be advanced by creating opportunities for the child to experience the pleasure of achieving that which he can achieve, while at the same time learning to overcome the frustration resulting from his own limitations. The intention is to improve his experience of his body as the basis of other learning activities (Steenkamp & Steenkamp, 1992:32). If there are low expectations then a low level of performance is most likely and in many cases the result will then not indicate true potential (Davies, 1982:14). If the child with Down's syndrome cannot lead a life as normal as possible, his sense of purpose is diminished. This obstacle may be overcome by increasing greater participation of the child in all aspects of his care (Gallagher, 1983:173).

3.2.5 Conative experience

The conative development of the child is concerned with the basic driving forces which give rise to the child's behaviour (Vrey, 1990:36). The conative aspect of the child's experience includes needs, tendencies, impulses, aspirations, motives, aims, drives, wishes and the will. It implies a goal to be pursued and a will to achieve the goal. The will is the active striving toward the realization of a goal, in the act of the will the aspirations form the point of departure, the basis for the initiation of action (Du Toit & Kruger, 1991:95). Thus a motive (aspiration) should exist before the will is moved into action. According to Van den Aardweg and Van den Aardweg (1988:46) aspiration (motive) and will form an integrated whole in the psychological structure pertaining to conative experiences.

The child with Down's syndrome has a limited mental ability, and therefore unable to set himself attainable goals. He is also inherently poorly motivated and without a strong desire (aspiration) to pursue set goals. Many of the child's natural aspirations are curbed as he lives very much in the present and cannot envisage the consequences of his actions. The latter is due to the limited mental abilities of the Down's syndrome child (Wyne & O'Connor 1982:32-33).

The mentally handicapped child's learning problems start with his initial lack of motivation (aspiration) for a learning task. According to Kapp (ed.) (1991:308) there are two opposing viewpoints for this lack of motivation:

- The child is inherently poorly motivated and has little need to look for new stimulation on his own.

- The child's strong expectancy to fail. The child prefers not to try at all rather than risk failure by trying to succeed.

Research by Ingalls (1988:269) supports the latter viewpoint. It has been found that mentally handicapped children to whom a series of difficult tasks are given, are later no longer able to solve the most simple of tasks which they initially could do with ease (inability - failure - decreased motivation - further failure). It may be assumed that both viewpoints on motivation (will or aspiration) are true in the case of Down's syndrome children, namely that they are poorly motivated but that motivation is further weakened because they continually expect to fail (Burn & Gunn, 1993:54).

3.2.6 Social experience

Social development is the forming of relationships and associations with others. Social experience is marked by mutual interaction, friendliness, geniality with the aim of enjoying the society of companionship of others (Gouws & Kruger, 1994:110; Derbyshire, 1989:89-90). An adequate social life is an important component of adulthood. Zigler and Hodapp (1986:175) say social competence involves the child's degree of success in meeting social expectations (which differ at different ages) and the child's self actualization. This implies that skills should be available that enable the child to associate with others without being hampered by anxiety and lack of confidence, and that his behaviour will have positive results without harming others. Halliday (1989:76) states that social disabilities are part of the learning disabled (Down's syndrome) child's life, and that the child finds it very difficult to comply with the social demands of adulthood.

According to Steenkamp and Steenkamp (1991:71) the Down's syndrome child can be compared to a tourist in a foreign country. The child cannot speak the language well, he does not always understand what is expected of him, he experiences problems with procedures and value of money, he is not familiar with the social customs and does not know how to behave. The child needs special guidance to live with and alongside the other people in a particular community. Kapp (ed.) (1991:397) identifies the following causes regarding the social disability of the Down's syndrome child:

- Characteristics unique to the learning disabled child such as hyperactivity, perceptual disability, emotional liability, motor disability, attention deficiencies, language disability, impulsive and cognitive disability, impede the child's social development.
- The inability of the child to process information from social situations and to integrate and react meaningfully to these.
- The inability to adapt to social situations has a neurological basis.
- Social imperception which indicates an inability to understand the perceptions of the social field, perceptions of oneself in relation to the behaviour of others as well as to events and circumstances that involve others.

Suran and Rizzo (1989:311) maintain that the legacy of segregated education in special establishments for Down's syndrome children undoubtedly lessen opportunities for social experiences with normal children. Whatever the advantages which may accrue from "special schools" it denies the child the

opportunity of forming lasting and meaningful relationships with normal children. Darling and Darling (1982:45) claim that "special education" tend to stigmatize children through hostility, avoidance or at best by fictional acceptance. The child therefore primarily establishes relationships with the "own" who share his stigmatized status. Emphasis should be placed on normalizing social relations between the mentally retarded and ordinary people (Boer & Dunn, 1992:85).

3.3 FORMING OF RELATIONSHIPS

The term "relationship" implies an association between two referents and the child is busy throughout life with these relationships, giving them meaning and so forming a relationship (Vrey, 1990:20). Relationship is a particular mode in which the child, things, ideas, self and God are mutually connected. Such relationships are usually dynamic and interactive and are initiated by the individual (child) through his involvement and the assigning of meaning in his life-world (Du Toit & Kruger, 1993:10). Central to such a relationship is understanding - the attribution of significance or meaning through involvement and experience (Van den Aardweg & Van den Aardweg, 1988:193).

Since relationships mean the interaction between the child as one pole and a given section of reality as the other, there are two components involved. One of the components is the referents (parent and child) and the other is the nature and quality of the relationship. Nature refers to the cognitive component and quality to the affective component (Vrey, 1990:21). Since a relationship is formed by understanding the other pole, this attribution of meaning can only take place by way of involvement with a referent and with the quality of meaning formed during involvement and experience. As a

result of his limited cognitive ability the Down's syndrome child is not always able to adequately understand the other pole in a relationship and attribute appropriate meaning to it.

Pringle (1987:117) states that the adequate becoming of a child with Down's syndrome (disabled) in the long run depends far less on the nature, severity or onset of his condition than on the relationships formed with his parents first and foremost, then with siblings and peers, then teachers and eventually the society. These relationships will determine how the child experiences his disability and the degree to which he actualizes his limited abilities. For the purpose of a more detailed discussion the child's forming of relationships is split up into the broad categories of other people, things and ideas, the child himself and God.

3.3.1 Relationship with the self

Knowledge of one's identity consists of recognizing and identifying oneself and the formation of a self-concept. Vrey (1990:25) says by comparing himself with peers and others, with their achievements in handling natural or cultural objects, the child evaluates himself and his abilities in relation to the norms. All give rise to the self-concept and a polarization effect of self-acceptance or self rejection (Raath & Jacobs, 1990:1,12). According to Steenkamp and Steenkamp (1992:31) the child's experience of his body include three elements, namely, body image, body concept and body schema.

(1) Body image

Body image is the idea or concept one has of one's body. The child, as an outcome of his physical experience, enters into a relationship with the world

by means of his body (Du Plooy, Griessel & Oberholzer, 1992:62). Positive feedback and concomitant experiences of success result in a positive evaluation of the self and negative feedback and concomitant experiences of failure results in a negative evaluation (Du Toit & Kruger, 1991:37). The way people respond to each other is partially determined by physical characteristics. Kapp (ed.) (1991:298) say people with Down's syndrome have very distinctive physical traits, for example: a coarse skin, eyes that slant upwards, a short nose, a small mouth, a large tongue which often protrudes, broad hands and short fingers. Gerber (1985:21) feels that because of these features the child holds a distorted body-image of himself, and based on this image it is indeed impossible for the child to develop a positive self-concept. Le Roux (1985:73) adds that disturbed physical (motor) abilities compound this negative body image when the child compares himself with other children and realizes that in many areas he cannot even compete with them. The negative body-image held by the child may also be ascribed to the fact that their deficiencies are often over-emphasized while their positive attributes are not even mentioned (Suran & Rizzo, 1989:196). The child should be helped to accept his physique and develop a healthy body image in spite of being different from normal children.

(2) Body concept

According to Steenkamp and Steenkamp (1991:31) body concept refers to the cognitive knowledge an individual has of his body. The body concept is obtained by consciously learning all the parts of the body and their individual functions. As a result of the child's limited intelligence, Gerber (1985:282-283) concludes that if the child's awareness of his body, which includes his subjective image of himself, his intrinsic awareness of his body and its potential, and his objective knowledge of the body and body functions, does

not develop adequately, the total psychological becoming of the child will suffer. The child's development of independence could be hampered, a feeling of insecurity and negative self-concept created and the ability to explore be delayed (Raath & Jacobs, 1990:19).

(3) Body scheme

Body scheme is a totally unconscious cybernetic subcortical frame of reference which constantly changes and adapts as the result of proprioceptive feedback (Van Niekerk (ed.), 1991:200). It is the result from tactile experiences and sensations in the body scheme and regulates at any one moment the portion of the musculature and parts of the body in relation to one another and it varies according to the position of the body (Steenkamp & Steenkamp, 1991:31). The child's motor ability is associated with co-ordination between the brain, nerves and muscles in order to bring out certain actions such as walking, talking, etcetera.

Research has shown that deficiencies with regard to motor functioning are evident in children with Down's syndrome (Wyne & O'Connor, 1982:136-137; . These deficiencies are *inter alia* the following: poor co-ordination, deficiencies in spatial orientation and disturbances in laterality, balance and rhythm. Kapp (ed.) (1991:232) maintains that the learning disabled with motor deficiencies are inferior on the playground, in creative activities, in getting from one place to another and in completing a task , all because they cannot learn and perform the required motor skills. The continual failure and difficulty in mastering physical skills let the child feel inadequate and unsuccessful and he develops a poor self-concept.

3.3.2 Relationship with others

The child is born into a world of meaning, and because of his own involvement he can only find a place in the world in so far as he understands it (Vrey, 1990:73). Once the child begins to understand, relationships are formed. The child, as human being, forms relationships with other human beings (people) in his surrounding world. There is a remarkable difference between the normal and the disabled child (Down's syndrome), and this difference extends to the way in which they form relationships (Van Niekerk (ed.), 1991:21).

Steenkamp and Steenkamp (1991:32) point out that an apprehensible part of the Down's syndrome child's happiness depends upon his ability to maintain positive relationships with other people. The child must be supported in the forming of relationships to the point where it is possible to interact and enjoy optimal interpersonal and social functioning within the bound of his limitations. The establishing of meaningful relationships with the parents, peers, siblings and teachers play a significant role in the becoming of the child with Down's syndrome.

(1) Relationship with parents

Literature in the field of child development has come to the unanimous decision that the most significant others in the child's life is his parents (Vrey, 1990:22; Du Toit & Kruger, 1991:12; Le Roux, 1985:54). For the disabled child the interaction in the small, personalised reference group of the family means a safe haven from where he can face the outside world. Van den Aardweg and Van den Aardweg (1988:159) stated that a harmonious parent-child-relationship is the single most important factor alleviating the deficiencies of the disabled child.

The major source of the disabled child's self-view are the definition thereof transmitted by the parents. Parents who consistently spend time with and show interest in their disabled children, who are warm and loving yet firm are likely to encourage a salubrious relationship between parent and child. Bailey, Blasco and Simeonsson (1992:7) report that disabled children, because of their limited mental ability, may not always be able to understand their parents effort in the establishing of a healthy relationship.

According to Le Roux (1985:73) the child too has a part in the parent-child-relationship and shapes his parents' attitudes toward him - his crying, reactions, sex and appearance all shape his parents behaviour towards him. Kapp (ed.) (1991:396) states that the parent's relationship with a disabled child is problematic since birth. The child's first contact with the mother is often problematic, even burdensome, because of poor sleeping and eating habits and recurring sickness. Motor skills such as sitting, walking and talking are mastered with difficulty and later the child also experience problems with the mastering of academic skills. These factors can only contribute to a disturbed parent-child-relationship. Gerber (1985:21) feels that the Down's syndrome child's inability to meet the expectations of parents put further strain on the relationship between parent and child.

Three questions that are of great importance regarding the relationship between parents and their child with Down's syndrome are the following (Darling & Darling, 1982:6):

- Are parents accepting the child as he or she is?
- Are parents able to orientate to the child's disability?

- Can parents provide the necessary security (sheltered) space for the disabled child?

(a) Acceptance

Acceptance implies unconditional acceptance of the child - no preconditions may be set. The parent who sets preconditions or make certain demands before accepting a child, for example a healthy, normal body and a good mind, is already alienating himself from the child (Le Roux, 1985:49). Acceptance is more than mere intellectual acceptance or acquiescence. It is a spiritual and emotional oneness of the parent with the child and of the child with the parent - it is imperative for the establishment of a relationship of trust and understanding between parent and child (Gallagher, 163-164).

From a clinical viewpoint parental acceptance of their disabled child has often been associated with the parents ability to overcome their feeling of guilt. According to Suran and Rizzo (1989:88 -89) most parents acknowledge their child's limitations but are not pleased with it. They are, however, able to appreciate whatever abilities the child possesses and they love the child in spite of his or her disabilities.

Research has found that parents from a lower socio-economic status seem to be more accepting of their Down's syndrome child than their counterparts from the middle or upper class (Ingalls, 1988:52). It was also found that parents pre-existing attitude is likely to change as they become more attached to their disabled child (Kapp, (ed.), 1991:459). If the parents accept the child and the "problem", and if they live like a normal, healthy family integrated in the society, they will experience gratification in their efforts to educate the child (Eden-Piercy, Blacher & Eyman, 1986: 289). Such a family will also gain satisfaction from assisting other parents who are in a similar position.

(b) Orientation

Orientation is a modifying process to enable one to cope with or suit new conditions or situations (Van den Aardweg & Van den Aardweg, 1988:158). Children with Down's syndrome (disabled) arrest the normal family routine and cycle and the difficulties the family faces change over time but do not necessarily ease as the child grows older. Gallagher (1983;163) points out that the family must face several difficulties: the decision whether to institutionalize the child, the realization that the child may never be self-sufficient, and the problems what will arise when the parents die. The family members of the disabled child have to orientate themselves to these complex and continuing issues in order to maintain healthy relationships within the family.

Parents who are frustrated with the slow development of their Down's syndrome child may give up and restrict the child's development to the best of his limited capabilities (Wyne & O'Connor, 1982:35-36). Such a relationship between parent and child are characterised by frustration, anxiety, disappointment, inadequacy and guilt. To give the disabled child an even chance to develop, parents have to orientate themselves in helping the child actualizes his limited abilities (Van Niekerk (ed.), 1991:109).

Research done by Zigler and Hodapp (1986:156) has indicated that "vulnerable families" find it more difficult to cope with a disabled child than other families. Vulnerable families are subject to additional stress such as unemployment and inadequate education. Down's syndrome children in "vulnerable families" have more severe learning difficulties (Darling & Darling, 1982:6).

Vulnerable families also include those where the mother experiences difficulty to adjust to the child's condition and the mother-child-relationship is inadequately actualised (Zigler & Hodapp, 1986:157). According to Vrey (1990:73) the mother is an anchorage point in the family for the forming of further relationships. Therefore, an impaired mother-child-relationship reflects poor relationships within the family. There is a lack of family sharing in the support of the disabled child and the child's behaviour is socially intrusive, consisting of attention seeking and difficulties in concentrating (Birenbaum & Cohen, 1993:69).

(c) Security (safety)

Reality reveals that a harmonious relationship between parent and child is marked, among other things, by the presence of love, trust, shelter (security) and support (Van Rensburg, Landman & Bodenstein, 1994:529). To give a sense of security one needs to feel secure oneself. According to Pringle (1987:117-118) many parents of a disabled child do not feel secure themselves. They are worried about their lack of special knowledge and are afraid of being unable to meet the special needs of the child; many feel guilty and/or ashamed; some may be completely at a loss. Inevitably in most cases there are also less support from relatives and friends since they also lack the experience of bringing up a disabled child. Insecure parents are unable to provide the child with sufficient security for his adequate becoming. A child with Down's syndrome (disabled child) may seem to some parents as a burden and the special needs of the child is more often met with ridicule or contempt (Mitchell & Brown, 1991:130). The relationship with his parents will be impaired because the child will come to feel inferior and a failure.

Thurman & Widerstrom (1985:47) state that it is entirely natural for parents to feel concerned, and often extremely anxious, about their disabled child. However, this concern may often turn into over-anxiety or resentment if the parents have no clear knowledge about the nature of the disability and its short term as well as long term implications. Pringle (1987:118) says parental uncertainty may show itself in insecure and inconsistent handling of the child. It is therefore essential for parents to understand the child's condition in order to establish a happy, harmonious relationship which communicates warmth and confidence to the child instead of anxiety, uncertainty and hopelessness.

(2) Relationship with siblings

Siblings, brothers and or sisters are the child's first peers. Sibling relationships are usually the longest and most enduring of family relationships (Gouws & Kruger, 1994:116). The permanence of the relationship makes it possible for two individuals to exert considerable influence over the other through longitudinal interaction (Seligman & Darling, 1989:111). Older siblings tend to serve as role models for younger siblings and they also may serve as surrogate parents, taking on parental responsibilities.

According to Neumayer, Smith & Lundgren (1993:399) research has shown that sibling relationships in the majority of families with disabled children were no different from that in ordinary families. Darling and Darling (1982:162), however, cite cases of hostile, anxious, and resentful relationships between siblings in families with disabled children. Siblings felt unfairly treated as to the difference in the amount of parental attention bestowed on the disabled child. Gallagher (1983:165) also found that the presence of a disabled child in the family often results in problems of adjustments for the siblings. Orientation was more difficult in smaller families (2 to 3 children)

and in families where the siblings were younger than the disabled child. Findings by Gath (Boer & Dunn, 1992:101) also give evidence that disturbed relationships and behaviour is more common in families with only two children (one disabled), which indicates that life might be easier for a normal child when there is another normal child in the family. Cuskelly and Gunn (1993:89) indicate families where the normal siblings felt pressured to excel in order to compensate for a disabled brother or sister. If they are intellectually or psychologically unable to attain these expectations feelings of failure and hostility may result.

Gallagher (1983:165) and Parekh (1988:34) documented the following findings when families send their children with Down's syndrome to be institutionalised:

- The eldest male sibling showed greater tension when the child was in the institution than at home.
- The eldest female sibling showed greater tension when the child was kept at home. This was due to the fact that the eldest of the female siblings frequently functioned as surrogate mothers for the child with Down's syndrome.

Often normal brothers and sisters in a family are teased about their "daft" brother or sister. Normal children who have not been given a well tailored explanation to suit their level of understanding about a disabled sibling, are not adequately equipped to deal with such persecution. They are left to puzzle out by themselves why the child in the family is different (Shepperdson, 1988:72). This can only create mistrust and hostility in family relationships.

Gallagher (1983:166) reports that problems that were not anticipated early on in the Down's syndrome child's life can emerge when normal brothers and sisters set up their own homes. Although a harmonious relationship existed between siblings when still in the family home, the younger Down's syndrome child became hostile towards his older brothers and sisters and their children. He feels neglected and resents the attention paid by his siblings to their own children and by his parents to their grandchildren.

It must be noted, however, that research has shown that in the majority of cases, siblings of all ages, male or female, seemed to have been able to adjust (orientate) adequately to the presence of a Down's syndrome child in the family by adapting a stance of realistic acceptance (Shepperdson, 1988:68 - 69). Siblings who had experienced involvement in the growth and development of a Down's syndrome sibling exhibited a sense of pride that they had been part of it.

(3) Relationship with peers

For most children, peers (friends and other children approximately the same age) can at the same time be a source of pleasure, profound learning and pressure. Children enjoy each other's company which is apparent of the amount of time they spend together. Neumayer, Smith and Lundgren (1993:394) state that children most decidedly learn from their peers, observing different ways of behaving in various social situations such as parties, school, and other public gatherings. They also learn how to be a friend, how to form close, caring relationships with another person, how to give and take and how to compromise when they can't always get their own way. Du Toit and Kruger (1991:13) say in forming relationships with peers the child orientates himself socially and with regard to himself as a social being. While involved

with other children the child compares himself with them which is important for the establishment of his social identity and self-concept.

According to Byrne, Cunningham and Sloper (1988:31) children with Down's syndrome pass through a similar developmental progression regarding their relationship with peers than normal children. The only difference is that the stages of play and activities they enjoy reflect their developmental rather than their chronological age. Similarly, they interact more in the neighbourhood with children of a similar developmental level. Pringle (1987:122) has found that early separation of the Down's syndrome child to special and often distant schools means that the child may be deprived of opportunities to interact with other children and establish long-term relationships with them.

Findings by Wyne and O'Connor (1982:397) denoted that very few Down's syndrome children had friends from their neighbourhood who come to visit and play with them. Friends are important to all children, not as a end in itself, but they also serve the purpose for introducing each other to the normal way of life. It is, therefore, also important for the child with Down's syndrome to have friends from all walks of life. Most children with Down's syndrome are sent to institutions and/or attend special schools where they form relationships with children of a similar disposition. These schools and institutions are not always situated locally and the child is in effect isolated from "normal" peers in the neighbourhood (Shepperdson, 1988:108). The type of neighbourhood a child lives in could also foster or hinder the forming and developing of relationships with peers.

Many parents are of the opinion that their disabled child should take part in normal leisure activities with other children (Selikowitz, 1990:112). However, when Down's syndrome children take part in activities with normal

children they need assistance and direction. Playing with friends is therefore often more successful if organised around a specific activity in which the possibility exists to assist the Down's syndrome child. Shepperdson (1988:120) has found that parents do not always encourage interaction with normal children because it is likely that children with Down's syndrome may encounter hostility, ridicule or discrimination from people.

(4) Relationship with teachers

For a teacher to be effective in educating the child and for the child to feel safe and wanted in the classroom a healthy relationship between teacher and child should exist. Nel and Urbani (1990:11-16) regard mutual trust, mutual knowledge, mutual acceptance, mutual respect and authority as essential for a harmonious relationship between the teacher and child.

In essence the educational needs of the child with Down's syndrome are the same as those of normal children but the presence of a disability poses some special problems (Pringle, 1987:117). At school special difficulties are therefore likely to arise unless an early and correct diagnosis is made and the child is placed in a suitable school. If a teacher lacks knowledge of and experience with disabled children, he or she may feel unable to cope effectively and the teacher-child-relationship will be inadequately realised (Beatrice, 1993:121).

Teachers are among the unknown and important figures to any child. As the result of previous experience children with Down's syndrome are often reluctant to trust their teachers (Le Roux, 1985:77). This finding is confirmed by Steenkamp and Steenkamp (1991:20) when they claim that Down's syndrome children are very sensitive to the attitude of other people toward

them. The disabled child will only have trust in his teacher when he realizes that he is treated as a person, that he can freely approach the teacher without fear, and that the teacher has a genuine concern and interest in his special needs (Gallagher, 1983:36). The teacher should have affection for the child and not pity. The disabled child's teacher must be his educator and friend and possess particular personality traits. To be efficient in the education of the disabled child the teacher has to be emotionally well adjusted, enjoy teaching the child, and be able to establish emotional contact while retaining objectivity towards the child (Steenkamp & Steenkamp, 1991:20-21).

In order to educate the child efficiently the teacher should understand the child's particular background, abilities, interests and limitations. Pringle (1987:118) says when teachers understand the child they can convey this to him by their confident and continuous encouragement and support. If the child is aware of the teacher's knowledge of him, he is also aware of the teacher's interest in and concern for him. During their involvement with each other teacher and child get to know each other and a relationship of mutual understanding is established which is extended quantitatively and qualitatively by assimilation and accommodation (Du Toit & Kruger, 1991:13).

Du Plooy, Griessel and Oberholzer (1982:173) state that if a child is not accepted with love by his teachers, he will never experience the security the school can offer him to obtain a firm stand in the world. For the disabled child acceptance by the teacher as he or she is means unconditional acceptance and not as he or she should be. The child will also accept the teacher as a helper leading him to adulthood (Wyne & O'Connor, 1982:36). If mutual acceptance is minimal or absent the teacher will be unable to assist the child to adulthood.

In a final analysis Hutt (Steenkamp & Steenkamp, 1991:110) summarises as follows: "More than affection and good intentions toward the child are needed. Of course, it is basic that the teacher has feelings of warmth, acceptance and love for the child, but without the technical 'know how' the child becomes buried in a "sticky" morass of feelings of pity which eventually may prove to be a detriment to his becoming".

3.3.3 Relationship with objects and ideas

The child is always coming into contact with objects and ideas in his life-world. To assign meaning to objects, involvement and experience are necessary and the child enters into relationships with them (Du Toit & Kruger, 1991:14). These relationships are also extended, adapted and refined during involvement through meaning attribution, assimilation and accommodation with the result that the child's understanding of and orientation toward ideas and object in his world is improved (Vrey, 1990:177-178).

In constituting his life-world the Down's syndrome child establishes relationships with objects and ideas when he becomes aware of them. Piaget (Gunn, 1993:233) states that the child's knowledge of his life-world emerges from his experience and language provides a means of representing what is learned. The child learns to understand and give meaning to reality in a variety of ways, namely playing, laughing, singing, crying, eating, writing, etcetera. However, Op't Hof (1985:5,15) points out that because of his limitations the Down's syndrome child will make sense of his life-world in a different way than the normal child. He will establish his own distinctive relationships with objects and ideas according to his needs and abilities.

The Down's syndrome child with physical constraints may also have limited experiences with objects than their abled bodied peers (Kapp (ed.), 1991:430). A non-accessible environment or the constraint of well-meaning care givers may also deny the child of real life experiences and involvement with objects in the environment (Halliday, 1989:74). The child with Down's syndrome must be given the opportunity to form relationships with objects and ideas in his surrounding world to the best of his limited abilities. In doing this the child orientates himself towards the world and gives meaning to it (Urbani, 1982:39).

In conclusion it must be noted that the more perceptual skills the Down's syndrome child develops in acquainting himself with his life-world, the more readily he can understand it. The more interest the child shows and knowledge he has, the better prepared he will be for adequate orientation in his life-world. This will enable the child to be better equipped to respond to situations such as ones involving danger (Suran & Rizzo, 1989:218-219).

3.3.4 Relationship with God

The religious development of the child is the development of a spiritual relationship between the child and a supreme being or a divine power and indicates a belief in, a reverence for, a desire to please and the exercise of rites and rituals (Gouws & Kruger, 1994:188; Van Niekerk (ed.), 1991:280). The relationship between the child and his deity is characterised by a polarisation that implies belief or unbelief, peace of mind or the lack of it (Du Toit & Kruger, 1991:14).

In the Christian religion the standpoint is taken that man is a worthy being, that he, as a creation of God, is capable of overcoming the physical. Man is

accountable to God and is responsible to God with respect to his calling (Op't Hof, 1985:156). The "differentness" of the Down's syndrome child does not imply that he has less human dignity than the normal child. Urbani (1982:39) says the disabled child has been placed on earth with a purpose and forms a special relationship with God because of his limited abilities.

The Down's syndrome child mainly follows the religion of his parents because he does not have the ability to understand the abstract concepts, which abound in the religious sphere. The child's understanding is limited due to his limited cognitive abilities, his limited environment and experience, social contacts and perhaps poor parental guidance (Le Roux, 1985:55; Steenkamp & Steenkamp, 1992:36). The child cannot give meaning to religion on his own and therefore can only get to know God through the behaviour and *modus vivendi* of the parents who should therefore act as role models. Van den Aardweg & Van den Aardweg (1988:194) describe as follows: "The parents do not only teach the child to pray - the child sees his parents praying; he sees them participating in religious practices and living out what they believe."

The child with Down's syndrome must be specially led to a religious experience in which "acceptance" is manifested. Pringle (1987:40-41) says parents should encourage and help the child to find his own spiritual contentment through a personal acceptance and understanding of God and their disability. It should, however, always be kept in mind that little will be understood by the child with Down's syndrome that is foreign to his experience and which does not arise naturally from it. Parents should therefore not attempt to present religious truths to the child which are beyond his comprehension.

3.4 SUMMARY

The term experience means to be in motion and while being in motion to undergo or experience something. Experience also implies the acquisition of knowledge, getting to know and becoming aware of something. The child learns that experiences have a logical and emotional character which makes an experience so unique to the one who experiences. An experience can be positive or negative, as seen in physical perceptions (comfort or pain), social relationships (acceptance or rejection), with objects (success or frustration) and spiritual experiences (peace or confusion). Experience never occurs in a vacuum, but is related to a person's situation. Therefore, Down's syndrome children with a "limited situation" will also have more limitations on their experiences than their able-bodied peers.

The life-world of the child includes everything that has meaning for him or her, not only the geographical world but all the relationships with objects, ideas, people and the self. These relationships may be interdependent and interactive, they are always dynamic and ever increasing and changing.

The adequate becoming of the Down's syndrome child depends far less on the nature, severity or onset of his impairment than on the relationships formed with himself, other people (parents, siblings, peers, teachers), objects and things and God. The quality of these relationships will determine how the child experiences his disability and the degree to which he actualizes his limited abilities.

Parents experience of their child's impairment will be founded in the next chapter.

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CHAPTER 4

PARENTS' EXPERIENCE OF THEIR CHILD'S IMPAIRMENT

4.1 INTRODUCTION

The birth of a disabled child, or the subsequent discovery of a defect or an irregularity in the development of a child, produce ripples which extend from parents to the immediate family, to relations and friends to medical, educational and social services and society as a whole (Dyson, 1987:23).

Before addressing the problems experienced by parents with Down's syndrome children it is necessary to place in perspective parenthood, the relationship between parent and child and the role of the parents in the upbringing of the child.

4.2 PARENTHOOD

4.2.1 Responsible parenthood

The concept parenthood is synonymous with the acceptance of responsibility for the procreation and rearing of one's child (Urbani, 1982:42). Parents should have no uncertainties as to their responsibility as parents. They should be fully aware of the role, purpose and task, as well as the possibilities and limitations of their activities as regards the education of their children. Therefore no fixed pattern, formula or method can be prescribed to parents in regard of their responsibilities as parents. However, according to Pringle (1987:159) and Packard (Le Roux (ed.), 1992:110-112) the following can be

considered as skills needed by parents in the responsible guiding of the child towards optimal self-actualization:

- Parents must clearly show that they realize the task of bringing up a child with loving support and acceptance. Such parents demonstrate a relationship of warm, emotional closeness to the child and also show emotional involvement. This allows the child to experience security, trust and self-esteem.
- Responsible parents communicate with the child often. Frequent and efficient communication stimulates the child's intellectual development, acquisition of language and communication skills and enrich the child's educational milieu.
- Parents are the most important persons in the child's life and have the greatest influence on the development of a child's self-image. Parents who give credit for a child's positive qualities, listen to the child actively, show interest in him and have high expectations of and respect for him, help the child to develop a positive self-esteem.
- Competent parents encourage the child toward better achievement which contribute to the child's positive self-image. However, parents must not make unrealistically high demands on the child and expect too much of him or her.
- Parents must encourage the child to explore. Opportunities must be created for the child by means of enriching excursions

and by entrusting responsibilities to him or her.

- . A strong feeling of family unity must be instilled in the child by the parents. This can be done by, for example, "evenings at home", family meetings, family conversations and by joining children's activities (play, sport, excursions).
- . Efficient parents guide the child from parental discipline to self-discipline. Parents lay down clear rules and explain them to the child because they are important for his adequate socialization. By praising good conduct and by setting a good example, parents can teach the child self-discipline.
- . Responsible parents equip the child with an explicit set of values. They teach the child the difference between what is right and what is wrong, and equip him with a sense of responsibility and a set of fixed pro-social rules.
- . The competent parent helps the child to accept responsibility by allocating responsibilities and challenges to the child which he will be able to handle.
- . Efficient parents respect their children as human beings.
- . Accountable parents strive to be honest with their children. Honesty also means that parents must be specific and clear regarding any changes they expect children to make.

- Responsible parents avoid the use of vague, descriptive terms that can possibly label the child. Parents who ridicule or shame a child hurt the child emotionally, sometimes with more profound and long lasting effects than physical punishment might cause.
- To be successful in their parenting, parents must be willing to spend time, not only with the child but also in attending to, and thinking about changing their own behaviour as parents.

The child's welfare (physical, emotional, intellectual, volitional and spiritual) must be high priorities in the parents lives. Parents must be fully aware that their child has to be guided, protected, and safeguard in a responsible manner (Freude, 1991:13). The potentials and limitations of their child have to be taken into consideration on all his niveaux of becoming. Pringle (1987:40) is of opinion that the limitations of a child impose a greater responsibility on his parents. They have to take into account to what extent the child's limitations require special attention without being detrimental to other children in the family. Therefore parenthood, with a Down's syndrome child in the family, will be a more demanding and complex task to be performed than in a normal family (Kauffman & Hallahan, 1981: 688).

A child needs a mother as well as a father to provide him with enough self-confidence to lead him to extend the horizons of his life-world and simultaneously to accept his task as co-designer of a world of human co-existence (Nadler, Lewinstein & Rahav, 1991:19).

4.2.2 Parenthood embraces changed attitudes

Parenthood implies in all circumstances changed attitudes among the members of the family concerned, but more particularly the parents. Even before the birth the attitude of the mother changes when she experiences the baby as a reality. After the baby's birth her attitude changes to one of gratefulness and she welcomes this unique little being as a new member of the family (Vrey, 1990: 95-96). To the father the baby only becomes a reality when it is physically in the world. Before the birth of their baby both parents are looking forward to having a child. They inevitably think much about the future of the child and project favourable goals with high aspirations for the child. Parents want their children to be successful in life, well educated and financially secure. The possibility, however, exists that a baby might be born disabled. Gallagher (1983:12) says parents who are told that their child is disabled suffer a symbolic death of the child-to-be with a loss of all their dreams and aspirations.

The initial reaction to diagnosis of a child's impairment, whether it occurs immediately after birth or later, is some measure of shock. Le Master (Lamanna and Riedman, 1988:424) found that most parents experience the birth of a child with Down's syndrome as an "extensive" or "severe" crisis. A quite different crisis is faced by the parents of a disabled child namely the problem of adequate daily care. They realise that a disabled child implies a whole different series of attitudes, actions and inclinations that have to be acquired (Pringle, 1987:117). The arrival of the disabled child brings about considerably more change in the every day family routine and family budget than a normal child. Feeding difficulties, poor health and other problems associated with disabled children, will cause parents to loose more sleep,

keep more irregular hours and adopt to a different kind of orientation than required with the birth of a normal baby (Tunali & Power, 1993: 946).

Rossi (Lamanna and Riedman, 1988:425) describes the transition to parenting a disabled child as "abrupt". The new mother usually starts out on a twenty-four-hour day, with responsibility for a fragile and "mysterious" infant totally dependent on her for care. To a lesser degree this is also true for the father who now has to take over some of the mother's other duties.

4.2.3 Parenthood implies child-rearing

The family is regarded as the primary environment for rearing the child (Du Toit and Kruger, 1991: 54). Conscious of their vocation, parents concentrate on the child in order to equip, mould, lead him to and convince him of meaningful, conscious, voluntary and responsible acceptance of his task in life. *The child on the other hand is a minor who requires assistance, advice, guidance and moulding from the adult to enable him as a responsible person to fulfil his role as adult.* Child rearing in its true form must therefore answer to specific norms. The parents' task in childrearing include the following (Urbani, 1982: 44; Pringle, 1987:26 - 40):

- to win the child's confidence;
- to show faith in their child;
- to show that they accept their child;
- to show an interest in their child, that they care for him and to be sympathetic towards him;
- to make their child feel safe and secure;
- to build up a stable, affective relationship with their child;

- to support their child in his educational need;
- to show an understanding of their child;
- to exercise authority over their child (set requirement and limits); and
- to set norms and values for their child.

From the first moments of the child's existence in the world, he announces that he is someone who will take part in the life-world, a taking part which continues to the end of his life. According to Gouws and Kruger (1994:148) parenting is a continuous series of interactions between parent and child, aimed at helping the child to grow to adulthood. Suran and Rizzo (1989:265) found that parents with Down's syndrome children regard parenting as more difficult than parents with normal children. Except for being weighed down by all the demands of modern society parents cannot anticipate the society or environment in which their children will live as adults. They also have to cope with special demands made by the physical and mental limitations of the child.

4.2.4 Challenges of parenthood

Parents remain the primary influence on the child's cognitive, conative, social, affective, aesthetic, moral, religious and physical development towards realization of the goal of becoming, which is adulthood (Van den Aardweg & Van den Aardweg, 1988:60). The paramount challenge of parenthood is to adequately provide in the needs of the child. The child's need for love, acceptance, security, belonging, confidence, discipline, new experiences, praise and recognition and responsibility have to be met by parents to ensure optimal becoming (Brooks, 1981:98; Pringle, 1987:148 -151).

Lamanna and Riedman (1988:421) maintain that in modern society parenthood becomes more challenging because of the following reasons:

- . Parents are required to master attitudes and techniques that differ considerably from the ones they learned from their parents.
- . Today parents rear their children in a pluralist society, characterised by diverse and conflicting values. Often alien values which they have to observe and conduct their lives accordingly in order to guide the child effectively.
- . Parents have to compete with several other factors that may influence the child, for example the school, church, peers, television, movies and books.
- . Experts in childrearing (education) disagree among themselves which aggravate the confusion of parents.

In principle the challenges of parenthood in families with disabled children are similar to those with normal children but the presence of a disability poses some special challenges to parents. According to Suran and Rizzo (1989:399) and Urbani (1982:46) parents with a Down's syndrome child (an genetic impairment) will be faced with the following challenges:

- . Despite the fact that the child is disabled parents must be grateful to deity for the child.

- Parents must not succumb either consciously or unconsciously to rejecting the child by not accepting full responsibility to care for him or her.
- Parents must accept the disabled child as their own and not hesitate to let him experience love and security because he is a person in his own right and proud of himself despite the nature and scope of his impairment.
- Parents must grant the disabled child the "need to be different and the need to be the same". This means recognising the basic needs of all children but making due allowance for the differences imposed by the nature of a particular disability (Down's syndrome).

4.3 PARENTAL ROLES

The feminist movement helped to create a contemporary social ethos that the role of men and women should be interchangeable inside the family, as well as outside of it. However, research indicates that the marital and parenting role specialization that begins during transition to parenthood is normative of the normal or ideal. In many respects, role specialization is also traditional (Luster & Okagaki, 1993:131).

Parenting and the parental role of the normal and "not normal" child involve many different factors and processes. The child needs responsible parents (adults) to care for him, protect him and introduce him into the rules of the group or society in which he lives (Campion, 1985:71). Parents can best help

the child with Down's syndrome in the following ways (Wyne & O'Connor, 1982:277):

- Keep well informed about the child's progress and work at school.
- Show genuine interest and pride in the child's performance.
- Reinforce positive behaviours rather than exerting undue pressure.
- Maintain a predictable family schedule and routine that is as simple, quiet and relaxing as possible.
- Encourage the child to be a responsible, sharing member of the family and not to excuse inexcusable behaviours simply because the child has disabilities.

4.3.1 The role of the mother

Despite the changing role of fathers today, the primary responsibility for the children still remains with the mother in our society, whether she stays at home or works outside the home, whether the child is normal or "not normal" (Ingalls, 1988:33-34). According to Lamanna and Riedman (1988:415) cultural tradition stipulates that mothers assume primary responsibility for child rearing. Even in a changed society child care is still regarded as the personal responsibility of the mother. It is the mother who is expected to be the child's primary psychological parent, assuming the major responsibility for

the safety and upbringing of the child (Tunali & Power, 1993: 945).

Van den Aardweg and Van den Aardweg (1988:200) say the very fact that a child is accepted and cared for by the mother is a reassuring experience, a safe experience, in a strange, unknown world. To the child with Down's syndrome, or any disabled child, unconditional acceptance by the mother is even more important to the child. The mother is important as a person who can arouse the child's possibilities for forming confident relationships with other people and things (Le Roux, 1985:73). The cherishing care of the mother creates space in which the child feels at home. In the presence of the mother the child is safeguarded and from this place of safety he can venture out and explore the world under the watchful eye of the mother. This means guarding and protecting the child from sensory overload in a world unknown to him. The mother is the ever-present, the security and certainty of human relationships, the protection from danger and the restfulness of tranquil existence. The mother is the first embodiment of the world to the child. Vrey (1990:22) sees a harmonious mother-child relationship as a prerequisite for sound relationships with the world of things.

Regardless of the disability and the degree of the handicap, all children need the care and love that only a mother can offer. Research has shown that in seventy-nine percent of families the relationship between the mother and her Down's syndrome child are characterized by warmth, affection, enjoyment of each others company, and the mother's recognition of the child's "different" personality and "special" needs (Byrne & Cunningham, 1988:63).

4.3.2 The role of the father

The father's part in fostering the child's becoming is primarily a two fold one. Firstly, as breadwinner, it provides the child with security and principal disciplinarian as the head of the family. Secondly it provides the child with an adult model so that he can identify with a member of his own sex, if a boy, and also learn at first hand about the behaviour and attitudes of the opposite sex, if a girl (Pringle, 1987:61).

According to Halliday (1989:19) raising "normal" children is a challenging task, but for parents with a Down's syndrome child additional challenges and problems are inevitable. Medical expenses and special care can put a great deal of stress on the father's role as breadwinner. He might even be forced to seek additional sources of income which will adversely affect the family relationships. Faber (Henderson, 1986:20) states that fathers tend to have more unrealistic expectations of the Down's syndrome child than mothers.

Also more fathers than mothers feel that they are responsible for the child's condition. Byrne and Cunningham (1988:64) says that the guilt feelings of fathers is one of the reasons why they show more interest in residential care for the child. This can be seen as an instinctive reaction to try and protect the family.

4.4 PARENT'S REACTION ON LEARNING OF THEIR CHILD'S IMPAIRMENT

Although all parents react slightly differently to the news that the child has Down's syndrome, most share some similar feelings. They are ordinary

people reacting to an extraordinary situation. Reactions usually come from the heart, not from the head. No matter what they know, or are told, they may experience feelings that may surprise and shock them (Selikowitz 1990:5).

4.4.1 Parental experience

Researches like Mitchell and Brown (1991:43), Krause (1993:207) and Steenkamp and Steenkamp (1991:12) describe various stages that parents are thought to experience after hearing that their child has Down syndrome. The stages are :

- . Shock.
- . Denial or disbelief.
- . Anger.
- . Sadness.
- . Attachment.
- . Reorganisation.
- . Acceptance

(1) Shock

This phase is experienced by most parents immediately after hearing their child has a disability. They experience feelings of confusion, numbness, disorganisation and helplessness. In this stage they are unable to comprehend what they have been told concerning their child's condition. This state of shock can last for moments, or intermittently for days.

(2) Denial or disbelief

Disbelief of the reality of the situation often follows the shock reaction. Denial operates on an unconscious level to ward off excessive anxiety. Denial serves a useful, buffering purpose early on, but can cause difficulties if it persists. If over time and the face of clear evidence, parents continue to deny the existence of their child's handicap, one needs to be cautious that:

- they do not push their child beyond his or her capabilities;
- they do not fail to enrol their child in early intervention programmes; and
- they do not make endless and pointless visits to professionals to receive an acceptable diagnosis.

(3) Anger

When parents realise their child will not develop normally, anger develops. They may be angry with God (Why me?) or at their spouse for having produced a Down syndrome child. Anger is also frequently projected on to the professionals (doctors) for not healing the child, or (teachers) for not helping the child make significant learning progress. Anger can also spring from an unsympathetic community, insensitive professionals, inadequate services, fatigue due to long hospital stays, and similar attitudes. Also, excessive guilt can turn anger inward, and then the parent may blame himself or herself for the disability.

Expressing anger is often cathartic and cleansing, but when parents realise that their angry energy does not change their child's condition, and accept the chronic nature of the handicap, and its complications for the family, a sense of depression may set in.

(4) Sadness

Parents may feel depressed, despairing or just very sad. The phase of processing the situation can lead to secondary consequences such as disturbed relationships between parents or other members of the family. This stage is often linked to the grief felt after the loss of a loved one. In some ways parents are mourning the loss of the child that they had hoped to have, and, this may not be made any easier by the demands made on them by the child.

(5) Attachment

Many parents experience a time when they feel empty. Nothing seems to matter to them. They experience an overwhelming feeling of inadequacy as though their ability to reproduce normal children is in question. This has a great effect on their self esteem and may cause depression. They accept the reality of the disability but have lost some of the meaning of life. Withdrawal from society or social life occurs as a form of protest and self pity or in order to avoid disgrace. Parents respond aggressively or intensely to those people who show little appreciation for their torment. Post-natal blues affect all women to some extent making it even more difficult to cope with disappointment at this time.

(6) Reorganisation

This phase is characterised by realism and hope. Parents begin to orientate themselves to the new situation and adjust to the child. They are less inclined to notice the disability and more inclined to take notice of the baby. Although sorrow continues, the emotional trauma and loss of personal indignation is overcome and rational behaviour and well being is required. Parents consider their cup half-full, rather than half-empty.

(7) Acceptance

The parents try to put things into perspective and to integrate the child into the family. They attempt to make the most of a difficult situation and learn to cope with the special problems of caring for a disabled child. The parents are hopeful that the disabled child will fulfil certain expectations. Therefore, the child's abilities are continuously studied and exposed to various situations and the parents' expectations for the child are modified accordingly.

Acceptance is achieved when parents demonstrate *inter alia* the following characteristics:

- They are able to discuss their child's disability with relative ease.
- They display balance between encouraging independence and showing love.
- They are able to collaborate with professionals to make realistic short and long term plans.

- They can pursue personal interest unrelated to their disabled child.
- They can discipline the child appropriately without undue guilt.
- They can abandon overprotective or unduly harsh behavioural patterns towards their child.

In applying these stages to parents, one needs to be mindful that families are not homogenous and these stages may not be precisely applicable to all the families with disabled children. For some families these stages are cyclical, recurring when new development milestones are achieved or a crisis occurs for example when a child's condition worsens. Other factors that affect the manifestation of these stages include the possible impact of one's culture, whether all members experience the same stage at the same time, how long a particular stage lasts, and what accounts for differences in duration.

4.4.2 Intervention techniques

Operhory and Peters (Selignan & Darling, 1989:160) suggest various intervention techniques that can be used to help parents through the different reaction stages as discussed above. These intervention techniques involve the following.

(1) Denial stage

During this stage the professionals should gently provide an honest evaluation of the situation the parents are confronting. They should simply describe the

child objectively and indicate the care that is needed. They should not remove the parents hope or interfere with their coping style unless it is inappropriate or dysfunctional to their family.

(2) Anger stage

When parents reach the anger stage, professionals must create and open and permissive atmosphere so that parents can vent their anger and pain. They must be accepting of the parents criticism , even if it is directed towards them, without personalizing the parents remark or defending other professionals or themselves. It is important to keep in mind that projected anger reflects the parents own anxiety and stress in the face of a situation that will significantly change their lives. They should be mindful too that some parents have been treated so atrociously by professionals that their anger and frustration is derived from thoroughly objective circumstances.

(3) Bargaining stage

During this phase it is recommended that professionals discourage parents from dwelling on a review of the pregnancy. Parents feel that they can reverse the child's condition by engaging in certain redemptive activities. Professionals should point out the child's positive characteristics, encourage involvement and remain optimistic without giving any guarantees about the child's potential progress. It is also essential that while parents continue to establish a warm loving relationship with the disabled child, they nonetheless balance their lives with personally fulfilling goals and activities. Professionals need to be wary of parents who either fill their lives with a variety of outside activities at the expense of their child, or are so involved with the child that

their lives become severely restricted and they begin to withdraw from others.

(4) Depression stage

This stage can be characterized by mild or severe mood swings. The professionals need to be able to distinguish between clinical depression and milder forms of dysphoria. Mild, situational and time-limited depression is common and liable to emerge at various points in the disabled child's development. Parents need to be reassured that what they are experiencing is normal - not criticized for their feelings of depression. Professionals should be especially alert to signs of regression to earlier stages, although it should not necessarily be viewed with alarm. Anger and mild denial, for example, can resurface and should be considered normal unless these feelings become chronic, excessive and rigidly held.

(5) Acceptance stage

During this stage the professionals should continue to reinforce the positive aspects of the parent-child-relationship. Because a realistic adjustment to the disabled family member is achieved during this stage, it is typically characterised by fulfilling family relationships. Therefore, the need for professional help and support is unlikely to be crucial, although problems may emerge when the disabled child reaches certain developmental milestones.

4.5 SPECIAL NEEDS OF PARENTS

The first few weeks after a baby with Down's syndrome is born is typically a period of inertia for parents (Selikowitz, 1990:3). Generally a diagnosis have

been provided by the paediatrician but no specific course of action has been suggested. As a result many parents experience a feeling of powerlessness.

MacDonald (Darling & Darling, 1982:103) has noted that the period between the diagnosis of the child's disability and learning what to do about it, is the most traumatic period for the parent. When a normal baby is born, hospital staff, friends and relatives offer advice to the new parents. When a disabled baby is born the mother is often isolated in the maternity ward and is to a certain extent ignored by nurses, friends and family members who do not know how to react to the situation. Although there is no simple prescription for quick and painless adjustment to the fact that a child has Down's syndrome, there are four early needs of parents that should be taken into consideration (Freude, 1991:119):

4.5.1 Diagnostic information

Researchers like Freude (1991:120) and Selikowitz (1990:3) have found that there is a clear relationship between ways in which parents are informed of the disability and the acceptance of the problem. Darling and Darling (1982:113) state that most parents feel that a diagnosis should be:

- issued as soon as possible;
- presented to both parents simultaneously;
- presented in a honest but sympathetic manner; and
- accompanied by information on prognosis and treatment options.

Davies (1982:45) reaffirms this view and says that parents should be told in

a private place with no disturbances and have adequate time for information to be given, questions asked and further interviews should be scheduled.

Parents often complain that people, especially well meaning professionals and relatives insist they must accept their disabled child (Byrne & Cunningham, 1988:27). These parents are often angry and resentful about the way in which they were informed. Dyson (1991:625) states that a first negative contact with a professional, concerned with Down's syndrome children, can sour the future relationships with professionals.

In a study done in rural areas, Cheng and Tang (1995:7) found that the majority of the parents were told of their child's disability after minimal contact with the physician and within the first month after birth. These parents indicated a need for sustained and supportive communication as well as information on available community resources. Although these findings may be unique to rural communities, it shows the need for information and follow up services to be developed and made available to parents in all areas.

It is also important that doctors do not talk so "technically" that parents do not understand the information being given (Hanna, 1975:64). Professionals need to be concrete with their clients or patients and "check out" their communication when they sense that they are not understood. The use of professional jargon does not generate respect, it causes distance and implies aloofness. Research done by Smith and Rayan (Cheng & Tang, 1985:5) in China has shown that the lack of language and culture appropriate information concerning the nature of the disability, and the course of interventive actions, seemed to affect parents and children throughout diagnosis and treatment. The parents generally feel angry, guilty, frustrated and powerless. These

findings indicated that considerable work needed to be done to integrate Asian perspectives into professional work with these families. To Chinese parents Anglo or Asian professionals do not possess adequate explanations of mental retardation (eg. Down's syndrome) or other disabilities that are satisfactory from their point of view. Furthermore, most mental or health professionals do not seem to incorporate cultural or social perspectives in their diagnosis and treatment of minority groups. They suggest that new models need to be developed for these families that incorporate cultural perspective into service delivery systems in health and mental health fields.

4.5.2 Knowledge of Down's syndrome

When parents of handicapped children are asked to state their greatest needs, the majority first mention the need to know the exact nature of the handicap (Burne & Cunningham, 1988:20). They want a truthful, direct and simple explanation of their child's defect and the future implications thereof. After obtaining the information they usually want to know what needs to be done next. They seek information about the available services, intervention programs, and special equipment that will assist them in the child's adequate development. They also need to talk to somebody who understands their needs and feelings and wants to help (Lynch & Stalock, 1988: 79).

According to Darling and Darling (1982:124) most parents have an action orientation when learning about their disabled child. They feel a strong need to do something to maintain their self-esteem as parents. Unfortunately, this need is sometimes misinterpreted by professionals as an expression of parental guilt and consequently discounted in importance. Many physicians regard any treatment for the disabled child as futile when cure is not possible. Thus they

stall, not only on diagnosis and prognosis, but also in recommending any kind of treatment for the child (Shearer, 1981:78). Such stalling does not meet the parent's need to do something for their child and generally increases their feelings of powerlessness.

Dyson (1987:138) is of the opinion that the information which could and should be a major resource for parents of disabled children is denied in a variety of intentional and unintentional ways as follows:

- . The information is not given at all.
- . Information is inaccurate, partial and insensitively phrased.
- . Information is given too late.
- . Parents are informed separately.
- . Information is only offered after the parent's suspicion and anxieties have been aroused.
- . Parents are given information once only.
- . Only verbal information is given to the parents.
- . Information is given in terms that are confusing or jargon that is not clearly understood by parents.

Furthermore, sometimes the information that is given is in itself unhelpful, no alternatives is presented, opinions are not distinguished from facts and important additional details are missed (Lynch & Stalock, 1988:80).

Human beings constantly strive to make sense of their experiences. Dyson (1991:626) says when events seem random to the parents, and they feel out of control, most of them try to rationalise their experience and establish order in their lives. Consequently when parents feel anomie they are likely to engage in behaviour that will restore their sense of meaning and purpose.

During their children's infancy most parents become engaged in a process of seekership. They read books, consult experts, write letters and make telephone calls in an attempt to find answers to their questions and alleviate the anomie that they feel. Most parents find the answers they are seeking and their quest ends in normalisation. According to Seligman and Darling (1989: 55) the ideology of normalisation contains the following elements:

- acceptance of the inevitable (it could happen to anyone);
- partial loss of the taken for granted (taking it on a day to day basis);
- redefinition of good and evil (there is always someone worse off); and
- discovery of true values (you appreciate your child's progress more when you just don't take it for granted).

As the disabled child moves through adolescence and approaches adulthood parents are forced to start thinking more seriously about the future. Parents again search for solutions similar in ways to the searches undertaken by parents whose children have just been diagnosed. Gillham (1985:153) says parents search for such things as:

- appropriate living and employment;
- financial and legal advice; and

- social, recreational and when deemed appropriate sexual opportunities for the children.

Thus, as adulthood approaches, the normalisation orientation so common among families during childhood years, is likely to be threatened by a new awareness of unmet needs (Darling & Darling, 1982:173).

4.5.3 Support to parents

Nadler, Lewinstein and Rahav (1991:21) says that soon after diagnosis parents need to have support counselling available to them. Such support could, according to Glenn (1985:349) embraces the following:

- Reduce current stress and leave less painful experiences which will not adversely influence any future crisis.
- Show parents that professional support is useful and productive, thus encouraging them to be aware of the potential of support and seek it out before any severe crisis is upon them.
- Help parents to understand the process through which they are going and methods of analysing what is happening (eg. by developing goals and coping strategies). In the past parents were expected to overcome any feelings of bitterness, resentment, guilt and disappointment in relationship to their child's disability, and to achieve a normalised life style in which the disabled child was not the primary focus of their attention. More and more professionals are coming to realise

that these goals are unrealistic , if not, impossible for most parents of seriously disabled children to attain. Counselling must be action-orientated, helping parents to know and to do, in addition to understanding feeling. The role of the counsellor is thus one of facilitation - that is educating parents in the process of effectively meeting and working to overcome societal constraints.

When parents encounter difficulties in meeting the disabled child's special needs they are likely to continue to search for appropriate services and helpful professionals. Byrne and Cunningham (1988:111) say that to be truly affective, professionals must learn to take the role of the parents. Dyson (1987:127) points out that there is some evidence to suggest that professionals are often uncertain of what is expected of them and suggests that a successful counselling relationship must rely on a give and take basis between parents and professionals. Dyson (1987:127) says the following should be taken into consideration for adequate counselling:

- The parent's point of view must be respected.
- The professional should carefully explain the reasons for recommending a particular course of treatment to parents.
- The parents should be consulted on all major treatment decisions affecting the child.
- The professional should not blame the victims by assuming that the parents are responsible for their own problems.

- Professionals should be truthful with parents at all times.
- Professionals should always find (or make) time to listen to the parents.
- Parents should be shown how to carry out treatment procedures at home that are consistent with the procedures employed in professional sitting.

Parents experience a plethora of contradicting emotions when they first learn their child is disabled. The professional should acknowledge to the parents that their dreams and plans for their child may be severely shaken. It is essential that the professional accept these distressing feelings and not to encourage the family to deny or repress them (Dyson, 1987:128).

Facilitative counselling according to the "Laborde and Seligman" model is recommended by Seligman and Darling (1989:164) to help parents to recognise that they can still, to a large degree, live normal productive and comfortable lives. This counselling procedure to help parents cope can be summarised as follows:

- The professional must encourage parents to seek help for their child as soon as possible.
- Especially in the case of a child with Down's syndrome early infant stimulation can minimize mental retardation.
- Parents blame themselves for the child's disability but are rarely at fault. It is important that the professional helps parents understand that the child's condition is not of their own doing.

Although merely telling them that they are not at fault may not alleviate their guilt and therefore the role of genetic factors must be made very clear to them.

- . Unable to shed their guilt feelings some parents begin an endless and unproductive search for the cause of their child's disorder as for a "cure". Parents may base their feelings on perceived misdeed or they may focus on behaviour or bad thoughts that occurred during pregnancy. Professionals need to listen and not pass off such rumination as unimportant.
- . Parents may also wish to "make up" for supposed past indiscretion by overprotecting their child, holding the child back from activities that can facilitate his or her growth and independence. Professionals need to help parents explore their guilt, understand its negative effect on the family and ideally curb their overprotective behaviour.
- . In terms of rejection, professional support can help parents separate their confused feelings of anger about becoming the parent of a Down's syndrome child, from their generally positive feelings towards the child.
- . Family members may love their child but find an aspect, or aspects, of the disabled child's condition difficult to accept. Also, feelings of rejection, like other emotions are cyclical - they come and go over time. It is important for professionals to help family members realise that feelings of anger and

occasional or limited rejection are normal and that their expression is acceptable.

- Professionals must also help parents cope with their feelings of shame, which involve the expectation of ridicule or criticism from others.

Facilitative counselling must also attend to the concerns that surface or resurface as the child approaches different stages in his life cycle. Darling and Darling (1982:211) state that the following counselling techniques are appropriate at different stages in the life of the child:

- During the postpartum period diagnostic information, hope and support are important.
- During the child's infancy parents need information about treatment and peer support.
- During early childhood family roles, tensions, child management problems and financial difficulties can be resolved.
- During school years parents require advocacy to obtain an appropriate school placement for the child.
- During adolescence children may become active participants in decisions about their own treatment, residential and other plans to be made for their future.

Bailey, Blasco and Simeonsson (1992:1-10) investigated the expressed needs of mothers and fathers of Down's syndrome children. The results showed that mothers expressed significantly more needs than the fathers. The most prevalent needs expressed by mothers were as follows:

- Family and social support.
- Explaining the child's condition to others.
- Opportunities to meet other parents of children with similar disabilities.

Birenbaum and Cohen (1993:67-74) proposed the following in helping families with Down's syndrome children:

- Personal care and family support should be included in health care requirements.
- Family centre care should be promoted.
- Appropriate programs and care should be provided for young adults no longer in school.
- Financing and organising family support should be administratively simple.
- Medical aid should be expanded to increase the use of home and community based services.

- Financial support should be provided

For most parents with Down's syndrome children, information on practical activities which can be reasonably expected to help the baby's development, can be very therapeutic. In the first days, explaining that within the context of the wider issue, various activities with the baby can facilitate development, give parents positive ideas which can be immediately implemented. It is essential that the parents achieve success and are able to observe short-term, positive benefits (Brooks, 1981:45). If they do not achieve some success in their first attempts, they are likely to develop negative expectations about their own abilities, the baby and the future. In turn, they are more likely to be less willing to try other ideas, seek out information or work with services. Belief in the value of such activities is reflected by the rapid expansion of early intervention programmes in recent years (Byrne & Cunningham, 1988:47).

4.5.4 Intervention programs

Just as the child benefits indirectly when the parent is counselled, the parents benefit indirectly from a child's intervention program. When children acquire new skills and begin to function a little more independently their parents can enjoy some relief from the constant burden of caring for them. According to Emery and Tuer (Luster & Okagaki, 1993:135) intervention may have the following forms:

- Screening and evaluation which determines whether the child is in fact disabled - the child's present level of functioning. This information is then used to determine an appropriate invention strategy for the child.

- Medical or surgical intervention which generally precedes other forms of treatment and include some of the following people:
 - Paediatrician.
 - Neurosurgeon.
 - Plastic surgeon.
 - Psychiatrist
- Education intervention will include early intervention, preschool programs and special and prevocational education.
- Therapeutic intervention which consists of physical therapy, speech therapy and occupational therapy.
- Behaviour management helps parents with special behaviour problems associated with various disabling conditions especially mental retardation.
- Recreational intervention provides both enjoyment and therapy to the handicapped child.
- All these intervention strategies attempt in some way to change the Down's syndrome child by improving functioning, appearance and self satisfaction.

It has been known that the results of intervention are dramatic. For example many Down's syndrome children who would have been institutionalized thirty years ago, now participate in infant stimulation and nursery school programs that enable them to function in the upper range of moderation (Darling & Darling, 1982:220).

Professionals must not assume that they have a right to intervene in families simply because these families have a Down's syndrome child. Parents must be active participants in determining what kind of help they need and how much help is needed. When families agree that therapeutic intervention would be beneficial, professionals trained in a family system perspective can be tremendously helpful to them (Seligman & Darling, 1989:180).

4.5.5 Meeting other parents

Cunningham (1982:39) and Selikowitz (1990:39) feel that parents should talk to other parents who have children with similar disabilities. This should be of a great benefit in terms of obtaining information and receiving support. Support groups can be led by professionals, by members, or members with professional consultation available (Freude, 1991:15).

Cheng and Tang (1995:19) state that parent organisations and self help groups are effective ways to help parents with disabled children because:

- they provide a means of obtaining peer support;
- it is a means of sharing positive and mutual experience;
- effective coping skills can be learned; and
- they can advocate their needs and common concerns to policy-makers through collective effort.

Prior to their association with other parents, many parents feel sorry for themselves and assume that their problems are more serious than those of others. Through association parents come to know of more seriously affected children and become grateful that their own problems are not worse (Davies, 1982: 46).

Bondo (1980:20) explains that her most helpful experience was meeting a couple who like them, had a late addition to the family, a Down's syndrome child. The encouraging talk they had with the couple about the daily happiness their daughter gave them without complaining over the amount of work involved, did a great deal to ease their situation in the days to come.

In South Africa, Down's syndrome associations are established in the major cities, enabling parents easy access to these professionals. Edelstein (1984:73) explains the goals of these associations as follows:

- To assist families in orientating to the birth of a child with Down's syndrome.
- To provide informational services to the parents regarding the phenomenon of Down's syndrome.
- To increase public awareness regarding Down's syndrome.
- To help parents embark on programmes of stimulating exercises and diet plans to bring the best out of the child.
- To provide parents with needed advice.

- To provide counselling services for parents during times of shock and distress.
- To provide support during initial diagnosis.

Professionals should be sensitive to the fact that some parents prefer to avoid contact with families of other disabled children. Some parents, however, are pleased to meet regularly with parents facing similar problems, and some become highly involved in the organisation of self-help groups (Freude, 1991:155). When parents with disabled children are able to share their problems, joys and sorrows, they help themselves as well as others.

4.6 THE EMOTIONAL EFFECT OF CARING FOR THE DISABLED

Cheng and Tang's (1995:19) research indicated that the parents of Down's syndrome children, particularly the mothers, are very distressed. They feel that there is very little they can do to improve the condition and tend to avoid the problem. Bailey, Blasco and Simeonsson (1992: 7) suggest that chronic stress is caused by the hardship experienced by the family of a disabled child. They have summarised the hardships suffered by parents of disabled children in the following eight groups:

- Financial hardships which results from medical consultations, medications, hospitalization, specialised treatment and equipment programming.
- Strained emotional relationships in the family which include overprotection, rejection, less time for other members of the family and scapegoating of the child. One parent blaming the

other believed to be genetically responsible for the child's disablement will increase the overall tension and conflict in the family. The experiencing of difficulties in managing family relationships sometimes result in marital disharmony and marital breakdown.

- The inevitable modification in family activities and goals which include more general hardships related to leisure activities, career opportunities and family organisation. Both the amount and flexibility of leisure are reduced in these families. Similarly, increased tasks and time commitments make it difficult for parents, especially mothers to pursue careers.
- The need for geographic proximity to medical facilities reduces flexibility in family responsibilities, and may contribute to overall family stress, parental responsibilities and general family disorganisation.
- Family social life which includes negative reactions from friends and neighbours, parents and sibling embarrassment at how the child looks and acts, fear of accidents and limited mobility can all lead to family isolation.
- The time burdens of providing daily therapy or treatment for the child. This includes special diets, appointments to medical facilities or the like.

- Family contact with large institutions which are potential stressors that emerge from medical treatment and schooling.
- Parental grieving due to the fact that the child's life opportunities are often restricted and the parent may even anticipate an early death of which the psychological hardship can be significant.

In examining these potential stressors closely, it is clear that some very basic human needs can be threatened by having a Down's syndrome child in the family. The needs of a disabled child range from immediate material needs (safety, financial security) to higher level needs such as achievement. In each case the inability to fulfil some specific need, such as a sense of security or a satisfactory social life, appears to be the source of potential stress. These needs are parallel to the needs identified by Maslow (Herman, 1994:418). These findings were also confirmed by Dyson (1993:207) who found that parental stress pertained to all aspects of caring for the child with disabilities and included everyday care, pessimism about the child's future and concern about the child's physical and behavioural characteristics.

According to findings by Krause (1993:404) fathers reported more stress from personal consequences of parenting, in other words fathers were consistently more troubled than were mothers by various aspects of their relationships with their disabled child. Fathers may turn inward, towards their families, whereas mothers turn outward toward social support networks in the face of a "crisis" regarding the disabled child's development. Dyson (1991:623-629) suggests that in order to lessen stress, intervention should be directed at increasing the child's competence, caretaking of the child and changing parental perception,

for it appears that these are the key areas that contribute to parental stress.

4.7 SUMMARY

Childbirth classes often prepare expectant parents for the birth of a normal baby. As a result of this socialisation for normality, combined with culturally negative, stereotyped and stigmatized images of Down's syndrome individuals, most parents feel shocked and are greatly saddened by the birth of a such a child.

Since the birth of their Down's syndrome child the parents will be subject to a series of predictable potential crises. The first crisis is invariably precipitated by the knowledge of the existence of the disability itself and it will be enormously susceptible at that time to traumatic mismanagement, the effects of which will reverberate agonizingly down the years. The second crisis will arise whenever educational placement is considered. The third crisis comes at school leaving. All too often the child's sudden emergence from a protective environment into a harsh world of reality with it's problems of employment, sexuality and marriage proves overwhelming. The next certain crisis is that of impending parental old age and the inability to provide support.

These problems should be discussed with professionals who are able to offer not just a crisis intervention service, but what so many parents have expressed as their prime need, a continuity of competent and compassionate contact orientated to prevention and dedicated to communication.

Basically the positive handling of the matter of a disabled child in the family is a sober acceptance of reality and an objective, goal directed point of view, rather than negative speculation on possible causes. Acceptance of the fact that the child is intellectually impaired, especially a whole-hearted acceptance of the child as part of the family with appreciation of his individuality, pride in what he or she can achieve and tolerance of the child's imperfections.

In the following chapter the planning of the research will be explained.

CHAPTER 5

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CHAPTER 5

PLANNING OF THE RESEARCH

5.1 INTRODUCTION

In the preceding chapters the life-world of the child with Down's syndrome was described, and the parent's experience of such a child's impairment were delineated by means of available relevant literature. The literature study revealed definite differences between the life-world of a disabled child and the life-world of a normal child. Parents experience their Down's syndrome child in ways that differ remarkably from that experienced by parents with only normal children. The education of a child with Down's syndrome is also quite different from that of a normal child. In this chapter the research methodology used in the investigation of the life-world of the parents' with Down's syndrome children will be described.

5.2 SELECTION OF RESPONDENTS

With the aim of administering a questionnaire to the parents of children with Down's syndrome the researcher contacted the Association for Down's Syndrome in Durban in order to obtain the names of institutions and schools that care for these children. The following names were supplied:

- . Westridge Park School.
- . Sunfield Home.
- . Overport Down's syndrome parents' group.

With the assistance of the abovementioned school and institutions a list was

compiled with the names of parents with Down's syndrome children. Parents were contacted telephonically and appointments made with those who were willing to participate in the investigation. The researcher visited these parents on the arranged dates and had the questionnaire completed in her presence. In being present the researcher was able to assist parents in cases where they might experience any difficulty in understanding or interpreting questions. From the personal visit to parents the snowball technique developed - the names of other parents with Down's syndrome children were given to the researcher.

Because of the limited number of Indian parents with Down's syndrome children in the Durban area no random selection of correspondents could be made. Thirty-five Indian couples with Down's syndrome children were contacted by telephone. Researcher looked for and succeeded in getting twenty Indian couples where both parents (mother and father together) were willing to act as respondents.

5.3 THE RESEARCH INSTRUMENT

5.3.1 The questionnaire as research instrument

According to Van Rensburg, Landman and Bodenstein (1994: 504) a questionnaire is a set of questions dealing with some topic or related group of topics, given to a selected group of individuals for the purpose of gathering data on a problem under consideration. Van den Aardweg and Van den Aardweg (1988:190) say the questionnaire is a prepared question form submitted to certain persons (respondents) with a view to obtaining information. Churchill and Peter (Schnetler, 1993: 77) have shown that this measuring instrument has the greatest influence on the reliability of research data. The characteristics of measurement are best controlled by the careful

construction of the instrument. There is, however, insufficient appreciation for the fact that a questionnaire should be constructed according to certain principles (Kidder & Judd, 1986:128-131; Behr, 1988:155-156).

A well-designed questionnaire is the culmination of a long process of planning the research objective, formulating the problem, generating the hypothesis, etc. A poorly designed questionnaire can invalidate any research results, notwithstanding the merits of the sample, the field workers and the statistical techniques (Huysamen, 1994:2). In their criticism of questionnaires Berchie and Anderson (Schnetler, 1993:61) object to poor design rather than to questionnaires as such. A well-designed questionnaire can boost the reliability and validity of the data to acceptable tolerances.

It therefore stands to reason that questionnaire design does not take place in a vacuum. According to Dane (1990:315-319) the length of individual questions, the number of response options, and the format and wording of questions are determined by the following:

- . The choice of the subject to be researched.
- . The aim of the research.
- . The size of the research sample.
- . The method of data collection.
- . The analysis of the data.

Against this background the researcher can now look at the principles that determine whether a questionnaire is well-designed. It is thus necessary to draw a distinction between questionnaire content, question format, question order, type of questions, formulation of questions and validity and reliability of questions

5.3.2 Construction of the questionnaire

Questionnaire design is an activity that should not take place in isolation. The researcher should consult and seek advice from specialists and colleagues at all times during the construction of the questionnaire (McBurney, 1994:98). Questions to be taken up in the questionnaire should be tested on people to eliminate possible errors. A question may appear correct to the researcher when written down but can be interpreted differently when asked to another person. There should be no hesitation in changing questions several times before the final formulation keeping the original purpose in mind. The most important point to be taken into account in questionnaire design is that it takes time and effort and that the questionnaire will be re-drafted a number of times before being finalised. A researcher must therefore ensure that adequate time is budgeted for in the construction and preliminary testing of the questionnaire (Kidder & Judd, 1986:243-245). All of the above was taken into consideration by the researcher during the designing of the questionnaire for this investigation.

An important aim in the construction of the questionnaire for this investigation was to keep it as short as possible, and to present the questions as simple and straightforward as possible. The researcher further aimed to avoid ambiguity, vagueness, bias, prejudice and technical language in the questions.

The aim of the questionnaire (Appendix A) was to obtain information regarding Indian parents' experience of their Down's syndrome child. The questions were formulated to establish the following:

- Parents' knowledge about the disability of their child.
- Parents' knowledge of the possibilities of a child with Down's syndrome.

- Available support to parents.
- Acceptance of the Down's syndrome child in the family and community.

The questionnaire was sub-divided into the following sections:

- Section one which dealt with the biographical information of the respondents.
- Section two and three focused on the parent's knowledge of their child.
- Section four examined the support available to the parents.
- Section five explored the acceptance of the child with Down's syndrome in the family and community.
- Section six investigated the parents' perception of the child's experience of his or her impairment

5.3.3 Characteristics of a good questionnaire

Throughout the construction of the questionnaire the researcher had to consider the characteristics of a good questionnaire in order to meet the requirements necessary for the research instrument to be reliable. The characteristics of a good questionnaire that were considered by the researcher are, according to Van den Aardweg and Van den Aardweg (1988:190), Mahlangu (1987:84-85) and Norval (1988:60) the following:

- . It has to deal with a significant topic, one the respondent will recognize as important enough to warrant spending his or her time on. The significance should be clearly and carefully stated on the questionnaire and on the accompanying letter.
- . It must seek only that information which cannot be obtained from other sources.
- . It must be as short as possible, but long enough to get the essential data. Long questionnaires frequently find their way into the wastepaper basket.
- . Questionnaires should be attractive in appearance, neatly arranged and clearly duplicated or printed.
- . Directions for a good questionnaire must be clear and complete and important terms clearly defined.
- . Each question has to deal with a single concept and should be worded as simply and straightforwardly as possible.
- . Different categories should provide an opportunity for easy, accurate and unambiguous responses.
- . Objectively formulated questions with no leading suggestions should render the desired responses. Leading questions are just as inappropriate in a questionnaire as they are in a court of law.

- Questions should be presented in a proper psychological order, proceeding from general to more specific and sensitive responses. An orderly grouping helps respondents to organise their own thinking so that their answers are logical and objective. It is preferable to present questions that create a favourable attitude before proceeding to those that are more intimate or delicate in nature. Annoying and/or embarrassing questions should be avoided if possible.

5.3.4 Advantages and disadvantages of the questionnaire

Data can be gathered by means of a structured questionnaire in *inter alia* the following ways: a written questionnaire that is mailed, delivered or handed out personally; personal interviews; telephone interviews (Kidder and Judd, 1986: 221). Each mode has specific advantages and disadvantages which the researcher needs to evaluate for their suitability to the research question and the specific target population being studied, as well as the relative cost. The researcher used the written questionnaire as research instrument taking into consideration the following advantages (Mahlangu, 1987:94-85; Norval, 1988:60).

(1) Advantages of the written questionnaire

The following may be listed as the advantages of the written questionnaire:

- Affordability is the primary advantage of written questionnaires because it is the least expensive means of data gathering.

- Written questionnaires preclude possible interviewer bias. The way the interviewer asks questions and even the interviewer's general appearance or interaction may influence respondent's answers. Such biases can be completely eliminated with a written questionnaire.
- A questionnaire permits anonymity. If it is arranged such that responses were given anonymously, this would increase the researcher's chances of receiving responses which genuinely represent a person's beliefs, feelings, opinions or perceptions.
- They permit a respondent a sufficient amount of time to consider answers before responding.
- Questionnaires can be given to many people simultaneously, that is to say that a large sample of a target population can be reached.
- They provide greater uniformity across measurement situations than interviews. Each person responds to exactly the same questions because standard instructions are given to the respondents.
- Generally the data provided by questionnaires can be more easily analyzed and interpreted than the data obtained from verbal responses.
- Using a questionnaire solves the problem of non-contact when the respondent is not at home "when the interviewer calls".

When the target population to be covered is widely and thinly spread, the mail questionnaire is the only possible method of approach.

- . Through the use of the questionnaire approach the problems related to interviews may be avoided. Interview "errors" may seriously undermine the reliability and validity of survey results.
- . A respondent may answer questions of a personal or embarrassing nature more willingly and frankly on a questionnaire than in a face to face situation with an interviewer who may be a complete stranger. In some cases it may happen that respondents report less than expected and make more critical comments in a mail questionnaire.
- . Questions requiring considered answers rather than immediate answers could enable respondents to consult documents in the case of the mail questionnaire approach.
- . Respondents can complete questionnaires in their own time and in a more relaxed atmosphere.
- . Questionnaire design is relatively easy if the set guidelines are followed.
- . The administering of questionnaires, the coding, analysis and interpretation of data can be done without any special training.
- . Data obtained from questionnaires can be compared and inferences made.

- Questionnaires can elicit information which cannot be obtained from other sources. This renders empirical research possible in different educational disciplines.

(2) Disadvantages of the questionnaire

The researcher is also aware of the fact that the written questionnaire has important disadvantages. According to Van den Aardweg and Van den Aardweg (1988:190), Kidder and Judd (1986:223-224) and Mahlangu (1987:84-85) the disadvantages of the written questionnaire are *inter alia* the following:

- Questionnaires do not provide the flexibility of interviews. In an interview an idea or comment can be explored. This makes it possible to gauge how people are interpreting the question. If questions asked are interpreted differently by respondents the validity of the information obtained is jeopardized.
- People are generally better able to express their views verbally than in writing.
- Questions can be answered only when they are sufficiently easy and straightforward to be understood with the given instructions and definitions.
- The mail questionnaire does not make provision for obtaining the views of more than one person at a time. It requires uninfluenced views of one person only.

- Answers to mail questionnaires must be seen as final. Re-checking of responses cannot be done. There is no chance of investigating beyond the given answer for a clarification of ambiguous answers. If respondents are unwilling to answer certain questions nothing can be done to it because the mail questionnaire is essentially inflexible.
- In a mail questionnaire the respondent examines all the questions at the same time before answering them and the answers to the different questions can therefore not be treated as "independent".
- Researchers are unable to control the context of question answering, and specifically, the presence of other people. Respondents may ask friends or family members to examine the questionnaire or comment on their answers, causing bias if the respondent's own private opinions are desired.
- Written questionnaires do not allow the researcher to correct misunderstandings or answer questions that the respondents may have. Respondents might answer questions incorrectly or not at all due to confusion or misinterpretation.

5.3.5 Validity and reliability of the questionnaire

There are two concepts that are of critical importance in understanding issues of measurement in social science research, namely validity and reliability (Huysamen, 1994:1-3). All too rarely do questionnaire designers deal consciously with the degree of validity and reliability of their instrument. This

is one reason why so many questionnaires are lacking in these two qualities. Questionnaires have a very limited purpose. In fact, they are often one-time data gathering devices with a very short life, administered to a limited population. According to McBurney (1994:102) there are ways to improve both the validity and reliability of questionnaires. Basic to the validity of a questionnaire is asking the right questions phrased in the least ambiguous way. In other words, do the items sample a significant aspect of the purpose of the investigation? Terms must be clearly defined so that they have the same meaning to all respondents (Cohen & Manion, 1989: 111-112).

Kidder and Judd (1989:53-54) mention the fact that although reliability and validity are two different characteristics of measurement, they "shade into each other". They are two ends of a continuum but at points in the middle it is difficult to distinguish between them. Validity and reliability are especially important in educational research because most of the measurements attempted in this area are obtained indirectly. Researchers can never guarantee that an educational or psychological measuring instrument measures precisely and dependably what it is intended to measure (Van den Aardweg & Van den Aardweg, 1988:198; McBurney, 1994:121). It is essential, therefore, to assess the validity and reliability of these instruments. Researchers must therefore have a general knowledge as to what validity and reliability are and how one goes about validating a research instrument and establishing its reliability (Huysamen, 1994:1-3).

(1) Validity of the questionnaire

Van Rensburg, Landman and Bodenstein (1994:560) define validity as the extent to which a measuring instrument satisfies the purpose for which it was constructed. It also refers to the extent to which it correlates with some

Van Rensburg, Landman and Bodenstein (1994:560) define validity as the extent to which a measuring instrument satisfies the purpose for which it was constructed. It also refers to the extent to which it correlates with some criterion external to the instrument itself. Validity is that quality of a data-gathering instrument or procedure that enables it to determine what it was designed to determine. In general terms validity refers to the degree to which an instrument succeeds in measuring what it has set out to measure. Behr (1988:122) regards validity as an indispensable characteristic of measuring devices.

Van den Aardweg and Van Den Aardweg (1988:237), Mulder (1989:215-217) and Dane (1990:257-258) distinguish between three different types of validity:

- . Content validity where content and cognitive processes included can be measured. Topics, skills and abilities should be prepared and items from each category randomly drawn.
- . Criterion validity which refers to the relationship between scores on a measuring instrument and an independent variable (criterion) believed to measure directly the behaviour or characteristic in question. The criterion should be relevant, reliable and free from bias and contamination.
- . Construct validity where the extent to which the test measures a specific trait or construct is concerned, for example, intelligence, reasoning, ability, attitudes, etcetera.

It means that validity of the questionnaire indicates how worthwhile a measure is likely to be in a given situation. Validity shows whether the

identify and characterize (Schnetler, 1993:71). If the ability or attitude is itself stable, and if a respondent's answers to the items are not affected by other unpredictable factors, then each administration of the instrument should yield essentially the same results (Dane, 1990:158).

The validity of the questionnaire as a research instrument reflects the sureness with which conclusions can be drawn. It refers to the extent to which interpretations of the instrument's results, other than the ones the researcher wishes to make, can be ruled out. Establishing validity requires that the researcher anticipates the potential arguments that sceptics might use to dismiss the research results (Dane, 1990:148-149).

The researcher employed the questionnaire as an indirect attempt to understand the life-world of Indian parents with Down's syndrome children. Because of the complexity of the respondents attributes one is never sure that the questionnaire devised will actually measure what it purports to measure. Items in the questionnaire cannot be measured like height, mass, length or size. From the interpretation of the results obtained and the sureness with which conclusions could be drawn, the researcher is, however, convinced that the questionnaire to a great extent did measure that which it was designed for.

(2) Reliability of the questionnaire

According to Van Rensburg, Landman and Bodenstein (1994: 512) reliability is a statistical concept and relates to consistency and dependability. Consistency of obtaining the same relative answer when measuring phenomena that have not changed. A reliable measuring instrument is one that, if repeated under similar conditions, would present the same result or a

near approximation of the initial result. Van den Aardweg and Van den Aardweg (1988:194) and Kidder and Judd (1986: 47-48) distinguish between the following types of reliability:

- . Test-retest reliability (coefficient of stability) - consistency estimated by comparing two or more repeated administrations of the measuring instrument. This gives an indication of the dependability of the results on one occasion and on another occasion.
- . Internal consistency reliability. This indicates how well the test items measure the same thing.
- . Split-half reliability. By correlating the results obtained from two halves of the same measuring instrument, we can calculate the split-half reliability.

In essence, reliability refers to consistency, but consistency does not guarantee truthfulness. The reliability of the question is no proof that the answers given reflect the respondent's true feelings (Dane, 1990: 256). A demonstration of reliability is necessary but not conclusive evidence that an instrument is valid. Reliability refers to the extent to which measurement results are free of unpredictable kinds of error. Sources of error that effect reliability are *inter alia* the following (Kidder & Judd, 1986:45):

- . Fluctuations in the mood or alertness of respondents because of illness, fatigue, recent good or bad experiences, or temporary differences amongst members of the group being measured.

- . Variations in the conditions of administration between groups. These range from various distractions, such as unusual outside noise to inconsistencies in the administration of the measuring instrument such as omissions in verbal instructions.
- . Differences in scoring or interpretation of results, chance differences in what the observer notices and errors in computing scores.
- . Random effects by respondents who guess or check off attitude alternatives without trying to understand them.

When the questionnaire is used as an empirical research instrument there is no specific method, for example the "test-retest" method, to determine the reliability of the questionnaire. Therefore, it will be difficult to establish to what extent the answers of the respondents were reliable. The researcher, however, believes that the questionnaires in this investigation were completed with the necessary honesty and sincerity required to render the maximum possible reliability. Frankness in responding to questions was made possible by the anonymity of the questionnaire. In the coding of the questions it was evident that questionnaires were completed with the necessary dedication.

5.4 PILOT STUDY

A pilot study is an abbreviated version of a research project in which the researcher practises or tests the procedures to be used in the subsequent full-scale project (Dane, 1990:42). For the purpose of the pilot study in this research project six Indian families with Down's syndrome children were selected. The pilot study is a preliminary or "trial run" investigation using

similar questions and similar subjects as in the final survey. Kidder and Judd (1986:211-212) say the basic purpose of a pilot study is to determine how the design of the subsequent study can be improved and to identify flaws in the measuring instrument. A pilot study gives the researcher an idea of what the method will actually look like in operation and what effects (intended or not) it is likely to have. In other words, by generating many of the practical problems that will ultimately arise, a pilot study enables the researcher to avert these problems by changing procedures, instructions and questions.

The number of participants in the pilot study is normally smaller than the number scheduled to take part in the final survey. Participants in the pilot study and the sample for the final study must be selected from the same target population. For the purpose of this study the researcher conducted a pilot run on six parents with Down's syndrome children from other race groups.

According to Plug, Meyer, Louw and Gouws (1991: 49-66) the following are the purposes of a pilot study, and these were also the aim of the researcher in this survey:

- It permitted a preliminary testing of the hypothesis that leads to testing more precise hypotheses in the main study.
- It provided the researcher with ideas, approaches and clues not foreseen prior to the pilot study.
- It permitted a thorough check of the planned statistical and analytical procedures, thus allowing an appraisal of their adequacy in treating the data.

- . It greatly reduced the number of treatment errors because unforeseen problems revealed in the pilot study resulted in redesigning the main study.
- . It saved the researcher major expenditures of time and money on aspects of the research which would have been unnecessary.
- . Feedback from other persons involved were made possible and led to important improvements in the main study.
- . In the pilot study the researcher tried out a number of alternative measures and selected only those that produced the best results for the final study.
- . The approximate time required to complete the questionnaire was established in the pilot study.
- . Questions and/or instructions that were misinterpreted were reformulated.

Through the use of the pilot study as "pre-test" the researcher was satisfied that the questions asked complied adequately to the requirements of the study.

5.5 ADMINISTRATION OF THE QUESTIONNAIRE

If properly administered the questionnaire is the best available instrument for obtaining information from widespread sources or large groups simultaneously. The researcher personally visited Indian parents with Down's

syndrome children in the Durban area to have the questionnaire completed. This method of administration facilitated the process and a return rate of 100% was obtained.

5.6 THE PROCESSING OF THE DATA

Once data was collected, it had to be captured in a format which would permit analysis and interpretation. This involved the careful coding of the 20 questionnaires completed by the parents with Down's syndrome children. The coded data was subsequently transferred onto a computer spreadsheet using the Quattro Pro 4.0 statistics computer programme. Data was converted into frequency tables to enable the researcher to analyze the findings by means of descriptive statistics.

Descriptive statistics serve to describe and summarise observations (Van Rensburg, Landman & Bodenstein, 1994:355). Frequency tables, histograms and polygons are useful in forming impressions about the distribution of data. According to Van den Aardweg and Van den Aardweg (1988: 65-76) frequency distribution is a method to organize data obtained from questionnaires to simplify statistical analysis. For the purpose of this study frequency tables were employed to provide percentages that reflect the number of responses to a certain question in relation to the total number of responses.

5.7 LIMITATIONS OF THE INVESTIGATION

This investigation was constrained by a number of factors. The following are likely factors that might have influenced the reliability and validity of the questionnaire:

- The possibility exists that, because of the cautiousness of parents of disabled children, they might not have been frank and truthful in their responses.
- The sensitive nature of certain items in the questionnaire might have elicited false or misleading responses and influenced the reliability of the results.
- The investigation was confined to parents of Down's syndrome children living in an urban area (Durban) only. Different responses might have been elicited from parents in rural areas.
- Difficulty was experienced in finding enough Indian parents with Down's syndrome children . This resulted in only a relative small number of questionnaires being available for analysis which would have influenced the validity of the results.

5.8 SUMMARY

In this chapter the planning and design of the empirical research was discussed and a comprehensive description of the questionnaire as research instrument was given.

In the following chapter the data obtained from the completed questionnaires will be analyzed.

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CHAPTER 6

PRESENTATION AND ANALYSIS OF THE RESEARCH DATA

6.1 INTRODUCTION

The objective of this chapter is to discuss the data which was collected from the questionnaires completed by twenty couples (father and mother together) with Down's syndrome children. Findings from the data will be interpreted and commented on. Apparent patterns and trends reflected will be discussed. Thereafter the responses to specific questions will be presented by means of descriptive statistics.

6.2 DESCRIPTIVE STATISTICS

The descriptive method of research seeks to describe a situation as it is - in this study the life-world of Indian parents with a Down's syndrome child. There is no intervention on the part of the researcher by means of experimental control or the establishing of possible causes and effects. By means of descriptive research, the aim was to seek the settings in the Indian family with a Down's syndrome child, with reference to the parent's experience of the child's impairment. The data obtained from the questionnaires was organized in frequency tables to simplify statistical analysis. Frequency tables are useful in forming impressions about the distribution of data. For the purpose of this study, frequency tables were employed to provide percentages that would reflect the number of responses to a certain question in relation to the total number of responses.

6.2.1 Parents' age at birth of Down's syndrome child

Table 1 **Distribution according to the parents' age at the birth of the child with Down's syndrome**

| | Age | Father | Mother |
|---|--------------|-------------|-------------|
| 1 | 0 - 20 year | 0% | 5% |
| 2 | 21 - 25 year | 10% | 15% |
| 3 | 26 - 30 year | 20% | 15% |
| 4 | 31 - 35 year | 20% | 15% |
| 5 | 36 - 40 year | 10% | 20% |
| 6 | 41 - 45 year | 40% | 30% |
| | TOTAL | 100% | 100% |

Table 1 shows that half of the mothers (50%) were older than 35 years, and 30% were older than 40 years when they gave birth to the child with Down's syndrome. This finding correlates with the findings from other researchers as indicated in Chart 1 (cf. 2.3). The risk of having a child with Down's syndrome increases with the age of the mother (Lane & Stratford, 1985:98).

Although Table 1 shows that most of the fathers (50%) were also older than 36 years, research has shown that there is no relationship between the incidence of Down's syndrome and the age of the father at the birth of such a child (Suran & Rizzo, 1989,219).

6.2.2 Parents' place of residence

Table 2 Distribution according to the parents' place of residence

| | Place of residence | % |
|---|---------------------|-------------|
| 1 | Own house | 65% |
| 2 | Own flat | 5% |
| 3 | Rented house | 0% |
| 4 | Rented flat | 25% |
| 5 | Living with parents | 5% |
| | TOTAL | 100% |

The majority of couples (parents) (65%) were house or flat owners (Table 2). It is primarily the parents' task to make the child feel at home in the world and to prepare him for the demands of life which will be made on him. For this, a permanent space, a family space or home, is necessary. Kapp (ed.) (1992:465) says that a caring space, i.e. an own family home, is experienced by the child as *personal space* - a place of trust and intimacy, to which the child attributes certain meaning and certain value with regard to his own situatedness in the world.

6.2.3 Age of child with Down's syndrome

Table 3 **Distribution according to the ages of the children with Down's syndrome**

| | Age of children | % |
|---|-----------------|-------------|
| 1 | 0 - 5 years | 45% |
| 2 | 6 - 10 years | 15% |
| 3 | 11 - 15 years | 25% |
| 4 | 16 - 20 years | 5% |
| 5 | 21 - 25 years | 10% |
| | TOTAL | 100% |

According to Table 3 most of the children (45%) with Down's syndrome were younger than 5 years. Compared with the mothers' ages in Table 1 (cf. 6.2.1), this is a further indication that mothers older than 35 years, fall in the "high risk" group of giving birth to a child with Down's syndrome.

6.2.4 Types of Down's syndrome

Table 4 **Distribution according to the type of Down's syndrome the child has**

| | Type of Down's syndrome | % |
|---|---------------------------------|-------------|
| 1 | Trisomy 21 - Down's syndrome | 70% |
| 2 | Translocation - Down's syndrome | 0% |
| 3 | Mosaicism - Down's syndrome | 0% |
| 4 | Not known by parents | 30% |
| | TOTAL | 100% |

Nearly three quarters of the couples (70%) indicated that their child has Trisomy 21 - Down's syndrome. However, during the researcher's interviews with the parents (mother and father), it became evident that they were merely informed about the type of Down's syndrome, but did not really understand the true meaning of the child's condition. Surprising was also the fact that as many as 30% of the parents did not know what type of Down's syndrome their child has. During the interviews it emerged that these parents were not even aware of the existence of the different types of Down's syndrome.

6.2.5 Position of the Down's syndrome child in the family

Table 5 **Distribution according to the position of the Down's syndrome child in the family**

| | Position | % |
|---|---------------|-------------|
| 1 | Eldest | 40% |
| 2 | Second child | 25% |
| 3 | Third child | 5% |
| 4 | Fourth child | 15% |
| 5 | Fifth child | 0% |
| 6 | Sixth child | 0% |
| 7 | Seventh child | 5% |
| | TOTAL | 100% |

For the majority of couples in Table 5, the child with Down's syndrome was their first born. In the interviews with these couples, most of the mothers remarked that they were unaware of the possibility of giving birth to a Down's syndrome child. The majority of mothers over thirty-five expressed the

opinion that it was the responsibility of their family doctor or the gynaecologist to inform them about the risks of having a first child at that age. Because they were in the "high risk" group, they also felt that the necessary tests should have been performed during the pregnancy to establish if the child was healthy (normal) or not (cf. 4.7.1).

6.2.6 Number of disabled children in the family

Table 6 Distribution according to the incidence of disabled children in the family

| | Number of disabled children in the family | % |
|---|---|-------------|
| 1 | One child only | 100% |
| 2 | Two children | 0% |
| 3 | Three children | 0% |
| 4 | More than three children | 0% |
| | TOTAL | 100% |

All the couples involved in the research had only one disabled child in the family (Table 1). Research has found that the incidence of more than one child with Down's syndrome in a family is highly uncommon - 1 out of every 600 000 families (Suran & Rizzo, 1989:216). After the birth of a disabled child most parents will take the necessary precautions to prevent having a another disabled child (Gallagher, 1983: 57-8).

6.2.7 Type of school the child is attending

Table 7 **Distribution according to the type of school the children with Down's syndrome are attending**

| | Type of school | % |
|---|---|-------------|
| 1 | Special school for Down's syndrome children | 0% |
| 2 | Special school for the mentally disabled | 50% |
| 4 | Normal school(mainstream) | 5% |
| 4 | No school | 45% |
| | TOTAL | 100% |

According to Table 7 half of the children (50%) attend to Special Schools for the Mentally Disabled. This relates to a distinctive trait of the Down's syndrome child, namely mental handicap (cf.2.6.2). The 45% children not attending any school is the same as the percentage (45%) of children younger than 5 years and thus not of a school-going age (cf. Table 3). During interviews with the parents of children attending Schools for the Mentally Disabled, it appeared that they were disillusioned with the opportunities offered at these schools. The general feeling amongst the parents was that special classes for Down's syndrome children should be established in normal (mainstream) schools.

6.2.8 Payment of medical expenses

Table 8 **Distribution according to who is responsible for paying the medical expenses of the child with Down's syndrome.**

| | Medical costs covered by a medical aid | % |
|---|---|-------------|
| 1 | Covers 100% of medical costs | 10% |
| 2 | Covers 90% of medical costs | 0% |
| 3 | Covers 80% of medical costs | 10% |
| 4 | Covers 70% of medical costs | 10% |
| 5 | Do not belong to a medical aid | 70% |
| | TOTAL | 100% |

Seventy percent of the parents indicated that they do not belong to a medical aid and are therefore solely responsible for the child's medical expenses (cf. Table 8). Because children with Down's syndrome generally suffer from some kind of accompanying physical ailments, they need frequent medical care (cf. 2.5). This increases the financial burden of the parents, and often forces the father to seek additional means of income which may have a detrimental effect on the family's life (cf. 4.5).

6.2.9 Parents' learning about their child's disability

Table 9 **Distribution according to when parents learned that their child has Down's syndrome**

| | Question | % |
|---|----------------------------------|-------------|
| 1 | During pregnancy (Amniocentesis) | 0% |
| 2 | Immediately after birth | 90% |
| 3 | More than a week after birth | 5% |
| 4 | More than a month after birth | 5% |
| | TOTAL | 100% |

From Table 9 it is clear that the majority of parents (90%) were informed about their child's disability immediately after birth. The 10% that learned about their child's disability a week or a month after birth, delivered their babies at home. They were only informed about the child's disability when they took the child for a medical examination after realising themselves that something was amiss. The finding that none of the parents (0%) knew that the wife was expecting a Down's syndrome child, can possibly be attributed to the following:

- Amniocentesis is a medical procedure not often performed and some parents have moral objections against it. It is also costly.
- Expecting mothers are not informed of the possibility of having a Down's syndrome child - being in the high risk group of mothers because of age or hereditary factors.

6.2.10 Persons who discovered the disability

Table 10 **Distribution according to the persons who discovered that the child has Down's syndrome**

| | Person who made the discovery | % |
|---|-------------------------------|------------|
| 1 | Physician | 85% |
| 2 | Nurse | 5% |
| 3 | Myself | 5% |
| 4 | Genetic counsellor | 5% |
| | TOTAL | 100 |

According to Table 10 in the majority of cases (85%) the diagnosis of Down's syndrome was made at birth by the presiding medical practitioner - gynaecologist and/or general practitioner. Because of the distinctive traits a baby with Down's syndrome has at birth, a rather accurate preliminary diagnosis can be made without any specialised tests (cf. 4.6.1). The nurses (5%) who discover the new born baby had Down's syndrome, were doing the deliveries by themselves. The 5% diagnosed by the genetic counsellor was due to the absence of clear external distinctive Down's syndrome traits directly after birth (Gallagher, 1983:55).

6.2.11 Parents' knowledge about Down's syndrome

Table 11 **Distribution according to the parents' knowledge about Down's syndrome**

| | Parent's knowledge | Yes | No | Uncertain | TOTAL |
|---|---|------|-----|-----------|-------|
| 1 | Do you as parent know that: Down's syndrome is a genetic defect? | 80% | 0% | 20% | 100% |
| 2 | The child's condition will improve? | 90% | 0% | 10% | 100% |
| 3 | The child's condition will worsen? | 10% | 0% | 90% | 100% |
| 4 | The child's condition will remain unchanged? | 0% | 0% | 0% | 0% |
| 5 | It is possible to have more than one child with Down's syndrome? | 80% | 20% | 0% | 100% |
| 6 | The extent to which the child will be independent in future? | 60% | 20% | 20% | 100% |
| 7 | Clinics for genetic counselling exist? | 60% | 40% | 0% | 100% |
| 8 | As a parent I would like to know more about my child's impairment | 100% | 0% | 0% | 100% |

Table 11 shows that most of the parents (80%) were aware of the fact that Down's syndrome was a result of a genetic defect (cf. 2.2.1). It was gleaned from the interviews with the parents that they were uncertain about what the term "genetic defect" really meant. As many as 20% of the parents did not even know that Down's Syndrome was caused by a genetic defect. Their explanation for this was that they did not have access to the relevant

professional people in this regard.

The majority of parents (90%) were conscious of the possibility that the child's condition will change while the rest (10%) were uncertain about it (Table 11). Most of the parent's (90%) also believed that the child's condition will improve. None of the parents even considered the possibility that the child's condition will remain unchanged. The latter is confirmation of the findings in the literature study (cf. 2.6).

It is surprising that as many as 20% of the parents did not know that the possibility of having more than one child with Down's syndrome exists. Possible reasons for this finding might be: parents are not sufficiently informed about all the facts of Down's syndrome; lack of availability of information sources; a deliberate avoidance of more information because of fear of negative knowledge (cf. 4.6.2).

Most of the parents (60%) reported that they were aware of the extent to which their child will become independent (cf. 2.6). The finding that the same percentage of parents (60%) knew about the existence of clinics for counselling is proof of the important role clinics play in supplying parents with the information and support they need. However, an alarmingly high percentage of the parents (40%) were unaware of the existence of clinics for Down's syndrome children. Clinics do not only serve as information centres, but also play an important role in supporting parents in dealing with the inevitable problems experienced in raising a child with Down's syndrome (cf. 4.6). All the parents indicated that they would like to know more about their child's impairment. A similar trend was discovered in the literature study when other research findings were examined (cf. 4.6).

6.2.12 Sources of information

Table 12 **Distribution according to the persons who provided parents with information regarding their Down's syndrome child**

| | Persons who provided information | % |
|---|---|-------------|
| 1 | Physician | 45% |
| 2 | Nurse | 5% |
| 3 | Down's syndrome Association | 25% |
| 4 | Genetic counsellor | 20% |
| 7 | Media (Books, T. Videos) | 5% |
| | TOTAL | 100% |

From the findings in Table 12 it is evident that most of the parents (95%) were provided with information by people who have the necessary knowledge about Down's syndrome.

The responses from the majority of parents (70%) in Table 13 reflects the same preference for information as in Table 12 - they prefer to obtain their information from persons with professional knowledge (cf. 4.5). The notable number of parents (30%) that indicated that they favoured the social worker for more information, bank on the social workers' authority to obtain financial assistance for them. These parents can also not afford the consultation fees of professionals.

Table 14 indicates the type of information parents required most. It seems that adequate education of the child is high on the priority list, because most of the parents (80%) would like more information regarding their child's chances of "normal" schooling.

6.2.13 The need for more information

Table 13 Distribution according to the persons(sources) from which parents would like to obtain more information regarding their Down's syndrome child

| | Persons (sources) of information | % |
|---|----------------------------------|-------------|
| 1 | Family physician | 10% |
| 2 | Gynaecologist | 10% |
| 3 | Paediatrician | 15% |
| 4 | Genetic counsellor | 15% |
| 5 | Nurse | 5% |
| 6 | Down's syndrome association | 15% |
| 7 | Social worker | 30% |
| | TOTAL | 100% |

Table 13 was discussed under 6.2.12

6.2.14 Nature of information required

Table 14 Distribution according to the kind of additional information parents with Down's syndrome children would like to acquire

| | Kind of information required | % |
|---|---|-----|
| 1 | The child's occupational choices | 60% |
| 2 | The child's chances of normal schooling | 80% |
| 3 | The child's marriage expectations | 40% |
| 4 | Likelihood of having more disabled children | 5% |

Table 14 was discussed under 6.2.12

6.2.13 The need for more information

Table 13 Distribution according to the persons(sources) from which parents would like to obtain more information regarding their Down's syndrome child

| | Persons (sources) of information | % |
|---|----------------------------------|-------------|
| 1 | Family physician | 10% |
| 2 | Gynaecologist | 10% |
| 3 | Paediatrician | 15% |
| 4 | Genetic counsellor | 15% |
| 5 | Nurse | 5% |
| 6 | Down's syndrome association | 15% |
| 7 | Social worker | 30% |
| | TOTAL | 100% |

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| 2 | The child's chances of normal schooling | 80% |
| 3 | The child's marriage expectations | 40% |
| 4 | Likelihood of having more disabled children | 5% |

Table 14 was discussed under 6.2.12

6.2.15 Parents' expectations of their disabled child

Table 15 **Distribution according to the parents' expectations of their child with Down's syndrome**

| Question | Yes | No | Uncertain | TOTAL |
|---|------|-----|-----------|-------|
| Do you as parent think your child: | | | | |
| Will be able to get married? | 10% | 15% | 75% | 100% |
| Will eventually qualify for an occupation? | 40% | 10% | 50% | 100% |
| Will in future be able to support himself? | 15% | 5% | 80% | 100% |
| Your child's future pose a particular problem to you? | 10% | 70% | 20% | 100% |
| As the parent of a disabled child I: | | | | |
| Require more information regarding education and/or training? | 95% | 5% | 0% | 100% |
| Need to know more about my child's vocational potential | 100% | 0% | 0% | 100% |
| Am in need of assistance in raising my child | 85% | 15% | 0% | 100% |

The majority of parents as Table 15 shows, expressed their uncertainty about the future of their child - 75% was doubtful about the child's likelihood to get married, 50% was unsure if the child will ever qualify for an occupation and for 80%, the child's future independence was unpredictable (cf. 2.6). A relationship exists between the response of nearly all the parents (95%) that indicated their need for more information regarding education and/or training

prospects for disabled children, and the response of all the parents (100%) who required more knowledge about the child's vocational possibilities. If education and/or training prospects are adequate the vocational possibilities of the child will improve.

6.2.16 Assistance to parents in raising their disabled child

Table 16 **Distribution according to parents seeking assistance in raising their child with Down's syndrome.**

| | Persons approached for assistance | % |
|---|---|-------------|
| 1 | Other parents with Down's syndrome children | 25% |
| 2 | Teachers at the child's school | 5% |
| 3 | School counsellor | 10% |
| 4 | Private counsellor | 10% |
| 5 | Down's syndrome clinics | 10% |
| 6 | Down's Syndrome Association | 30% |
| 7 | Do not seek help | 10% |
| | TOTAL | 100% |

Table 16 indicates that a significant percentage (30%) of the parents prefer to go the Down's Syndrome Association for help, while 25% of the parents consult with other parents with Down's syndrome children. According to Suran and Rizzo (1989:465) some parents have more trust in asking for help from people in similar circumstances. Parents with Down's Syndrome children perceive each other as experiencing comparable problems regarding the raising of their disabled children. They are therefore in a better position

to offer advice or assistance to each other (cf. 4.6.5).

6.2.17 Problems experienced by parents

Table 17 **Distribution according to problems experienced by parents with Down syndrome children**

| | Question | Yes | No | TOTAL |
|---|---|------|-----|-------|
| 1 | I receive adequate assistance with the raising of my child | 60% | 40% | 100% |
| 2 | I was forced to find extra (or other) work for the sake of the child's treatment | 30% | 70% | 100% |
| 3 | I experience problems in transporting my child for medical treatment | 25% | 75% | 100% |
| 5 | I feel there is a need for an advisory/support service to solve problems experienced by parents with Down's syndrome children | 100% | 0% | 100% |

A notable number of parents (40%) according to Table 17 stated that they do not receive adequate assistance in the raising of their disabled child. Interviews revealed that this lack of assistance includes help from spouses, family members, the community and professional services (doctors, counsellor, etc.). Nearly a third of the parents (30%) were also forced to find additional means of income in order to pay for special treatment (medical and educational) brought about by a disabled child (cf. 2.5). All the parents reiterated the finding that there is a need for support and/or advisory services for parents with Down's syndrome children (cf. 6.2.16; 4.6).

6.2.18 Family members' attitude towards parents of the disabled child

Table 18 Distribution according to family members' attitude towards parents after the birth of their Down's syndrome child

| | Attitude of family members | % |
|---|---------------------------------------|-------------|
| 1 | Everyone was most sympathetic | 75% |
| 2 | Only certain members were sympathetic | 15% |
| 3 | They behaved coldly towards me | 0% |
| 4 | Only certain members behaved coldly | 10% |
| | TOTAL | 100% |

Most of the parents (75%) were assured of the sympathy, and therefore also the empathy and understanding, of the other members in the family (Table 18). Parents are always in need of solace after the birth of a Down's syndrome child support (Bailey, Blasco & Simeonsson, 1992:6-7).

6.2.19 Reaction of family members towards a disabled child

Table 19 Distribution according to the family members' reaction towards the Down's syndrome child

| | Reaction of family members | % |
|---|---|-------------|
| 1 | They are extremely sympathetic | 80% |
| 2 | They are aloof towards the child | 0% |
| 3 | They are extremely cold towards the child | 10% |
| 4 | They pity the child | 10% |
| | TOTAL | 100% |

The majority of family members (80%) were sympathetic towards the child (cf. Table 19). Parents are appreciative of family members who show their sympathy towards the disabled child.

6.2.20 Attitude of neighbours/friends towards parents of the disabled child

Table 20 Distribution according to the attitude of neighbours/friends towards the parents of the Down's syndrome child

| | Attitude of neighbours/friends | % |
|---|-------------------------------------|-------------|
| 1 | The majority were sympathetic | 50% |
| 2 | Only some were sympathetic | 15% |
| 3 | I am uncertain about their attitude | 5% |
| 4 | Most of them were helpful | 20% |
| 5 | Only some were helpful | 10% |
| | TOTAL | 100% |

Table 20 shows that most of the parents (70%) experienced their neighbours/friends as sympathetic and helpful regarding their disabled child. These neighbours and friends make it easier for the parents to cope with the day-to-day problems of caring for the child, and also to focus on the positive aspects life (Halliday, 1989:97).

6.2.21 Reaction of neighbours/friends towards the disabled child

Table 21 **Distribution according to neighbours/friends reaction towards the Down's syndrome child**

| | Reaction of neighbours/friends | % |
|---|----------------------------------|-------------|
| 1 | They are extremely sympathetic | 60% |
| 2 | They are aloof towards the child | 0% |
| 3 | They are cold towards the child | 10% |
| 4 | They pity the child | 30% |
| | TOTAL | 100% |

Table 21 indicates that nearly two thirds (60%) of the parents perceived their neighbours/friends as extremely sympathetic towards the Down's syndrome child. The sympathy of some neighbours and friend's even intensifies into pity as indicated by 30% of the parents. Children do not want people's pity, but want them to understand their impairment and the accompanying problems (Matson & Mulick, 1983:89).

6.2.22 Acceptance of Down's syndrome child

Table 22 **Distribution according to the acceptance of the Down's syndrome child in the family and community**

| Question | Yes | No | Uncertain | TOTAL |
|---|------|-----|-----------|-------|
| Does the attitude of the family create a problem for you? | 10% | 80% | 10% | 100% |
| Does the attitude of neighbours/friends create a problem for you? | 5% | 90% | 5% | 100% |
| Should other people be better informed about Down's syndrome? | 100% | 0% | 0% | 100% |
| Is your disabled child fully accepted by your family? | 100% | 0% | 0% | 100% |
| Is the Down's syndrome child fully accepted by brothers and/or sisters? | 75% | 0% | 25% | 100% |
| Is the child fully accepted by your friends? | 80% | 0% | 20% | 100% |
| Is the child fully accepted by your neighbours? | 80% | 0% | 20% | 100% |
| Does the child with Down's syndrome accept his/her disability? | 0% | 10% | 90% | 100% |

Table 22 shows that between 80% and 90% of the parents felt that the disposition of their family, neighbours and friends creates no problems for them. However, all the parents were of the opinion that people outside the family should be better informed about Down's syndrome. Dyson (1991:626) found that the negative reactions in the form of neighbours who stare and make unkind comments; complain about the disabled child's behaviour; and refuse to let their normal children play with the child, stem from a mixture of

ignorance, prejudice and rejection. People generally have a more sympathetic and positive attitude towards disabled children after learning more about their impairment (Carr, 1985:37).

All the parents in Table 22 stated that the disabled child was fully accepted in the family. The unconditional acceptance of the child implies that a place is made for the child in the parent's (family's) world (cf. 3.3.2 (1)). This means that the parents, and other family members make themselves available to give support to the child (Kapp (ed.), 1991:459). The majority of parents (75%) indicated that the disabled child is accepted by other siblings in the family (the 25% parents that were uncertain only have one child). For the adequate orientation of disabled children, it is imperative that they experience acceptance and affection from brothers and/or sisters (cf. 3.3.2(2)). Acceptance of disabled children by friends and neighbours, as indicated by the majority of parents (80%) is particularly important to assess the child's ability to relate to adults outside the family and to respond to their authority in a reasonable fashion (Gallagher, 1989:352).

People who have no disability have difficulty in understanding what it is like to be handicapped (Bondo, 1980:11). Therefore it is not surprising that so many of the parents (90%) expressed their uncertainty in answering the question whether the Down's syndrome child accepts his/her ability or not. Clarke (1986: 54) says it is difficult to imagine what it is like to be intellectually impaired (like the child with Down's syndrome).

6.2.23 Parents perception of the child's experience of his impairment

Table 23 **Distribution according to the parents' perception of the Down's syndrome child's experience of his/her impairment**

| | Question | Yes | No | TOTAL |
|---|--|-----|-----|-------|
| 1 | Do your Down's syndrome child play with other children? | 80% | 20% | 100% |
| 2 | The child's disability prevents him/her from playing normally with other children? | 80% | 20% | 100% |
| 3 | Other children do not want to play with a Down's syndrome child? | 80% | 20% | 100% |

According to Gillham (1986:27) the child with Down's syndrome is often exposed to ridicule from his peers (or other children) because of his physical appearance and inability to communicate on the same level. This finding was confirmed by 20% of the parents in Table 23. During the interviews with the parents it also emerged that some parents are not very keen on letting their children play with a Down's syndrome child. The possibility exists that the child can become isolated if his disability prevents normal socialization with other children (cf. 3.2.6; 3.3.2(3)).

6.2.24 Parents' experience of their Down's syndrome child

Table 24 **Distribution according to the parent's experience of their child's impairment**

| | Question | Yes | No | TOTAL |
|---|--|-----|-----|-------|
| 1 | Were you shocked on learning your child has Down's syndrome? | 90% | 10% | 100% |
| 2 | Do you hold anyone directly responsible for the child's disability? | 5% | 95% | 100% |
| 3 | Does the child's future independence pose problems to you? | 70% | 30% | 100% |
| 4 | Have you experienced any crisis periods in raising the child? | 40% | 60% | 100% |
| 5 | Did the birth of the child affect your plans for having more children? | 10% | 90% | 100% |
| 6 | Did you feel any need for counselling after the birth of the child? | 80% | 20% | 100% |
| 7 | Are you overprotective of your child with Down's syndrome? | 85% | 15% | 100% |

The initial reaction to the diagnosis of a child with Down's syndrome - whether it occurs immediately after birth or later - is some measure of shock (Dyson, 1993: 209). The majority of parents (90%) in Table 24 reported that they were shocked when they heard that their child has Down's syndrome (cf. 4.4). Byrne and Cunningham (1988: 102) have found that during the initial period of shock, many parents also experience a strong sense of guilt, as though in some way they were responsible for the child's defect. However, the responses in Table 24 show that only a very small percentage of parents (5%) blame somebody else directly for the child's disability.

Down's syndrome children are not expected to become totally independent in the community or to be in charge of their affairs outside of the home (Birenbaum & Cohen, 1993: 68-69). This limitation is realized by most of the parents (70%). Although the larger number of parents (60%) said they do not experience crises periods in raising a disabled child, most researchers have found that problems are faced by parents in providing daily care for the child. Being slow in reaching the different stages of independence, the child has to be fed, washed, clothed, etc. much longer than a "normal" child.

The majority of parents (90%) feel that the birth of a disabled child does not change their plans to have more children. Most of the parents (80%) felt that they need counselling after the birth of their disabled child. Social and emotional support for parents reduces anxieties caused by anger, guilt, beliefs and feelings of inadequacy (cf. 4.5).

Dyson (1991:628) has found that parents with disabled children may respond to their ambivalent feelings in a compensatory fashion - they become overprotective and self-sacrificing. This reaction is also experienced by the majority of parents (85%) with Down's syndrome children, in Table 25. It is, however, important that overprotection must be understood empathically rather than judgementally. Freude (1991:123) says that overprotection may be an attempt at restitution on the part of the parent, who experiences a profound sense of guilt and personal inadequacy for having produced a disabled child.

6.2.25 Counselling in family planning

Table 25 **Distribution according to persons giving counselling regarding family planning**

| | Counselling persons | % |
|---|---------------------------|-------------|
| 1 | Physician | 40% |
| 2 | Nurse | 10% |
| 3 | Social worker | 0% |
| 4 | Genetic counsellor | 25% |
| 5 | Down Syndrome association | 25% |
| | TOTAL | 100% |

Most of the parents (65%) in Table 25 preferred to obtain guidance in family planning from professional, qualified people in that field, namely a physician or genetic counsellor (cf. 4.5).

6.3 SUMMARY

In this chapter, some order was given to the range of information provided by the parents in their answers to the questions in the questionnaire. In organizing the data in frequency tables, the researcher was able to interpret and discuss the findings and make some deductions from the data.

In the next chapter a summary of the previous chapters will be given and certain recommendations offered.

CHAPTER 7

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CHAPTER 7

SUMMARY AND RECOMMENDATIONS

7.1 INTRODUCTION

In this final chapter a summary of the previous chapters will be given and some of the most important findings from the research will be discussed. This will be followed by recommendations, some points of critique on the study and a final remark.

7.2 SUMMARY

7.2.1 Statement of the problem

The problem addressed in this study concerned the special needs and problems, that are created for parents and the family with the birth of a Down's syndrome child. Being intellectually impaired the child with Down's syndrome has a significant influence on the life-world of his parents and the normal functioning of the family.

From the findings of the literature study and the empirical research the questions in 1.3 can be answered as follows:

- Indian parents experience their Down's syndrome child as having special needs and they face problems quite different from those faced by parents with only "normal" children.

- Many parents are aware of what caused their child's condition but need to know more about the implications of the impairment and the future prospects of the child.
- Parents of disabled children want neither pity nor admiration for their "self-sacrifice, patience, love, nobility," or all the other mouthings. What they need most is the understanding of their problems by more people, and enough concern from the government and society to provide adequate education and therapy to give these children a better chance in life.
- Indian parents experience a lack of sufficient professional support to assist them as "special parents" to cope with their child's disability.
- Children with Down's syndrome do not experience their impairment as an objective, comprehensible event that occurs to the body; instead they experience the disability subjectively and bring their own experience to bear in making sense of it.

7.2.2 The child with Down's syndrome

Down's syndrome is the most commonly occurring form of mental retardation that is known to be caused by a genetic defect. It is also known as Mongolism because of the Eastern (Mongoloid) slant of the individual's eyes, or as Trisomy 21 because it is caused by the presence of an extra (third) chromosome (normally there are only two). The first detailed description of the disability was made in 1866 by doctor Langdon Down but it was only

confirmed in 1959 that Down's syndrome could definitely be linked to an extra chromosome. There are actually three types of Down's syndrome (cf. 2.2). The types are identified on the basis of the way in which the additional chromosome originated, namely trisomy 21 -, mosaic - and translocation Down's syndrome.

Although a Down's syndrome child can result from any pregnancy, research has shown a definite relationship between the incidence of the condition and the age of the mother - the older the mother the higher the risk (cf. 2.3).

People with Down's syndrome have very distinctive traits, for example, fine straight hair, a coarse skin, eyes that slant upwards, a short nose with a low bridge, a small mouth, a relative large (often protruding) tongue, a short broad neck, broad hands, short fingers, low resistance to infection and mental retardation (cf. 2.4; 2.5).

There is a measurable differences between the development of Down's syndrome children and normal children. Their development is also marked by periods of little apparent progress and periods of rapid progress. Special services and resources, beyond those required by other children, are required for the development of the limited mental abilities of the Down's syndrome child. Differences in academic performance, social orientation, physical skills, language acquisition, and so on , need some form of special education (cf. 2.6).

7.2.3 The life-world of the Down's syndrome child

Experiencing is an act of orientating oneself. An individual directly experiences a situation and becomes the recipient of the values and meanings

of the particular situation. Experience is a way of giving meaning which can be accomplished on a physical, affective, cognitive and normative level (cf. 3.2.1). Children with disabilities, like Down's syndrome, have more limitations placed on their experience as their normal peers.

Affective experience is concerned with those aspects pertaining to emotions, feelings, moods and sentiments. In the exploration of their world children with Down's syndrome experience limitations as the result of their intellectual impairment. They experience situations and things which they cannot handle and which may increase their anxiety - an anxiety which may manifest as moodiness, aggression, jealousy and excessive tension seeking (cf. 3.2.2).

The cognitive experiences of the child embrace facets of analysis, synthesis, abstraction, comparison, etc. which leads to objective judgements, pronouncements and knowledge. As a result of the Down's syndrome child's intellectual impairment the cognitive development of the child is slow and limited. One of the most fundamental ways in which intellectually impaired children differ from normal children, of the same age, lies in the slowness and inefficiency with which they acquire knowledge and skills (cf. 3.2.3).

The Down's syndrome child reaches the physical developmental milestones (sitting, walking, etc.) later than the normal child. Even when at reaching adulthood these people move and act more slowly than the normal person. This physical impediment may limit the child's ability to investigate his life-world through exploration (cf. 3.2.4).

Social disabilities are part of the Down's syndrome child's life and consequently they find it very difficult to comply with the social demands of

adulthood. In this regard the Down's syndrome child can be compared to a tourist in a foreign country: He cannot speak the language well, he does not always understand what is expected of him, he experiences problems with procedures and is not familiar with the social customs (cf. 3.2.6).

The adequate becoming of the child with Down's syndrome largely depends on the relationships he forms with others, himself, objects and God. These relationships will determine how the child experiences his handicap and the degree to which he actualizes his limited abilities. In the relationship with himself the child experiences his body image as negative because of his distinctive physical traits and limited physical (motor) abilities (cf. 3.3.1).

The establishment of a harmonious relationship between parent and child depends on the parents' unconditional acceptance of the child, their ability to orientate to the child's disability and their capacity to provide the necessary security for the child (cf. (3.2.2(1))). Down's syndrome children have few "normal" friends from their neighbourhood.

7.2.4 Parents experience of their child's impairment

The concept parenthood is synonymous with the acceptance of responsibility for the procreation and rearing of one's child - whether the child is normal or impaired. Parents should have no uncertainties as to their responsibilities as parents of a disabled child. A parent of a disabled child may be defined as a "special parent". There are some significant differences between the problems encountered by the "special parents" of the Down's syndrome child and other disabled children and the parents of normal children. Special parents should be fully aware of their special role and task as well as the

possibilities and limitations of their activities as regards the raising of the disabled child (cf. 4.2.1).

Parenthood implies changed attitudes among members of the family concerned, but more particularly the parents. However, parenthood of a disabled child implies a whole different series of attitudes, actions and inclinations that have to be acquired (cf. 4.2.2). Although the challenges of parenthood of a Down's syndrome child share many similarities with those of a normal child, the presence of a disability poses some special challenges to parents - parents experience the raising of a disabled child as more demanding and complex (cf. 4.2.4). The roles parents play in parenting the normal and "special" child involve many different factors and processes. Despite the changing role of fathers today, primary responsibility for the children still remains with the mother - mothers often leave their jobs to care for their Down's syndrome child.

Most parents share the same feelings on learning about their child's disability. Their initial reaction is shock and disbelief often followed by denial. During this initial period many parents also experience a sense of guilt, as though in some way they were responsible for the child's defect. After the initial shock parents' feelings change to grief and mourning. In addition to their grief and mourning many parents also experience and express intense anger - anger towards God, faith or spouse that unjustly gave them a disabled child (cf. 4.4).

The greatest need of parents with Down's syndrome children is the need to know the exact nature of the child's disability. They want a truthful and simple explanation of their child's disability and the future implications thereof. They seek information about the available services, intervention

programs and special equipment that will assist them in the child's adequate development (cf. 4.7).

Parents need to have support and counselling available to them as soon as possible after the birth of a disabled child. Professional counselling will help parents to understand the process through which they are going, assist them in analysing what is happening to them and provide them with coping strategies (cf. 4.6.3). When parents encounter difficulties in meeting the special needs of the disabled child, they are likely to search for appropriate services and helpful professionals.

7.2.5 Planning of the research

This study utilized a questionnaire, constructed by the researcher, to gather data. The information sought was not available from any other source and had to be acquired directly from the respondents. When this situation exists, the most appropriate source of data is the questionnaire, as it can easily be adapted to a variety of situations.

With the aim of administering the questionnaire to the parents of children with Down's syndrome the researcher contacted the Association for Down's Syndrome in Durban in order to obtain the names of institutions and/or schools that care for these children. With the assistance of the schools and institutions a list of the names of couples with Down's syndrome children was compiled. These couples were contacted telephonically and appointments made to visit the parents who were willing to take part. The aim of the questionnaire was to obtain information from Indian parents regarding their experience of their Down's syndrome child.

7.2.6 Analysis and presentation of research data

The purpose of this chapter was to discuss the data collected from the questionnaires and to offer comments and interpretations on the findings. At the outset, an explanation and description was provided as to the methods employed in the categorisation of responses and the analysis of the data. This was followed by an examination of the responses to the questions in the questionnaire.

The following findings emanated from the descriptive statistics:

- Fifty percent of the mothers were older than 35 years, and nearly a third were older than 40 years when they gave birth to the child with Down's syndrome (cf. 6.2.1).
- Most of the parents knew that their child has Trisomy 21 - Down's syndrome. However, the parents were merely informed about the type of Down's syndrome, but did not really understand the true meaning of the child's condition. Nearly a third of the parents did not know what type of Down's syndrome their child has - they were not even aware of the existence of three different types of Down's syndrome (cf. 6.2.4).
- For most of the parents the child with Down's syndrome was their first born and the mothers were unaware of the possibility of giving birth to a Down's syndrome child. All the respondents had only one disabled child (cf. 6.2.5; 6.2.6).

- . Children of schoolgoing age attend Special Schools for the Mentally Disabled (cf. 6.2.7).
- . Most of the parents do not belong to a medical aid and are therefore solely responsible for the child's medical expenses (cf. 6.2.8).
- . Ninety percent of the parents were informed about their child's disability immediately after birth by the presiding medical practitioner - gynaecologist and/or general practitioner (cf. 6.2.9; 6.2.10).
- . Most parents were uncertain about what the term "genetic defect" really means and a fifth of them did not even know that Down's Syndrome was caused by a genetic defect. All the parents would like to obtain more information about their child's impairment from professionals (cf. 6.2.11; 6.2.13).
- . A notable number of the parents rely on the social workers' authority to obtain financial assistance for them (cf. 6.2.13).
- . The kind of information parents mostly required related to the educational possibilities of the child (cf. 6.2.14).
- . The majority of parents were uncertain about the future of their child with Down's syndrome. The majority of parents were doubtful about the child's likelihood to get married, ability to qualify for an occupation and future

independence (cf. 6.2.15).

- . Parents prefer to go to the Down's Syndrome Association for help or to other parents with Down's syndrome children (cf. 6.2.16).
- . Most parents feel they do not receive sufficient assistance regarding the problems they experience in the raising of their disabled child (cf. 6.2.17).
- . Parents and disabled children enjoy the empathy and understanding of the other members in the family (cf. 6.2.18; 6.2.19).
- . Parents experienced their neighbours/friends as sympathetic and helpful and this makes it easier for the parents to cope with the day-to-day problems of caring for the child (cf. 6.2.20).
- . Parents perceived their neighbours/friends as extremely sympathetic towards the Down's syndrome child. Sympathy of neighbours and friend's may even intensify into pity. Parents also felt that the disposition of their neighbours and friends create no problems for them (cf. 6.2.21).
- . All the parents were of the opinion that people outside the family should be better informed about Down's syndrome (cf. 6.2.22).

- . The perception of most of the parents were that the disabled child is fully accepted in all the families. However, most parents were uncertain if the child himself/herself accepts his disability (cf. 6.2.22).
- . The child with Down's syndrome is often exposed to ridicule from peers (or other children) because of his physical appearance and inability to perform on the same level as normal children (cf. 6.2.23).
- . Down's syndrome children are not expected to become totally independent in the community or to be in charge of their affairs outside of the home (cf. 6.2.24).
- . For most of the parents the birth of a Down's syndrome child did not change their plans to have more children but they did feel the need for counselling after the birth of their disabled child (cf. 6.2.24).

7.2.7 Aims of the study

The researcher formulated specific aims (cf. 1.5) to determine the course of this study. These aims were realised through a literature study, together with an empirical survey consisting of a structured questionnaire and informal, unstructured interviews with the parents of children with Down's syndrome. On the basis of the aims and findings of this study, certain recommendations are now formulated.

7.3 RECOMMENDATIONS

7.3.1 Diagnosis and early family needs

(1) Motivation

Findings from the questionnaire showed that less than fifty percent of the parents involved in this research were aware of the existence of the genetic services in the Department of Health (cf. 6.2.4; 6.2.12; 6.2.25). Parents do not always know the exact meaning of the term "genetic defect" and how it causes Down's Syndrome - they are not even aware of the existence of three different types of Down's syndrome (cf. 6.2.4; 6.2.11). None of the mothers in this investigation were aware of the possibility that they might give birth to a Down's syndrome child, the existence of prenatal tests to detect abnormalities or that they fall in the high risk age group for birth deficiencies (cf. 6.2.9).

The initial reaction of parents to the diagnosis of their child's disability is some measure of shock followed by disbelief and even denial (cf. 4.4; 6.2.24). Parents experience negative emotions of disappointment and anger, ambivalent feelings toward the child may give rise to additional guilt feelings - they were directly responsible for the child's defect (cf. 4.5). Most parents, therefore, feel the need for professional counselling after the birth of a disabled child. Such counselling is not always available to or affordable by parents.

The way in which parents are informed about their child's condition often has a profound effect on them (cf. 4.5). There is a clear relationship

between the way in which parents are informed of their child's disability and their initial reaction and acceptance of the news (cf. 4.6). Parents are often not familiar with the medical terms used to describe the child's condition to them. They need a truthful and simple explanation of the diagnosis, the child's prognosis and available services and intervention programs (cf. 4.6.2).

(2) Recommendations

The recommendations are:

- . The existing methods of advertising available genetic services to the public must be improved.
- . Genetic services must have access to authorities on genetic diseases and a multidisciplinary approach should be pursued.
- . More genetic counsellors/geneticists should be trained and employed to trace and advise high risk families.
- . More diagnostic facilities should be made available to parents for prenatal (amniocentesis) and postnatal examinations.
- . The correct information of the initial diagnosis regarding the child's disability must be disclosed to the parents in a "language" they can understand. The exact nature and

prognosis of Down's syndrome must be explained to the parents.

Professional counselling must be made available to parents to make the experience less painful and help them understand the process through which they are going.

7.3.2 Parent guidance and involvement programs

(1) Motivation

The parents of the intellectually impaired Down's syndrome child may experience a wide range of difficulties in the adequate upbringing of the child (cf. 4.2; 6.2.16;). Parents might be unable to adjust their expectations to the degree (mild to severe) of the child's disability - they do not understand the child's limitations (cf. 4.5.2). There are some significant differences between the problems encountered by the parents of "normal children" and those encountered by the parents of children with Down's syndrome (cf. 4.2.4: 6.2.17). The parent of a disabled child can therefore be seen as a "special parent".

The day-to-day problems of caring for the disabled child make it easy for the parents to focus on only the negative aspects in their life-world (cf. 4.5). The parents gradually became aware of missed developmental milestones as the child progresses - walking, talking, independent feeding, etc. are delayed (cf. 2.6.1). Special parents have to cope , more often than not, with all the implications brought about by the limitations of the disabled child (cf. 4.5.1).

Parents of mentally retarded children, as in the case with Down's syndrome, must also cope with problems related to the intellectual disabilities and dispense with such unfortunate labels such as "slow", stubborn and lazy". Equally problematic is the underestimation of the child's abilities - this imposes limitations on the extent to which the parents help the child actuate potentials (cf. 2.6.2). The education and planning for the future of a disabled child demands a great deal from the parents. Education implies particular problems for the parents and requires perseverance and dedication (cf. 6.2.15). Parents are often not aware of the child's experience of his impairment - they do not really know their child (cf. 6.2.23). Parents definitely need assistance in this regard (cf. 6.2.17).

(2) Recommendations

The recommendations are:

- . The Department of Health, in collaboration with institutions like the HSRC and Departments of Education at universities, should compile counselling programs for parents regarding the care and education of their disabled children .
- . Existing information concerning the caring for and education of disabled children must serve as guidelines in the compiling of counselling programs.
- . State Departments concerned with the disabled must give aid and support to Down's Syndrome Associations and

parent groups in respect of their functioning and with the establishing of new parents' groups and associations where necessary.

It should be possible for these associations and groups to work as closely as possible with the Genetic Services of the Department of Health

7.3.4 Further research

(1) Motivation

The life-world of Indian parents has been significantly and adversely affected by the birth of a child with Down's syndrome. The arrival of a disabled child seriously effects the normal family life and functions. The day to day problems of caring for the disabled child may result in parents focusing on the negative aspects of their life-world. Disappointment, overcome by the child's needs for special care, apprehensiveness about the child's future and their own, may discouraged parents and make them resentful, even bitter (cf. 4.4). Parents feel that they do not receive adequate support and assistance in coping with the problems of raising a Down's syndrome child.

Most disabled people, like "normal" people want to be individuals in their own right and also want to be independent (cf. 6.2.16; 6.2.17). These wishes imply that disabled children should receive education and/or training according to their abilities in order to have an occupation when they reach adulthood (cf. 6.2.14; 6.2.15).

Only Indian parents were involved in this research. As a result of cultural and other differences in the black, white, coloured and Indian population groups in the Republic of South Africa, there may be certain differences regarding the effect a Down's syndrome child has on the life-world of his parents.

(2) Recommendations

The recommendations are:

- . That similar research be conducted among the other population groups in the Republic of South Africa.
- . Research must be done concerning professional support available to assist parents of all population groups in coping with the problems of raising a Down's syndrome child.
- . Research should be done in connection with educational, training and occupational opportunities for disabled children of all the population groups.

7.4 CRITICISM

Criticism that emanates from this study include the following:

- . The sample of Indian parents with Down's syndrome children utilised in this investigation was not randomly selected and therefore the findings cannot be generalised.
- . The research was conducted on parents living in the Durban area only. Dissimilar responses might have been elicited from parents living in other areas (rural) where access to professional services and support systems might be different.
- . The respondents were all Indian parents. Research on a multicultural sample or a sample from another cultural group might have resulted in different findings regarding the influence of a Down's syndrome child on the life-world of the parents.

7.5 FINAL REMARK

The aim of this study was to reach a better understanding of the life-world of the parents of a Down's syndrome child. It is trusted that this study will be of value, particularly to parents with Down's syndrome children, parent support groups and health, welfare and educational authorities in the betterment of meeting the special needs of the Down's syndrome child and his parents. It is also hoped that the recommendations from this study will be implemented and thereby assist parents in raising their disabled child.

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APPENDIX A

STRICTLY CONFIDENTIAL

Questionnaire

**THE LIFE-WORLD OF THE INDIAN PARENT
WITH A
DOWN'S SYNDROME CHILD**

Dear Parent

QUESTIONNAIRE: THE LIFE-WORLD OF THE INDIAN PARENT WITH A DOWN'S SYNDROME CHILD

At present I am engaged in a research project at the University of Zululand under the guidance of Professor G. Urbani. The research is concerned with the *Life-world of the Indian parent with a Down's syndrome child*.

As one of the selected respondents, I have taken the liberty of writing to you in order to seek your assistance in acquiring information about your experiences relating to the research. I have attempted to keep the questions as simple as possible, and the completion of this questionnaire should not require more than twenty minutes of your time.

CONFIDENTIALITY

All information will be regarded as CONFIDENTIAL, and no personal details of any parent/respondent will be mentioned in the findings, nor will any of the results be related to any particular home, family or school.

Thank you for your co-operation.

Yours sincerely

.....

Mrs H. H. Moola

Instructions to the respondent

1. Please read through each statement carefully before giving your opinion.
2. Please make sure that you do not omit a question, or skip a page.
3. Please be honest when giving your opinion.
4. Please do not discuss statements with anyone.
5. Please return the questionnaire after completion.

Kindly answer all the questions by supplying the requested information in writing, or by making a cross (X) in the appropriate block.

1. SECTION ONE: BIOGRAPHICAL INFORMATION

1.1 Mother's age at birth of child with Down's syndrome? ____

1.2 Father's age at birth of child with Down's syndrome? ____

1.3 Place of residence?

Own house

☐

Own flat

☐

Rented house

☐

Rented flat

☐

Other (please specify) _____

1.4 Age of child with Down's syndrome? ____**1.5 What type of Down's syndrome does your child have?**

Trisomy 21-Down's syndrome

☐

Translocation-Down's syndrome

☐

Mosaicism-Down's syndrome

☐

Not known by parents

☐**1.6 Gender of child with Down's syndrome?**

Male

☐

Female

☐

1.7 Number of children in your family? ____

1.8 Position of disabled child in family? _____

1.9 Are there other disabled children in your family?

Yes

☐

No

☐

If yes, please specify the: number ____

disabilities _____

age/s _____

1.10 Is the child attending a special school?

Yes

☐

No

☐

If no, please give the main reason for your answer _____

1.11 Do you belong to a medical aid?

Yes

☐

No

☐

If yes, to what extent (%) are your medical costs covered concerning the child? _____

If no, who is responsible for the medical costs of the child? _____

2. SECTION TWO: PARENT'S KNOWLEDGE ABOUT THE DISABILITY OF THE CHILD

2.1 When did you, as a parent, first learn that your child had Down's syndrome?

During pregnancy (Amniocentesis)

☐

Immediately after birth

☐

Others (please specify) _____

2.2 Who made the discovery in respect of your child's impairment?

Physician

☐

Nurse

☐

Others (please specify) _____

2.3 Are you aware that your child's impairment is the result of a genetic defect?

Yes

☐

No

☐

2.4 Do you know how your child's condition will probably change in the future (Improve, worsen, remain unchanged)?

Yes

☐

No

☐

2.5 Are you aware of the possibility of having more Down's syndrome children?

Yes

☐

No

☐

3. SECTION THREE: KNOWLEDGE OF THE CHILD'S POSSIBILITIES

3.1 Are you aware of the extent to which your child will be independent in the future?

Yes

☐

No

☐

3.2 Who provided you with the abovementioned information?

Physician

☐

Nurse

☐

Social worker

☐

Genetic counsellor

☐

Family

☐

Friends

☐

Media (Magazines, television, videos)

☐

Other (please specify) _____

3.3 Would you like to know more about your child's impairment?

Yes

☐

No

☐**3.4 From whom would you like to obtain more information?**

Family physician

☐

Gynaecologist

☐

Paediatrician

☐

Geneticist

☐

Social worker

☐

Other (please specify) _____

3.5 What would you like to obtain more information about?

Your child's occupational choices

☐

Your child's chances of success at school

☐

Your child's marriage expectations

☐

The likelihood of having more disabled children

☐

3.6 Are you aware of the existence of clinics for genetic counselling?

Yes

☐

No

☐

If no, give a reason _____

3.7 Do you think your child will eventually be able to marry?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

3.8 Do you think your child will eventually be able to qualify for an occupation?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

3.9 Do you think your child will eventually be able to support him/herself?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

3.10 Does your child's future pose particular problems for you?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

3.11 Do you require information on education and/or training for your child?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

3.11 Do you require information on your child's vocational potential?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

4. SECTION 4: SUPPORT AVAILABLE TO PARENTS**4.1 Do you require assistance in raising your Down's syndrome child?**

Yes

☐

No

☐**4.2 Have you previously sought assistance in raising your child, and if so, from which of the following:**

Parents of other Down's syndrome children

☐

Teachers

☐

School guidance-officers

☐

School psychologists

☐

Psychologists in private practice

☐

Education clinics

☐

Other (please specify) _____

4.3 Was the assistance that you received from any of the above mentioned adequate/satisfactory?

Yes

☐

No

☐

Not applicable

☐

4.4 Were you forced to find other work for the sake of treatment of your Down's syndrome child?

Yes

☐

No

☐

4.5 Do you experience problems with transport to enable your Down's syndrome child to receive medical treatment?

Yes

☐

No

☐

4.6 Do you feel that there is a need for an advisory /support service with regards to the problems experienced by parents with Down's syndrome children?

Yes

☐

No

☐

5. SECTION 5: ACCEPTANCE OF THE DOWN'S SYNDROME CHILD IN THE FAMILY AND COMMUNITY

5.1 After the birth of your Down's syndrome child, the family's attitude towards you was:

Everyone was most sympathetic

☐

Only certain members were sympathetic

☐

They behaved coldly towards us

☐

Only certain members were cold towards us

☐

They pitied us

☐

5.2 How do your family members act to your Down's syndrome child?

They are extremely sympathetic

☐

They are aloof towards the child

☐

They are extremely cold towards him/her

☐

They pity him/her

☐

5.3 After the birth of our Down's syndrome child, our neighbours' and/or friends attitude towards us was:

The majority were sympathetic

☐

Only some were sympathetic

☐

I am uncertain of their attitude

☐

Most of them were very helpful

☐

Only some were helpful

☐

They pitied us

☐

5.4 How do your neighbours/friends act to your Down's syndrome child?

They are most sympathetic

☐

They are aloof towards him/her

They are cold towards him/her

☐

They pity him/her

☐

5.5 Does the general attitude of your family create a problem for you?

| | | |
|-----|----|-----------|
| Yes | No | Uncertain |
| | | |

- 5.6 Does the attitude of neighbours and/or friends create a problem for you?

| | | |
|-----|----|-----------|
| Yes | No | Uncertain |
| | | |

- 5.7 Do you think that other people should be better informed about Down's syndrome in order to understand the child better?

| | | |
|-----|----|-----------|
| Yes | No | Uncertain |
| | | |

- 5.8 Do you think your disabled child is fully accepted by your family?

| | | |
|-----|----|-----------|
| Yes | No | Uncertain |
| | | |

- 5.9 Do you think your Down's syndrome child is fully accepted by his/her brothers and/or sisters (if any)?

| | | |
|-----|----|-----------|
| Yes | No | Uncertain |
| | | |

5.10 Do you think your Down's syndrome child is fully accepted by your friends?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

5.11 Do you think your Down's syndrome child is fully accepted by your neighbours?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

6. SECTION 6: CHILD'S EXPERIENCE OF HIS IMPAIRMENT

6.1 Do you think that your Down's syndrome child accepts his/her impairment?

| | | |
|-----|----|-----------|
| Yes | No | Uncertain |
| | | |

6.2 Does your child play with other children in the neighbourhood?

Yes

☐

No

☐

Not applicable

☐

If no, please indicate, in your opinion, the most important reason:

The child's impairment prevents him from playing

normally with other children

☐

Other children do not want to play with your child

☐

Other children are not permitted to play with

him/her

☐

7. SECTION 7: THE PARENTS' EXPERIENCE OF THEIR DOWN'S SYNDROME CHILD

7.1 Were you shocked after learning that your child had Down's syndrome?

| | Yes | No | Uncertain |
|--------|-----|----|-----------|
| Father | | | |
| Mother | | | |

7.2 Do you hold anyone directly responsible for your child's disability?

Yes

☐

No

☐

If yes, who do you think is responsible the disability?

7.3 Have you experienced any crisis periods (situations) in raising your Down's syndrome child?

Yes, often

☐

Yes, but seldom

☐

No, never

☐

- 7.4 Did the birth of your Down's syndrome child affect your plans for having any further children?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

- 7.5 Did you feel the need for professional counselling at any time after the birth of your Down's syndrome child?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |

- 7.6 Who gave you counselling concerning family-planning:

Physician

☐

Nurse

☐

Social worker

☐

Genetic counsellor

☐

Others (please specify) _____

- 7.7 Are you overprotective of your Down's syndrome child?

| Yes | No | Uncertain |
|-----|----|-----------|
| | | |