THE QUALITY OF LIFE NEEDS OF XHOSA SPEAKING LEARNERS WITH DOWN SYNDROME: TWO CASE STUDIES

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DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety or in part submitted it to any university for a degree.

.............................................................. ..............................................................
Signature Date
The research focuses on the needs of Xhosa-speaking learners with Down syndrome. The needs of these learners are not known by the service providers. Different organisations base their service delivery to these communities on the needs of learners with Down syndrome from other cultures. It was therefore imperative for this study to discover the needs of Xhosa-speaking learners with Down syndrome from a disadvantaged background.

The study involves a case study of two Xhosa speaking learners with Down syndrome. A major aim was to depict the quality of life of the learners with Down syndrome. This was done from an ecosystemic perspective. In the case study the needs of these two learners with Down syndrome in a Xhosa community are portrayed through the voices of their parents, educators, neighbours, and the two learners with Down syndrome. The following means of data production were used: interviews and observations. The parents, siblings of the learners with Down syndrome, and the learners with Down syndrome were seen as experts in the process.
OPSOMMING

Die navorsing fokus op die behoeftes van die Xhosa-sprekende leerders met Down-sindroom. Die behoeftes van die leerders met Down-sindroom in die Xhosa-gemeenskap is nie bekend onder die diensverskaffers nie. Verskillende organisasies baseer hulle dienslewering aan die gemeenskappe van behoeftes van leerders met Down-sindroom vanaf ander kulture. Daarom is die voortsetting van die studie hoofsaaklik vir Xhosa-sprekende leerders met Down-sindroom uit 'n agtergeblewe agtergrond. In die gevallstudie word die behoeftes van die leerders met Down-sindroom sterk uitgebeeld deur ouers, opvoeders, bure en twee leerders met Down-sindroom.

Die studie word uitgebeeld deur 'n gevallstudie van twee Xhosa-sprekende leerders met Down-sindroom. Dit was baie belangrik dat die kwaliteit van die tipe lewe wat leerders met Down-sindroom het beskryf en uitgebeeld word. Dit was gedoen vanaf 'n egosistemiese perspektief beïnvloed deur 'n verduidelikende voorbeeld. Daar was van die volgende gebruik gemaak: onderhoude, observasies, voorbeeld-tegniek. Die doel van die onderhoude was om die behoeftes van leerders met Down-sindroom uit 'n Xhosa-agtergrond te reflekteer. Die ouers en susters van die leerders met Down-sindroom en die leerders met Down-sindroom was beskou as ervare in die manier hoe hulle die proses hanteer het.
This thesis is dedicated to:

The two learners with Down Syndrome

Who made this study possible:

Andiwe and Thandisile

And

Pana Skota, Mduduzi, Anelisa, Dolly and Elizabeth

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CHAPTER ONE

INTRODUCTION, THEORETICAL FRAMEWORK AND STATEMENT OF THE PROBLEM

1.1 INTRODUCTION

Learners with disabilities were previously discriminated against and were excluded from mainstream education. Within a newly established democratic South African society they now have the opportunity to be included in the community (Department of Education: White Paper, 2001:6). This study investigates the needs of the two Xhosa-speaking learners with Down syndrome as part of a larger project initiated by the Department of Educational Psychology at the Stellenbosch University (the Intellectual Disability Quality Lifespan Development Project).

The project supports the vision of Down Syndrome South Africa. Down Syndrome South Africa is an association that is working towards finding ways to improve the quality of life of all persons with Down syndrome. It aims at promoting the idea that people with independence, dignity and security are valued adults and full citizens in our society. As a rights and advocacy movement, Down syndrome South Africa strives to empower families through sharing information, encouraging research in the fields of early intervention, education, medical aspects and employment (M coteli, McKenzie & Schoeman, 1999).

The larger research project has the following aims:

- To establish quality life span development of learners with intellectual disability through the development and implementation of support programs;
- To produce quality research on Down syndrome and intellectual disability;
- To establish collaborative research relationships with other Universities and Organizations;
• To establish the needs of the selected sample of learners with Down syndrome in the Western Cape;

• To explore a selection of existing support programmes for learners with Down syndrome to extend the database on support;

• To extend the literature review on support for learners with intellectual disability.

On reviewing existing literature on Down syndrome in South Africa, I found that very little research had been done on the African perspective on disabilities, and the particular needs of the learners with Down syndrome. Therefore, it was for this reason that I embarked on this study. A further reason for choosing Xhosa speaking learners is that I would be able conduct research in the language of the participants.

This study involved a case study of two learners with Down syndrome from Guguletu and Nyanga Townships in the Western Cape. The main purpose was to explore the needs of these two Xhosa-speaking learners with Down syndrome, aged between 13 and 14 years old. It was hoped that the study would help with sufficient support in areas in which learners with Down syndrome need it. This chapter introduces the reader to this study, offers a brief description of the research design, the relevant policies to the study, and provides an outline of the study.

1.2 THE UNITED NATIONS AND THE DISABILITY

This section will discuss the history of disabilities as depicted by the United Nations. The historical overview and accompanying chronology will trace the activities of the United Nations in relation to the people with disabilities. It will also discuss some of the activities undertaken by the specialized agencies of the United Nations such as the World Health Organization (WHO) which has helped with equal opportunities for the people with disabilities while providing technical assistance; the United Nations Children's Fund (UNICEF), which supports childhood disability programmes and technical support in collaboration with Rehabilitation International; and the International Labour Office (ILO), will be illustrated.
1.2.1 The history of disability as described by the United Nations

Over the course of the United Nations' first half century, people with disabilities have gone from passively accepting whatever was made available to them, to actively asserting strength and confidence in their own abilities to lead self-reliant and independent lives (United Nations). The number of disabled persons continues to increase in tandem with growth of the world population. According to the United Nations the factors causing the increase in their number include war and other forms of violence, inadequate medical care, and natural and other disasters. The majority of people with disabilities live in isolated rural areas. Many live in areas where the services needed to help them are unavailable (United Nations).

The United Nations was founded on the principle of equality for all. The Preamble to the Charter affirms the dignity and worth of every human being and gives primary importance to the promotion of social justice. The General Assembly established the foundation for the promotion and protection of human rights in 1948, when it proclaimed the Universal Declaration of Human Rights. Article 25 of Declaration states that each person has "the right to security in the event of unemployment, sickness, disability etc".

The anti-discrimination principles were established by such human rights instruments as the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, which came into force in 1966.

The early years: 1945 - 1955

During its first decade of work in the field of disability, the United Nations promoted a welfare perspective of disability. It began with the promotion of the rights of people with physical disabilities, such as the blind. It concentrated on disability prevention and rehabilitation. During its sixth session in 1950, the Social Commission considered two reports, Social rehabilitation of the "physically handicapped" and social rehabilitation of the blind. A conference was convened in Geneva from 26 February to 3 March 1950 to discuss coordination among the specialized agencies in the field of rehabilitation of people with disabilities. It was attended by the United Nations Secretariat, the ILO, WHO, UNESCO, THE International Refugee Organization (IRO), and UNICEF. This led to the agreement on the need to establish international standards for education, treatment, training and placement of people with disabilities (United Nations).

The focus of the United Nations on disability issues shifted in the late 1950s from a welfare perspective to one of social welfare. In 1956, the International Social Service Review was founded, one of whose objectives was to raise awareness of disability issues and emphasize rehabilitation programmes around the world. The Declaration on the Rights of People with disabilities, adopted by the General Assembly on 9 December 1975, encouraged national and international protection of the rights of the people with disabilities. The recognition was given to the fact that people with disabilities were entitled to the same political and civil rights as others, including measures necessary to enable them to become self-sufficient. It further recognized their right to economic and social security, to employment, to live with their families, to participate in social and creative events, to be protected against all exploitation, abuse or degrading behaviour (United Nations).


The proclamation in December 1982 of the United Nations Decade of Disabled Persons (1983-1992), prompted a flurry of activity designed to improve the situation and status of the people with disabilities. The emphasis was placed on raising new financial resources, improving education and employment opportunities for the people with disabilities, and increasing their participation in the life of their communities and country. The Sub-Commission on Prevention of discrimination and Protection of Minorities had included people with disabilities in international human rights discourse, since its establishment. In August 1987, a mid-decade review of the United Nations Decade of Disabled persons was conducted at global meeting of experts in Stockholm, Sweden. The meeting recommended the importance of recognizing the rights of persons with disabilities after the decade.

Publication in 1989 of the Tallinn Guidelines for Action on Human Resources Development in the Field of Disability encouraged recognition of people with disabilities as agents of their own destiny rather than as dependent objects of Governments. On 17 December 1991, the General Assembly adopted the Principles for the Protection of Persons with Intellectual Disabilities and for the Improvement of Mental Health Care. On 16 December 1992, the General Assembly appealed to Governments to observe 3 December of each year as International Day of "Disabled Persons".
It is clear that the achievement of global human rights for all citizens is a matter of securing justice. It should be common sense for all civil societies to recognise the human resource potential in all of its members. It is imperative that the planners remain sensitive to the disability dimension early and throughout the development process.

One of the Major development goals of the United Nations continues to be promoting the quality of life of the world's disadvantaged, including people with disabilities.

### 1.3 THE DISCOURSES

The discourses will be discussed in order to show how disability is viewed at different levels. According to Fulcher (1989), discourses serve a particular interest. There are four main kinds of discourses that have constructed the field of disability. These will be discussed in the following section.

**MEDICAL DISCOURSE**

According to this discourse impairment is linked with disability. For example, in this study the two Xhosa speaking learners with Down syndrome are placed at the "Specialised school for learners with intellectual disabilities". The learners, therefore in the school are constructed as "disabled", and the disability is conceived of as an objective attribute, not as a social construct. Fulcher (1989), states these learners are excluded from mainstream social and economic life because of disability that is thought to be natural irremediable characteristic of the person.

**CHARITY DISCOURSE**

Fulcher (1989), mentions that recipients of special education are viewed as in need of assistance, as objects of pity and eternally dependent on others. The people with disabilities are seen as underachievers and people who are in need of institutional care. The charity discourse states that people in authority are always the decision-makers. They are the voices of the people with disabilities. It was for this reason that this study promoted the voices of the two Xhosa speaking learners with Down syndrome, in order for them have their needs known.
LAY DISCOURSE

This discourse relates to prejudice, hate, ignorance, fear. In the study this will be shown. The learners with Down syndrome are subjected to discrimination.

RIGHTS DISCOURSE

According to Fulcher (1989), this discourse is committed to extending full citizenship to all people. It stresses equal opportunity, self-reliance, independent and wants rather than needs. Therefore, the rights of the Xhosa speaking learners with Down syndrome are also protected.

1.4 THE CONSTITUTION OF THE REPUBLIC OF SOUTH AFRICA

It is important to highlight some of the sections in the Constitution of the Republic of South Africa, in order to reflect the rights of the learners with disabilities. The aim of this section is to show how the rights of the learners with disabilities are protected by the constitution, these include: health care, food, social security. The relevancy of the Constitution in this study is for the needs of the learners with disabilities to be looked after by the society in order to accomplish their quality of life and their needs.


Everyone shall enjoy all universally accepted fundamental rights, freedoms and civil liberties, which shall be provided for and protected by entrenched and justifiable provisions in the Constitution. The Constitution forbids discrimination and all learners; including learners experiencing barriers have the right to dignity.

Under the clause: Health care, food, water and social security, The Bill of Rights (1996) stipulates that:

- Everyone has the right to have access to
  (i) health services, including reproductive health care;
  (ii) sufficient food and water; and
  (iii) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.
• Everyone has the inherent dignity and right to have his or her dignity respected and protected.

Therefore, the Constitution clearly protects the rights of the learners with disabilities. The study will be in line with the constitution. The needs of the Xhosa speaking learners with Down Syndrome are protected by the Constitution.

1.5 THE OTHER RELEVANT POLICIES TO THE STUDY

Different policies which are relevant to the study will be discussed, in order to further reflect how the rights and the needs of the learners with disabilities should be included in all the social, educational, and health factors in the society.

1.5.1 The White Paper 6

As it was discussed in the previous section, it is important to discuss the White Paper six in order to show how the rights of the learners with disabilities are protected in the school situation. Particularly the rights of the learners with Down Syndrome as it is my discussion in the study.

The White Paper on Special Needs Education provides a comprehensive framework on the transformation process, which is needed to change the education system into one which will meet the needs of all learners (Department of Education, 1997:53). These areas are described as developmental initiatives and thus are regarded as key development processes in transforming the education system.

Professor Kader Asmal, the then Minister of Education in the Republic of South Africa in his introduction of the Education White Paper 6 in (2001), states:

"In this White Paper, we make it clear, that special schools will be strengthened rather than abolished … we will develop investment plans to improve the quality of education across all of them. Learners with severe disabilities will be accommodated in these vastly improved special schools, as part of an inclusive system." This creates hope for the learners with disabilities, because they will be able to enjoy equal opportunities.

Special needs education is a sector where the legacy of apartheid is very evident. The segregation of learners on basis of race was extended to incorporate segregation in the basis
of disability. White Paper 6 states that schools that accommodated white disabled learners were very well-resourced, whilst the few schools for black learners with disabilities were systematically under-resourced. Learners with disabilities experienced great difficulty in gaining access to education (Department of Education: White Paper 6, 2001:9).

1.5.2 The South African Schools Act of 1996

The South African Schools Act (1996), which embodies the principles in the Constitution and the White Papers on Education and Training, has ushered in a new era in the field of general education in South Africa and also special education.

The Act relates to the rights of all learners and the development of an integrated education system. The following are salient to this study:

- One of the key features of the new Act is the assertion of the right of equal access to basic and quality education for all learners without discriminating in any way.

- The Act thus embodies the right enshrined in the Constitution to equal access, the right to claim learning support so as to access the curriculum.

1.5.3 The National Commission on Special Needs in Education and Training and the National Commission for Education Support Service

In 1996 the then Ministry of Education, Prof. Sibusiso Bhengu appointed the National Commission on Special Needs in Education and Training (NCSNET) and the National Committee for Education Support Service (NCESS) to investigate and make recommendations on all aspects of Special Needs and Support Services in Education and Training in South Africa (DNE, 1997 in Engelbrecht, Green, Naiker & Engelbrecht, 1999:24). The general terms of reference of the NCSNET and NCESS were to advise the Minister of Education on the following:

- The immediate and long-term national and provincial needs and strategies for the education of learners with special needs in education.

- The support structures required by the Minister of Education, the provincial Ministers of Education.

- The training of personnel for specialised education and education support services.
• The implications of the policy of mainstreaming for general education and strategies for marketing the policy to communities.

• The organisation, governance and funding of schools providing education for learners with special education needs (Engelbrecht et al., 1999:16-17).

The NCSNET and NCESS attempted to identify barriers and needs as well as provide "guidelines for transformation" to create access to quality education for all learners (Department of Education, 1997:ix). The following principles were articulated in the NCSNET and NCESS report:

• Acceptance of principles and values contained in the Constitution and in the White Paper on Education and Training: The right to equality, protection, from discrimination, respect for human diversity, the right to equal benefit and protection from the law.

• Human rights and social justice for all learners: All learners should enjoy equal rights and protection of human dignity.

• Participation and Social integration: All learners must be given opportunity to participate in their communities, being provided with the widest possible educational and social opportunities.

• Equal access to single, inclusive education system: Appropriate and effective education must be organised in such a way that all learners have access within a single education system that is responsive to diversity (Department of Education, 1997:10-11).

These principles informed my entire study.

The Constitution and the principles underpinning the White Paper on Education and Training provide a basis for all the work of NCSNET and NCESS.

The vision of the work of NCSNET and NCESS is that of an education and training system that promotes education for all and fosters the development of inclusive and supportive centres of learning that enable all learners to participate actively in the education process so that they can develop and extend their potential and participate as equal members of society (Department of Education, 1997:10).
1.5.4 Batho Pele Principles

It was necessary to discuss the Batho Pele Principles to view the importance the National Government of the Republic of South Africa has put on the right to receive services regardless of the disability and social background.

The Republic of South Africa designed the service delivery for the people, in order to fulfil the needs of the people. Therefore, the Communication Services on behalf of Labour Relations and Transformation designed the following eight principles of Batho Pele (Batho Pele Principles, 2001).

- The public should be consulted about the level and quality of the services they receive from the government officials, and whenever possible, should be given a choice about the services that are offered.

- The public should be told what level and quality of public services they receive, so that they are aware of what they can expect from the government. The public should always be treated with courtesy and consideration. All members of the public should have equal access to the services they are entitled to. The public should be told how national departments and provincial administrations are run, how much they cost, and who is in charge.

- If the promised standard of service is not delivered, the public should be offered an apology, a full explanation, and a speedy and effective remedy; and when complaints are made, the public should receive a sympathetic and positive response.

- Public Services should be provided economically and efficiently, in order to give the public the best possible value for money.

1.5.5 The White Paper for Social Welfare

The White Paper for Social Welfare (1997) stipulates the principles, guidelines, recommendations, proposed policies and programmes for Social Welfare in South Africa. South Africans are called upon to participate in the development of an equitable, people-centred Social Welfare System, and are being afforded the opportunity to play an active role in promoting their own well being.
Resources are to be equitably distributed and address racial, gender, geographic, urban and rural. Equality of opportunity for people with special needs is also to be fostered. Social Welfare Services and programmes are to promote non-discrimination, tolerance, mutual respect, and diversity of all groups in society. Women, children, the physically and mentally disabled are not be excluded.

Community Development strategies are to address basic material, physical and psychosocial needs. There are inadequate support facilities to assist families to keep more severely disabled children in the home as long as possible. This is partly because there is a shortage, of care facilities for children with disabilities, particularly after the preschool phase. Those in need of special support are families with children, especially those who are under five years old, single parents, families caring for children or other members with disabilities and chronic illnesses. These families should be targeted for immediate action and should receive priority in family upliftment programmes.

The programmes for families and children should be based on the following guidelines:

- The rights of families and children should be protected.
- Families in need should receive comprehensive protection and support from the state and organisations. Family Support Programmes should address the fundamental cause of family disintegration.
- Poor families and children should be given first priority in the allocation of resources.

There is a connection between the White Paper for Social Welfare and my study, because it shows that the learners with Down syndrome have access to the services provided by the Social Welfare department, and their needs are protected.

1.5.6 White Paper on an Integrated National Disability Strategy

The White Paper on an Integrated National Strategy was produced in 1997 from the office of the then Deputy President of the Republic of South Africa, Mr Thabo Mbeki. The White Paper on an Integrated National Disability Strategy (1997) aims to represent the government's thinking about what it can contribute to the development of disabled people and to the promotion and protection of their rights.
It is important to mention the vision of the White Paper on an Integrated National Disability Strategy (1997) as follows:

In a society for all, the needs of all citizens constitute the basis for planning, and the general systems and institutions of society are accessible to all.

This forms part of my study in the sense that it affirms that the needs of the Xhosa speaking learners with Down syndrome should be known in order to help with support and planning of programmes which will help with development of the Xhosa Speaking learners with Down Syndrome.

The White Paper on an Integrated National Disability (1997), also mentions its objectives as follows:

the facilitation of the integration of disability issues into government developmental strategies, planning and programmes. One of the findings of the White Paper on an Integrated National Disability (1997) as mentioned under the heading (People with Severe Intellectual or Mental Disabilities) is that it is commonly considered that the specific needs of people with severe mental/intellectual disabilities fall outside the orbit of development. They are not provided with opportunities to participate in society to the best of their abilities. People with severe intellectual disabilities often have a low life expectancy, due to lack of care, support and access even to the most basic services. It is for this reason that my study will investigate the needs of the two Xhosa speaking learners with Down Syndrome in order to help with the process of development and support.

1.6 CLARIFICATION OF CONCEPTS

The following concepts are important for this study and therefore will need to be clarified.

1.6.1 Needs assessment

According to a number of researchers (Lund & McGechan, 1981; Manion & Morisson, 2000:391; Rossi & Freeman, 1993; Scriven & Roth, 1978; Stufflebeam et al., 1985; Suarez, 1994 in Cohen, 2001), needs can be defined in several ways:
TABLE 1.1: DEFINITION OF NEEDS

A discrepancy or underachievement (a difference between what is and what should be the case)

Needs are wants and preferences (e.g. for future planning, reflecting values).

Anticipated requirements for the future.

Anticipated problems for the future

A deficit (where the absence of feature under review is harmful.

A need assessment can be seen as the operationalization of the problem or needs. The data required for needs analysis can be derived from several sources, for example:

- Quantitative data from: structured surveys; "key person" (informants) surveys, structured interviews (Rossi & Freeman, 1993).

- Qualitative data from: semi-structured interviews with individuals and groups, focus groups, case studies, critical incidents and events, public meetings (Morrison, 1993).

Clearly the success of needs analysis could depend on the careful and appropriate sampling and targeting of parties concerned. Rossi and Freeman (1993:84) suggest that qualitative data are useful for determining the nature of the need, whilst quantitative data are necessary for determining the extent of the need.

A need analysis identifies the problem or need and then proceeds to identify the aims, content, implementation, target population and outcome of an intervention (Cohen, Manion & Morisson, 2000:393). The needs analysis for the purpose of future planning and development will tend to focus on aims and goals (Suarez, 1994).

It is important for the researcher to be clear on the purpose of the needs analysis being undertaken, for this determines the focus, methodology and outcome of the assessment. The critical factor in a needs assessment is the utility of the findings (Cohen et al., 2000:393).

According to Cohen and Manion (1994:39), four main steps can be followed in planning the needs analysis:
• **Step 1**: Make a decision about the purpose of the needs analysis and definitions of needs that are used. For example, the purpose of the needs assessment for the Xhosa-speaking learner with Down syndrome was done in order to facilitate the process of providing support and development.

• **Step 2**: Identify the focus of the needs analysis (in this case the focus was on the quality of life of the learners with Down syndrome in the Xhosa community.

• **Step 3**: Plan the methodology, sampling, instrumentation, data collection and analysis procedures and criteria to be used to judge the size, scope, extent, severity etc. In this study, interviews were used to collect the data. The interviews were recorded on audio tape and transcribed to explore the needs of the learners.

• **Step 4**: Plan reporting and the dissemination of the results: The process of reporting is done in Chapter Five: Discussion of Findings. This reflects the findings from the interviews conducted with different sub-systems.

1.6.1.1 **Phases of needs assessment**

Quality planning is essential for needs assessment to be successful. No matter how the process begins, some kind of structure must be set up to study the nature of problems and to determine whether action should be taken (Altschuld & Witkin, 2000:43). Altschuld and Witkin (2000:45) define needs assessment as the process of determining, analyzing, and prioritizing needs and in turn identifying and implementing solution strategies to resolve high-priority needs. Therefore needs analysis is seen as the process of analyzing needs once they have been assessed to determine causal factors and potential solution strategies and then to select the most likely solution strategy to be implemented.

According to Rodriguez (1988), there are three phases of needs assessment. These will be indicated below.

1.6.1.1.1 **Pre-assessment**

This can be viewed as the planning phase before the needs assessment can be done. No matter how it arises, once a decision is made to conduct a needs assessment, two important initial activities occur. A needs assessor is selected to lead the process of needs assessment.
and a needs assessment committee is chosen (Altschuld & Witkin, 2000:46). Survey is the major method of needs assessment.

Sork (1995) suggested that there are two basic criteria for prioritizing needs, namely, importance and feasibility.

**Importance criteria**

- How many individuals are affected by these needs (For example, in this study the two Xhosa speaking learners with Down syndrome, parents and siblings of the learners with Down syndrome, and teachers were the affected group)?
- To what extent would the need contribute to the community goals?
- Does the need require immediate attention?
- To what extent would resolving a need in this particular area have a positive effect on a need in another area? (The more positive the effect, the greater the importance.)

**Feasibility criteria**

- The degree to which an intervention can contribute
- The extent to which resources could become available for programmes to reduce the need.

In this study I had to go to the Special School at Nompumelelo to conduct the pre-assessment of needs. Next, I had to plan how the needs assessment was going to be conducted. Two learners were chosen for the case study.

1.6.1.1.2 **Assessment**

Assessment determines what additional data will be collected, specifies the procedures that will be used for obtaining data, analyses and interprets data, looks at causes of needs, and makes decisions relative to phase 3.
1.6.1.3 Post assessment

Final priorities are established, solution strategies are selected, and an action plan is developed, implemented and evaluated. Needs Analysis takes place after needs have been identified and prioritised. It consists of defining criteria for solution strategies examining alternative solutions in terms of the needs, and selecting and implementing the strategy that has the highest possibility of meeting the need. A need cannot be analysed before it has been identified (Altschuld & Witkin, 2000:45). It is clear that assessment of needs has to precede needs analysis. One cannot do needs analysis before doing needs assessment.

Since this study sets out to identify needs rather than to analyse already identified needs, I will use the term needs assessment.

According to Altschuld and Witkin (2000:143), needs assessments have many complex features and dimensions. They usually take place within the political and social environments of organizations and are often based on information obtained from a wide array of constituencies.

1.6.2 Maslow's hierarchy of needs

As a humanist psychologist, Maslow was concerned with the psychological growth and maturity of people. According to Maslow, human action is prompted by needs which may be arranged in a hierarchy (Louw, 1993:435). Maslow's hierarchy of needs emphasises the fact that as the more basic needs are satisfied, higher levels of needs which are characteristic of increased degrees of mental health, emerge.

Maslow's hierarchy (Louw, 1993:435) of needs is used as a vehicle to show the relationship between the quality of life of the Xhosa speaking learners with Down syndrome and universal human needs. For example, if the learner's needs are not met, he/she will not function optimally in society. The learner will always be disadvantaged, because his/her needs are not met. When the quality of life of the Xhosa speaking learners with Down syndrome is not known, it makes things difficult for the service providers in terms of support. The learners become disadvantaged. Maslow's hierarchy of needs is portrayed below:
Maslow's hierarchy of needs suggests that if their needs are not met, it will be difficult for Xhosa-speaking learners with Down syndrome to develop to the next level in life. Therefore, a link can be made between Maslow's hierarchy of needs and the quality of life of the learners with Down syndrome.

As mentioned, the needs of the two Xhosa speaking learners with Down syndrome will be explored through the concept of quality of life.

1.6.3 Down Syndrome

John Langdon Down, a physician at the Earlswood in England, first described Down syndrome in 1866 (Lorenz, 1998:1). Two of one parent's chromosomes are joined together and so do not separate properly when the gender cells are formed in their baby. As a result the baby, has the usual two copies of chromosome 21 plus some additional 21st chromosome material. Down syndrome is a chromosomal aberration and not a disease. Many people with Down syndrome function at the moderate level of retardation. Some of the individuals may
require only a few supportive services to get along on a daily basis, but others may continue to require some help throughout life (Mash & Wolfe, 2002:241). According to (Brown, Greer, Aylwood & Hunt, 1990 in Mash & Wolfe, 2002:241), children with Down syndrome often show significant age-related gains in adaptive functioning from one to six years of age. But as they grow older, their pace of development levels off or even declines. Similarly, as they grow older, a deceleration is often seen in their rate of social development. According to Mash and Wolfe (2002:142), these children continue to develop in intelligence, but they do so at slower rates throughout the childhood years.

1.6.4 Intellectual disability

The most commonly used criteria are based on categories of scores on standardised intelligence tests. Learners with intellectual disabilities are identified as those whose IQ scores fall in the lowest 5% of the population that is with measured IQs of 70 or less (Engelbrecht & Green, 2001:198).

Intellectual ability is understood as the capacity to think, reason, and learn (acquire context- and age-appropriate knowledge and reflective ability). Intellectual and cognitive differences refer to levels of educational and social functioning that require special learning accommodations and teaching strategies (Lomofsky & Skuy, in Engelbrecht & Green, 2001:188).

The IQ cut off for the diagnosis of mental retardation is 70. Children with IQs of 70 and over are not considered as intellectually disabled. The following table provides the degrees of severity of intellectual disability:

**TABLE 1.2: DEGREES OF SEVERITY OF INTELLECTUAL DISABILITY**

<table>
<thead>
<tr>
<th>Degree of Severity</th>
<th>Intelligence Co-efficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild Intellectual Disability</td>
<td>50-55 approximately 70</td>
</tr>
<tr>
<td>Moderate Intellectual Disability</td>
<td>35-40 to 50-55</td>
</tr>
<tr>
<td>Severe Intellectual Disability</td>
<td>20-25 to 35-40</td>
</tr>
<tr>
<td>Profound Intellectual Disability</td>
<td>Below 20 or 25</td>
</tr>
</tbody>
</table>

Degrees of Severity Intelligence Co-efficient (The Diagnostic and Statistical Manual of Mental Disorders, 1994:40).
Learners with disabilities refer to the group of learners with physical, sensory, intellectual or multiple impairment (NCSNET & NCESS, 1997:149). Most learners with severe and profound intellectual difficulties have multiple disabilities that create barriers to learning (Kirk, Gallagher & Anastoasiow, 1993 in Engelbrecht & Green, 2001:200).

I am aware of the concept of mental retardation that is used to refer to learners with intellectual disabilities. For the purpose of this study I prefer the term learners with intellectual disabilities. Since barriers to learning exist primarily within the learning system, the White Paper 6 adopts the use of the terminology "barriers to learning and development". I, however, will retain the internationally acceptable terms of "disability" and "impairments".

The following table illustrates different levels of intellectual disability, and the expected achievements, as depicted by (Kirk et al., 1993:173):

**TABLE 1.3: LEVELS OF SPECIAL NEED IN COGNITIVE FUNCTIONING**

<table>
<thead>
<tr>
<th></th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe and Profound</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aetiology</strong></td>
<td>A combination of unfavourable environmental conditions and genetic factors</td>
<td>Metabolic defects or disorders</td>
<td>Same criteria as in moderate but may differ in degree</td>
</tr>
<tr>
<td><strong>Prevalence</strong></td>
<td>About 10 in every 1000 persons</td>
<td>About 3 in every 1000 persons</td>
<td>About 1 in every 1000 persons</td>
</tr>
<tr>
<td><strong>School expectations</strong></td>
<td>Needs special curriculum adaptations for appropriate education and can learn academic skills up to grade 6</td>
<td>Needs major adaptations in educational programs (may learn up to grade 2 level in academic subjects)</td>
<td>May attain limited self care</td>
</tr>
<tr>
<td><strong>Age 6 to 20</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Kirk et al., 1993:173)

Physical characteristics and obvious developmental delay in all areas generally indicate severe and profound intellectual disability, and some forms of moderate disability, very early. Signs of less severe intellectual disability are evident in two main areas of functioning namely thinking/learning and adaptive behaviour (Limofsky & Skuy, in Engelbrecht & Green, 2001:198).
1.6.5 Quality of life

There are a number of definitions, which have been coined by different researchers. Brown (1998:323) defines quality of life as the development of well-being. Felce and Perry (1997:323) define quality of life according to five clear areas of well-being which need to be considered for a comprehensive understanding of quality of life. These are physical well-being, material well-being, social well-being, emotional well-being and productive well-being. Quality of life should be seen as a holistic concept encompassing all areas of the individual's life: employment, education, social relationships, accommodation, and leisure and recreation (Felce & Perry, 1997:322). Quality of life is based on dynamic values, which change depending on the context in which quality of life is measured (Haas, 1999:728). Haas (1999) defines quality of life as a multidimensional evaluation of an individual's current life circumstances in the context of the culture in which he or she lives and the values he or she holds. Quality of life is primarily a subjective sense of well-being encompassing physical, psychological, social, and spiritual dimensions.

Quality of life has also been defined as the extent to which an individual has control over his or her environment regardless of baseline (Felce & Perry, 1997:323). Quality of life is experienced when a person's basic needs are met and when he or she has the opportunity to pursue and achieve goals in major life settings. The quality of life of an individual is intrinsically related to the quality of life of other persons in his or her environment (Goode, 1994:148).

The quality of life of the Xhosa-speaking learners with Down syndrome will be discussed using these sub-systems, namely, school where the learners are placed, the parents of the learners with Down syndrome, the community, social factors, economic factors, political factors, the siblings and the two Xhosa speaking learners with Down syndrome. This will be shown in the figure below:
The framework for Needs Assessment of the learners with Down syndrome was based on Bronfenbrenner's (1995) ecological systems theory. According to Bronfenbrenner (1995), this theory emphasises that the developing person is embedded in a series of environmental systems that interact with the person to influence development. Bronfenbrenner (1995) describes the different levels of the ecology as follows:

- **The Microsystem:** It refers to the actions and interactions that occur in the person's immediate surroundings. For example, for most young infants the microsystem may be limited to the family. According to Shaffer (1999:63), this system eventually becomes much more complex as children are exposed to day care, preschool classes, youth-groups and neighbourhood playmates. In my study the microsystem of the Xhosa speaking learners with Down syndrome will be: the African family, in this case the mother, the extended family, the siblings.
• **The Mesosystem**: This refers to the connections or interrelationships among such microsystem as homes, schools and peer groups (Shaffer, 1999:64). For example in the home of the learner with Down syndrome in the Xhosa community, this refers to interrelationships between the home, the school and the peer group.

• **The Macrosystem**: It is defined as the larger cultural or sub-cultural context in which development occurs (Shaffer, 1999:65). The larger cultural context is the dominant culture in an individuals sub-system. For example, in South Africa this can be seen as the race to which the individual belongs. In this case, the child with Down syndrome's macrosystem is the African community and the sub-cultural system is the Xhosa community in the Western Cape, which includes the social, economic and political factors.

• **The Exosystem**: This refers to the social systems that children and adolescents do not directly experience, but that may nonetheless influence their development (Shaffer, 1999). For example, in the study one part of Andiwe's exosystem is her mother's work environment. In Thandisile's situation, his exosystem will be his mother's selling business.

The data analysis was presented in the different sub-systems of the ecosystem in the Xhosa context (Adapted from Bronfenbrenner's ecological system in Shaffer, 1999:64) as follows:
1.7 STATEMENT OF THE PROBLEM

I grew up in the Eastern Cape, in a small town called Tsolo at St Cuthberths. In what follows I reflect on my knowledge about disabilities in the early years of my life, before my awareness of disabilities as a result of education.

As the young boys in the Eastern Cape, we were exposed to different beliefs about disabilities. Some of them will be listed below:

- The family with a child or person with a disability was seen as being cursed: the belief was that the family or the parents of the child with a disability had committed a serious sin to God. Therefore, they had been punished.
The mother or the family with a child or person with a disability had laughed at a person with a disability as the result she will have a child with a disability. It was mentioned earlier in the chapter that one was not allowed to laugh at the person with disability.

One was not supposed to share the clothes or food with a person with a disability. The belief was that a disability was infectious. (The Xhosa word for that would be *ukosulela*).

One would not even touch or shake hands with a person with a disability.

We were not even supposed to walk next to the person with a disability. Seeing a person with a disability was seen as bad luck. The belief was that something bad was going to happen.

One was not even allowed to swim with a person with disability or share clothes and eat the same food.

These were the beliefs that were held by Xhosa boys in my community. Mouton (2000) argues that research is necessary in order to prove hearsay is valid. This is done scientifically by researchers. According to Mouton (2000:137), research problems are usually formulated to address real-life problems. The research problem refers to "process by which the researcher has identified a real-problem and "translated" it into a research problem. I have adopted the three world's framework (Mouton, 2000:137 cited in Newmark, 2001:2) and used it as a point of departure in relating it to research on individuals with Down syndrome. The three worlds are presented from a perspective of general knowledge production. I also use this framework to contextualise the research problem of my study.

- **World 1**: Everyday life and lay knowledge (the 'ordinary social and physical reality that will live in … we live as ordinary human beings in multiple contexts' (for example, Xhosa-speaking learners with Down syndrome) (Mouton, 2000:138 in Newmark, 2001:2).

- **World 2**: Science and scientific research. It is not possible to produce scientific results that are infallible and absolutely true, but we are motivated as scientists to constantly strive for the most truthful and most valid results (Mouton, 2000:138).
**World 3:** The world of meta-science where we "submit our research to critical reflection". The meta-disciplines such as philosophy and the methodology of science are located in world three as they all involve reflection on the nature of science and scientific research (Mouton, 2000:189).

According to Mouton (2000:142), the distinction between the three worlds is an analytical distinction because these worlds are really interwoven. For example, on (World 1) are the needs of the Xhosa-speaking learner with Down syndrome who comes from a disadvantaged background in the period of ten years of democracy in South Africa.

The following sub-questions were the point of departure for this study:

What are the needs of the Xhosa speaking learners with Down syndrome, with regard to support and development?

The following sub-problems were also identified:

- To what extent does the Xhosa community accept the people with disabilities?
- How does the school (Nompumelelo Special School) support learners with Down syndrome?
- How does the family include the child with Down syndrome in everyday household chores?

The model for quality of life (Adapted from Goode, 1994:149) used in this study, will be depicted below to show the link between the needs of the learners with Down syndrome and quality of life as discussed by Goode, 1994:149).
The following are the aspects of life contributing to well being or the quality of life:

- Support and nurture through family and community.
- Access to cultural and leisure activities.
- Personal safety and protection (Goode, 1994:148).

Using the following factors which affect well-being or quality of life of the Xhosa speaking learners with Down syndrome helped with the process of interviewing the participants regarding the needs of the learners with Down syndrome from the Xhosa background:

- What is necessary for the well being of two Xhosa speaking learners with Down syndrome?

- What factors affect their well-being and in what way?

The quality of life indicators have been displayed below, in order to make a link between the quality of life of the two Xhosa speaking learners with Down syndrome. This will help further in the study to show whether the exemplary indicators as shown by (Schalock, 2000),...
are also reflected by the two Xhosa speaking learners with Down syndrome. The link will be shown in Chapter Five.

**TABLE 1.4: QUALITY OF LIFE INDICATORS**

<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>EXEMPLARY INDICATORS</th>
</tr>
</thead>
</table>
| Emotional well-being | • Safety  
|                     | • Spirituality  
|                     | • Happiness  
|                     | • Freedom from stress  
|                     | • Self-concept  
|                     | • Contentment  |
| Interpersonal relations | • Intimacy  
|                     | • Affection  
|                     | • Family  
|                     | • Interactions  
|                     | • Friendships  
|                     | • Supports  |
| Material well-being | • Ownership  
|                     | • Financial  
|                     | • Security  
|                     | • Food  
|                     | • Employment  
|                     | • Possessions  
|                     | • Socio-economic status  
|                     | • Shelter  |
| Personal development | • Education  
|                     | • Skills Fulfilment  
|                     | • Personal competence  
|                     | • Purposeful activity  
|                     | • Advancement  |
| Physical well-being | • Health  
|                     | • Nutrition  
|                     | • Recreation  
|                     | • Mobility  
|                     | • Health care  
|                     | • Leisure  
|                     | • Activities of daily living  |
| Self-determination | • Autonomy  
|                     | • Choices  
|                     | • Decisions  
|                     | • Personal control  
|                     | • Self-direction  
|                     | • Personal goals  |
| Rights             | • Privacy  
|                     | • Voting  
|                     | • Access  
|                     | • Due process  
|                     | • Civic responsibilities  |
| Social inclusion   | • Acceptance  
|                     | • Status  
|                     | • Work environment  |

(Schalock, 2000:122)
The study was limited to a specific group, i.e. Xhosa speaking learners with Down syndrome. It was explored with the intention of finding out the needs of Xhosa speaking learners with Down syndrome.

1.8 RESEARCH AIM

This study strives to investigate the needs of the two Xhosa speaking learners with Down syndrome with regard to support and development. The needs will be investigated through exploring the quality of life of two learners with Down syndrome from the Xhosa community. Through exploring the quality of life of the learners with Down syndrome, I would like to contribute to defining the needs of all learners with Down syndrome.

1.9 THE RESEARCH PROCESS

The procedures and events during this research were documented and recorded to ensure successful research progression. I adopted a qualitative, non-experimental approach. The basic skills required of the researcher to analyse this kind of qualitative or symbolic material involve collecting, classifying, ordering, synthesizing, evaluating and interpreting (Cohen et al., 2000:164).

The research method of my research was a case study which focused on the needs of two learners with Down syndrome. It was hoped that this would provide a needs analysis of Xhosa-speaking learners with Down syndrome. According to Cohen et al. (2000:181), "[a] case study is a specific instance that is frequently designed to illustrate a more general principle; it is the study of an instance in action. Case studies can establish cause and effect, indeed one of their strengths is that they observe effects in real contexts, recognizing that context is a powerful determinant of both causes and effects". Stuurman (1999:103) argues that "a distinguishing feature of case studies is that human systems have integrity to them rather than being a loose connection of traits, necessitating in-depth investigation". The case study involved two learners with Down syndrome who are Xhosa speaking (a girl and a boy), who are 13 and 14 years old, respectively. The ecosystemic framework was used in order to provide the way of approaching this study.

According to Merriam (1998:8), "[t]he qualitative researcher is usually the primary agent for data production and analysis. Qualitative research often involves fieldwork as well as an
The role, which I took as the researcher, was that of a participant observer, trying to understand the world of human experience of the children with Down syndrome in the Xhosa community, and allowing the participants to express their needs.

Good rapport with the participants (Thandile, Thandile's mother, Thandile's sister and Aunt, the neighbours, the teachers and the principal, Andiwe, Andiwe's mother, Andiwe's sister, the neighbour) of my research was established, permission was gained from the Western Cape Education Department, Nompumelelo Special School, Education Management and Development Centre: Metropole South. An extensive literature review for the study was undertaken in order to derive information on the latest refinements of key concepts, and also to take into account what other researchers have done in the area.
TABLE 1.5: THE STRUCTURE OF THE RESEARCH

CHAPTER ONE
RESEARCH PROBLEM

CHAPTER TWO
LITERATURE REVIEW

CHAPTER THREE
• 2 CASE STUDIES
• RESEARCH DESIGN
• QUALITATIVE STUDY

CHAPTER FOUR
IMPLEMENTATION OF THE STUDY
• Xhosa speaking learners with Down syndrome
  DATA COLLECTION
  - Documentation and records
  - Observation
  - Interviews
• DATA ANALYSIS
• DATA CONSOLIDATION
• DATA VERIFICATION

DATA INTERPRETATION

CHAPTER 5
CONCLUSION & RECOMMENDATIONS

(Adapted from Goodyer, 1997:97)
1.10 OVERVIEW OF CHAPTERS

Chapter One provided an introduction to the study within the context of educational transformation in South Africa. It also included a statement of the problem, the research aim and a clarification of certain concepts. Chapter Two is concerned with a literature review of studies done on Down syndrome. The discussion explores the genetic causes and risks of Down syndrome, the adolescence phase of development, the relevance of Piaget's theory of cognitive development to the African child. In Chapter Three the research design and methodology is presented. Chapter Four presents the case studies undertaken within an ecosystem framework with specific reference to the needs of the Xhosa speaking learners with Down syndrome. In Chapter Five I discuss the findings and provide recommendations and possibilities for further investigation arising from this study.

1.11 SUMMARY OF THE CHAPTER

In this chapter, I presented the questions that were the point of departure of my research. I also outlined the way my research was conducted and the perspective from which it was approached. I also explained the framework within which I conducted my study, which is the ecosystemic framework. It was also necessary to mirror the international view on disabilities. Seminal terms used in the study were also explained to make it easier for readers to follow the study.

Chapter Two will explore key research on learners with Down syndrome, providing a national as well as an international perspective. I will also attempt to highlight the way the Down syndrome disability is viewed within African culture.
CHAPTER TWO

LITERATURE REVIEW: CHILDREN WITH DOWN SYNDROME

2.1 INTRODUCTION

In this chapter, I will explore the way learners with Down syndrome are described in the literature in order to present an account of the genetic causes and risks of Down syndrome as well as the mental characteristics of learners with Down syndrome.

Piaget's theory of cognitive development will be discussed in order to see the extent to which it provides an appropriate means of describing the development of the Xhosa speaking child. In attempting to gain a clear understanding of the needs of the Xhosa speaking learners at a particular stage, particular attention will be paid to the adolescent phase.

The history of disability in Africa is a little-researched topic. Nevertheless, it is essential for the researcher to reflect on what other researchers on the topic have done. This will include the attitudes within the African community towards people with disabilities. As was mentioned in Chapter One, the Xhosa language does not have a specific name for Down Syndrome, therefore, a reference will be made to the disability in general. The topic will show some of the African myths about disabilities.

Finally, as the reflective practitioner, I need to reflect on my knowledge of disabilities, prior to being enlightened by the literature. My reflection will take us back three decades ago to the Eastern Cape.

2.2 THE GENETIC CAUSES AND RISKS OF DOWN SYNDROME

Our bodies are made up of thousands of cells. These cells are of different types; namely, there are skin cell, blood cells, nerve cells etc. The cells group together to produce the different parts of the body such as the bones and skull, the muscles, the heart, liver and kidneys. According to Cunningham (1982) there is a master plan which controls and programmes development, and it is the job of the chromosomes to carry out this master plan from
generation to generation, and from cell to cell. If something happens to alter the plan, like an extra chromosome, then the developing person will be different.

Down syndrome is a genetic condition that is caused by cell division in an embryo produced by the fusion of an egg and sperm. Each of the sex cells contains 23 individual chromosomes. Down syndrome is often referred to as Trisomy 21, because the majority of affected children have a third copy of chromosome 21 in all their cells, instead of the usual two. As a result, the baby has 47 chromosomes instead of 46 (Lorenz, 1998:1).

Three types of chromosomal aberrations are recognised in the case of Down syndrome (Kaplan & Sadock, 1981:859; Kaplan & Grebb, 1994:1027):

**Trisomy 21**

When the number 21 pair sticks together a person has Trisomy 21. The people with Trisomy 21 have a special set of physical and intellectual ability, which is collectively called Down syndrome (Cunningham, 1982; 74). If a trisomy of numbers 13 or 18 is formed, the individual can develop either Patau's syndrome or Edwards' syndrome (Stratford, 1989:166).

Translocation indicates the fusion of two chromosomes, most often chromosomes 21 and 15. The result is a count of 46 chromosomes (despite the extra chromosome 21). This disorder is usually inherited.

Non-disjunction after fertilization (therefore not inherited) in any cell division causes mosaicism. Both normal and trisomic cells are found in various tissues and constitute the second type of chromosomal aberrations. The question has been asked whether people with Mosaic Trisomy 21 differ from other types of Down syndrome. The answer is that generally children with Mosaic Trisomy 21 have less marked or fewer of the physical characteristics of Down syndrome, and they are seen to have a slightly higher intellectual ability and language development than those with Trisomy 21 (Cunningham, 1988:78).

The genetic basis of the Down's syndrome was discovered in Paris in 1959 when Professor Jerome Lejeune, first identified the characteristic combination of chromosomes. The Mosaic form of Down's syndrome occurs when the embryo is produced from two normal sex cells, but then develops a trisomy as the cells continue to divide. The causes of Down's syndrome Trisomy 21 have been diagrammatically explained in Table 3.
The overriding feature of Down syndrome is intellectual disability (Kaplan, Sadock & Grebb, 1994:1027). The majority of learners with Down syndrome belong to the moderate to severely disabled, although mental development appears to progress normally from birth to six months of age, after which a gradual decline in mental ability is observed. People with Down syndrome are described as placid, cheerful and cooperative, but during adolescence this easy disposition changes and emotional and behavioural difficulties are recorded. Other important signs in a newborn include hypotonia (decreased muscle tone), small stature, hyper-flexibility of joints, oblique palerbral tissue, abundant neck, a small, flattened skull, high cheekbones and protruding tongue. The hands are broad and thick, with a single palmary transversal crease, and the little fingers are short and curved inward (Hallaham & Kauffman, 1994:125; Kaplan & Sadock, 1981:858; Kaplan, Sadock Grebb, 1994:1027, Louw, 1992:275).
The above figure shows how Down syndrome is caused. Although the mother had 46 chromosomes and the father had 46 chromosomes, the fertilised egg has 47 chromosomes which results in the baby being born with Down syndrome.
2.3 THE DEVELOPMENTAL CHARACTERISTICS OF DOWN SYNDROME

Children with intellectual disabilities have frequently been characterised as developing very slowly (Goodman, 2003:1). One theory explains that the children with Down syndrome progress through the same sequence of developmental stages in the same order as typically developing children but do so at a slower rate.

Children with Down syndrome have been found to have difficulty in inhibiting responses and switching visual attention (Cuskelly, Zhang & Hayes, 2003:247). They were also found to be less able to delay gratification when asked to do so by their mothers than were typically developing children of the same mental age (Cuskelly et al., 2003:247). Generally it seems that children with Down syndrome do not acquire skills at the same mental age as is typical of children.

2.3.1 Non-verbal communication and language of the child with Down Syndrome

Communication skills are the most important prerequisites for social interaction. Individuals who cannot talk are limited in their social relationships. However, non-verbal communication skills are also extremely important in the early life of the child. Non-verbal skills may reflect the child's desire to communicate as well as some understanding of how to communicate.

Children with Down syndrome exhibit language delays. For instance, these children's expressive language is often much weaker than receptive language, especially in communication ability beyond the 24-month level (Wolfe, 2002:241). There is also evidence (see, for example, Sigman & Ruskin, 1999) that children with Down syndrome are less likely to request objects or assistance with objects than other children of the same developmental level. Lewis (2003:206) suggests that syntactic problems observed in the language of children with Down syndrome may reflect problems in retaining long sentence in their memories in order to process them.

Another language problem is that the spoken language of children with Down syndrome is characterised by poor articulation that often makes it difficult for others to understand what they are saying (Kumin, 1994; Stoel-Gammon, 1997 in Lewis, 2003:207).
2.3.2 Social and emotional development of children with Down Syndrome

Children with Down syndrome have considerable powers of imitation and generally have a good sense of humour. An alternative explanation proposed by Fidler and Hodapp (1999 in Lewis, 2003:205) is that individuals with Down syndrome may be perceived as sociable because they tend to have more baby-like facial features than other children.

The general impression, supported by clinical description, is that children with Down syndrome are particularly socially responsive. Children with Down syndrome are more likely to participate in social behaviour, for example, singing or dancing (Ruskin, Kasari & Sigman, 1994:68). Children with Down syndrome also exhibit a higher proportion of social interaction such as making and accepting social initiations than the group of children with developmental delays (Ruskin et al., 1994:68). Although children with Down syndrome appear to be specifically impaired in language abilities, this is not true for their non-verbal communication, play skill, empathic responsiveness, pro-social behaviour or peer engagement (Ruskin et al., 1994:68).

Children with Down syndrome also interact with peers, both in and out of school. Out of school the level of involvement with other children seems to be lower for children with Down syndrome.

2.3.3 Piaget's stages of cognitive development

In this section, the developmental stages as depicted by Jean Piaget will be discussed. Piaget proposed four major periods or stages of cognitive development: the sensorimotor stage (birth to age 2), the pre-operational stage (ages 2-7), the concrete-operational stage (ages 7 to 11 or 12), and the formal-operational stage (ages 11, 12 and beyond (Shaffer, 1999:54)). These stages are discussed in order to highlight the development of the child at a specific stage, and also to show how the child with Down Syndrome develops as compared with his or her peers.

It is also essential for this discussion to reflect critiques of Piaget's cognitive stages.

Piaget defined intelligence as a basic life process that helps an organism to adapt to its environment. Piaget uses adapting to mean that the organism is able to cope with the demands of its immediate situation (Shaffer, 1999:53). Piaget says when the hungry infant grasps a bottle and brings it to her mouth, she is behaving adaptively. According to Shaffer
(1999:53), "Cognitive developments are age-related changes that occur in mental activities such as attending, perceiving, learning, thinking, and remembering".

Piaget (in Shaffer, 1999:53) also refers to the scheme or cognitive structure, which is an organised pattern of thought or action that is used to cope with or explain some aspect of experience (Shaffer, 1999:53). Piaget claims that infants have no inborn knowledge or ideas about reality, but actively construct new understandings of the world based on their own experiences. He terms this 'assimilation'. Piaget also said that children modify their existing schemes in order to incorporate or adapt to new experiences. He termed this process 'accommodation' (Shaffer, 1999:53). Piaget believed that we continually rely on the complementary process of assimilation and accommodation to adapt to our environments.
<table>
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<tr>
<th>AGE</th>
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<th>PRIMARY SCHEMES</th>
<th>DEVELOPMENTS</th>
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| BIRTH - 2 YEARS | SENSORIMOTOR   | • Infants use sensory and motor capabilities to explore and gain a basic understanding of the environment. At birth they have only innate reflexes with which to engage the world.  
• By the end of the sensorimotor co-ordinations | • Infants acquire a primitive sense of "self" and "others."  
• They learn that objects continue to exist when they are out of sight (object permanence). |
| 2 – 7 YEARS     | PRE-OPERATIONAL| • Children use symbolism (images and language) to represent and understand various aspects of the environment.  
• They respond to objects and events according to the way things appear to be.  
• Thought is egocentric; meaning that children think everyone sees the world in much the same way that they do. | • Children become imaginative in their play activities.  
• They gradually begin to recognise the other people may not always perceive the world as they do. |
| 7 – 11 YEARS    | CONCRETE OPERATIONAL | • Children acquire and use cognitive operations (mental activities that are components of logical thought). | • Children rely on cognitive operations; they understand the basic properties of and relations among objects and events in the everyday world. |
| 11 YEARS AND BEYOND | FORMAL OPERATIONS | • Adolescents' cognitive operations are reorganised in a way that permits them to operate on operations (think about thinking).  
• Thought is now systematic and abstract. | • Logical thinking is no longer limited to the concrete or the observable.  
• They are capable of systemic, deductive reasoning that permits them to consider many possible solutions to a problem and to pick the correct answer. |

(Shaffer, 1999:53)

2.3.3.1 Critiques of Piaget's view

One of the primary concerns of Piaget's critics is his lack of scientific rigour. A major basis for this criticism rests on Piaget's method of data collection, namely, the interviewing method. According to Norris (1991:38) there was no uniformity on the questions asked. Each child was interviewed individually and the interviewer based each question on the child's
previous response. In addition, many of Piaget's basic concepts such as assimilation, accommodation and equilibrium are not defined or operationalised precisely (Santrock & Yussen, 1987 in Norris, 1991:39). According to Santrock and Yussen (1987), Piaget regularly underestimated the intellectual capabilities of infants, pre-school children and grade-school children, all of whom show much greater problem-solving skills when presented with simplified tasks with which they were more familiar, thus allowing them to display their competencies (Bjorklund, 1995 cited by Shaffer, 1999:56). According to Shaffer (1999), Vygotsky viewed cognitive growth as a socially mediated activity. Vygotsky also rejects the notion that children progress through the same stages of cognitive growth. He also notes that Piaget largely ignores important social and cultural influences on human development.

2.3.3.2 Is Piaget's theory of cognitive development relevant to the African child?

Price-Williams (1961) conducted one of the earliest Piaget's studies in Africa (see Mwamwenda, 1995:115). Piagetian studies carried out in Africa particularly with regard to concepts such as conception of quantity, weight, volume and number, transitive inference, and class inclusion have shown that Piaget's theory can be validated cross-culturally.

However (Mwamwenda, 1995:115) poses a fascinating question on Piagetian studies in Africa which are related to the role of education. This is that if cognitive development is susceptible to environmental effects, it is logical to expect African children who have had some formal education to perform better than those who have had no formal education at all.

It seems that the background and the environmental circumstances of the child influence his or her performance.

2.3.3.3 Adolescence phase

Since the case study concerns two adolescents within a Xhosa environment, it follows that a literature review had to focus on this developmental stage. I found that though there is a great deal of literature relating to other groups, there is not much literature on this stage of the development of the African child.

The period of adolescence ranges from the age of about 12 to about 21 years (Mwamwenda, 1995:63). Louw (1993:537) defines adolescence as the developmental stage between childhood and adulthood. Accelerated growth and changes are experienced by both girls and
boys, at different times. Girls experience change and accelerated growth roughly two years ahead of boys at about 12 until about age 18. Boys experience similar change from about 14 until they turn 21 (Mwamwenda, 1995:63).

The section below will discuss the changes experienced by boys, and girls, the psychological effects of physical changes, early and late maturation, social development, identity crisis, adolescent sexuality, and emotional development.

The changes that occur universally in adolescents include rapid physical growth hormonal changes, increasing sexual desires, the development of secondary sexual characteristics and the ability to reproduce. The pituitary gland is responsible for the overall control of bodily activity and also facilitates growth. The adrenals facilitate the functioning of the nerves and muscles (Mwamwenda, 1995:64). Boys experience greater increases in muscle size and muscular strength.

It is not easy for all adolescents to accept the changes they experience. Although some are happy with the changes, a number of adolescents become dissatisfied with their physical appearance (Mwamwenda, 1995:63).

The changes, which have been mentioned above, do not occur at the same age. Some develop changes at an early age, and others develop these changes at the late stage (Louw, 1993:559). It is interesting that in many traditional African societies adolescent sexual exploration is encouraged. In traditional Xhosa culture, adolescents spend much time in same age peer groups in which sexual exploration is a normal part of life (Louw, 1993:538).

For most adolescents it is a time of uncertainty. They are normally caught in the middle of childhood and adulthood. They are not really sure who they are for the changes threaten the individual's sense of wholeness. According to Erikson (1968; 1981 in Louw, 1993:543), the most accurate description of identity development during adolescence is that of identity crisis, since adolescents are engaged in redefining themselves and their role in society. In order for the adolescents to overcome the identity crisis he or she has to conform in the following ways (Louw, 1993:544):

- Their view of themselves should correspond with the view that others have of them.
• They should commit themselves to a role that not only satisfies their needs, but also meets society's requirements.

• Idealistic achievement expectations should be replaced with realistic achievement expectations.

• They should identify with one sexual orientation in order to establish a sex-role identity.

• They should regard certain values so highly that they are able to establish their own basic philosophy which serves as an anchor in life.

Adolescents experience many emotions in their relationships with their parents, their peers and society. The emotions may vary in nature, from aggressiveness to joyousness (Mwamwenda, 1995:75).

To sum up, for the purpose of this study I explored the limited African perspective on the adolescence as presented by Mwamwenda (1995), due to the limited literature on the African perspective. The parts of African perspective on which I focused were emotional development and physical changes. It is important to note that the child with Down syndrome may experience the same changes at a slower rate than other children.

**2.4 THE QUALITY OF LIFE OF THE LEARNERS WITH DOWN SYNDROME**

It needs to be mentioned that the concept of quality of life is a social construct that affects programme development and service delivery in education (Halpern, 1993 in Schalock, 2000:116). An understanding of this concept helps to sensitise communities to the need for service delivery for people with disabilities. Quality of life has also been considered an important aspect in planning, delivering, and evaluating services for people with disabilities (Schalock, Keith, Hoffman & Karen, 1989 in Watson & Keith, 2002:304). Quality of life of people with disabilities has the same components as quality of life of people without disabilities (Watson & Keith, 2002). Different authors have found that it is important to connect the notion of quality of life of individuals with disabilities to that of people without disabilities. In the context of education, it is important for planning and delivery of services to be responsive to individual student's goals strengths and needs. Although it is clear that
quality of life is a major goal in service delivery to people with disabilities, little is known about the quality of life of school-age children with disabilities (Watson & Keith, 2002:305). The definition of quality of life was already highlighted in Chapter One. In this section the objective is to depict, the quality of life for adolescents with intellectual disabilities, comparing the quality of life of school-aged children with and without disabilities. Quality of life also needs to be conceptualised.

2.4.1 The quality of life for adolescents with intellectual disabilities

The focus of the study is on two Xhosa speaking learners with Down syndrome at the adolescence stage (between the ages of 13-14 years). Therefore, it is important for this section to depict the quality of life for adolescents with intellectual disabilities.

Measures of quality of life have been used to determine the extent to which an individual's needs and desires are being met, including the assessment of service needs for adults, and also assessment of individual's outcomes, such as, empowerment, independence, social belonging, community integration, and satisfaction (Schalock & Keith, 1993 in Kraemer, McIntyre & Blacher, 2003:250).

Integration in the community or a gaining a sense of belonging has proved to be one of the most important factors influencing quality of life for people with intellectual disabilities. A sense of belonging through interdependence is needed (Kraemer et al, 2003).

2.5 THE EFFECTS THE CHILD WITH DOWN SYNDROME HAS ON THE FAMILY

There is no substantial evidence that having a brother or sister with Down syndrome has any major or permanent ill effects on the large majority of children (Cunningham, 1988:43). Argyrakauli and Zafiropulon (2003:192), however, suggest that intellectual disability may result in additional stresses, which can lead to lower levels of social self-esteem. The effects the child with Down syndrome has on family will therefore be discussed on different sub-systems of the family, namely: the siblings, the mother, and the father.
2.5.1 The experience of the family of the child with Down syndrome

Families and children are so different that it is impossible to say what effect the birth of the baby with Down syndrome has on the family. According to Cunningham (1988:26-39), the following may be the experiences of the parents of the child with Down syndrome:

- Shock and belief: when the parents first hear that the baby has Down syndrome they are shocked.
- Feelings of grief: most parents experience a sense of grief, and loss when the baby has Down syndrome.
- Feelings of uncertainty: feelings of uncertainty are also associated with feelings of inadequacy about being able to help the child.
- Feelings of inadequacy: some parents have an overwhelming feeling of inadequacy.
- Feelings of embarrassment: having a child who is different, looks different and behaves differently and sometimes even needs to be treated differently from the norm can be embarrassing. If parents do not learn to live with this embarrassment, it can lead to withdrawal from social contacts and eventual isolation.
- Feelings of anger and hostility: other families will experience feelings of anger and bitterness, and they feel cheated by having a baby with Down syndrome.

Finally, having a child with disability could cause great stress in marriages and could increase the risk of separation (Cunningham, 1988:54).

2.5.1.1 Siblings of the child with Down syndrome

The determining factor in the relationship amongst the siblings is the way siblings relate to one another. If the parents find it difficult to come to terms with the child's disability, the siblings also tend to find it difficult. For example, if the parents feel resentment towards the child with Down syndrome, and are constantly drawing attention to the difficulties and restrictions the disability imposes on their lives, the children often develop the same feelings (Cunningham, 1988:43).
2.6 THE HISTORY OF DISABILITY IN AFRICA

There are limited sources providing information on the history of disabilities in Africa. It is for this reason that I have had to rely on Baloyi's work.

In the past, people with disabilities used to be openly rejected in some African cultures. In other African cultures they used to be killed. This destruction was performed in a most cruel way. In some African cultures the child was given boiled water to drink so it could die. Others pulled out the umbilical cord; while yet others left the child in the forest (Baloyi, 1997).

One should note that in the Xhosa language there is no single word for a particular disability. The isiXhosa word for any disability is *Isidalwa or Isilima* (the "disabled"). But the isiZulu word, *Ukukhubazeka* (Disabled), is increasingly being used to distinguish between the various disabilities. Therefore one can refer to different disabilities by saying, *Ukukhubazeka ngokwamalungu omzimba* ("physically disabled") or *Ukukhubazeka ngokwasengqondweni* (Intellectually impaired).

According to (Baloyi, 1997:64), the following examples are most common and prominent beliefs on the causes of disabilities:

- **Uncooked liver**: the liver of a slaughtered brown cow (*Inkomo Emdaka*) or a goat should be served at the wedding feast when cousins marry. It must be eaten raw to prevent their having a child with a disability.

- **Pregnant women are not permitted to look at the disabled**: if they do, the belief is that they will produce a similar child.

- **Laughing at the disabled**: the belief is that if one laughs at the disabled or ridicules them, one will have a child with disabilities.

- **Witchcraft**: Many black people, even today, believe in the influence of witchcraft. They believe that disabilities are associated with witchcraft.

- **Rituals**: Many Xhosa people still believe that the failure to respect any of the rituals, like the ritual of initiation (circumcision), known as *Ulwaluko*, and the ritual of
welcoming the newborn baby in the family, known as *imbeleko*, results in a child with a disability.

- Many boyfriends: According to the African tradition if a girl has many boyfriends before she is married, she will give birth to a baby with a disability.

- Divorced man: If a man remarries, the new wife is not allowed to use the belongings of the previous wife. If she does, she will have a child with disability.

- Incest: it is believed that if people from the same family engage in sexual intercourse, a baby born as a result will be disabled.

In the following section the different attitudes of different sub-systems in the African community will be depicted: the father, the mother, the siblings, the neighbours towards the child, and the child with disabilities to himself or herself.

There are various members in the family of the black South Africans. They are the parents, siblings, grandparents and relatives. A family with a person with disabilities is regarded as a unique family (Baloyi, 1997:8).

The National Organisation of Disability (NOD, 1993:43) and Kisanji (1995:113 cited in Baloyi, 1997) have revealed statistics on the general population's mixed attitudes towards people with disabilities; but with a large amount of sympathy for people with disabilities.

In the black community attitudes differ: Some say a person with disabilities imposes burdens and restrictions upon any family unit, already constrained by poverty and deprivation. In the African community to have a member with disabilities is seen as the embarrassment, burden, result of sin, witchcraft, or a curse (Marule, 1994:6 cited in Baloyi, 1997:9).

### 2.7 SUMMARY OF THE CHAPTER

This chapter provided a picture of Down syndrome, which emphasised the crucial need to understand the African perspective on disabilities in order to understand how this disability is viewed within an African community. The quality of life of the people with disabilities was also mentioned in order to be able to highlight the needs of learners with Down syndrome.

Chapter Three provides a discussion on how the study will be conducted.
CHAPTER THREE

RESEARCH DESIGN
AND METHODOLOGY

3.1 INTRODUCTION

There is no single blueprint for planning research. The purpose of the research determines the methodology and design of the research (Cohen et al., 2000:73). It is therefore, important to reflect on how the information will be presented. This study will be presented within an ecosystemic framework.

According to Charles (1998:2) "Research is called for when one has a substantial question in mind that has no readily available answer. A researcher seeks out information related to that question and tries to make sense of it so that the question can be answered". For example, in this study the research question is: How can the quality of life of the learners with intellectual disability help to identify with the needs of Xhosa speaking learners with Down syndrome?

In this chapter, the research design will be discussed under the following sub-headings: case study method, participants and social context, sample, methods of data production.

3.2 THE RESEARCH DESIGN

3.2.1 Theoretical framework of the study

It is essential to describe the theoretical framework. Terre Blanche and Durrheim (1999:36) see a theoretical framework as being central to the research design as it influences the research problem and the manner in which the research is conducted. Any researcher will always have a theoretical perspective/framework in which he or she is conducting the study. The framework helps the researcher with an approach in his or her study. A metaphor of a roadmap can be used to depict the framework. For instance, a roadmap shows the direction, the distance, and different routes to get to a particular destination as well as the point of departure. A person uses a roadmap to find a way to his/her destination. The framework, therefore, establishes the point of view, and the point of departure. When the person enters
the city or town he or she comes with ready knowledge, such as the meaning of signs, which he or she uses to find the destination. In that sense a framework can be defined as the means to achieve certain ends.

Theoretical perspectives are also particularly useful in helping us understand individual people in relation to their social context (Donald, Lazarus & Lolwana, 1997:33). But we also bring our own knowledge in any situation.

This study was done from a theoretical perspective. The ecosystemic perspective has evolved out of a blend of ecological and systems theories (Donald et al., 1997:35). It shows how individual people with their sub-systems at different levels of the social context are linked in interdependent and interacting relationships. According to (Donald et al., 1997:35) this can be explained metaphorically by using the spider's web, "Anything that happens in any part of the spider's web is felt in all other parts. Therefore, the ecosystem perspective sees the interdependence and relationships between different organisms and their physical environment, these relationships should be seen as the whole. I therefore, represent the relationships of the Xhosa speaking learner with Down syndrome in his or her community as adapted from Donald et al. (1997:35) as follows:
Donald et al. (1997) state that this representation is based on the idea of the individual in interactive relationships with different levels of organisation in the social context. The levels portrayed above can be seen as interacting with other levels and also influencing each other. For example, in the Xhosa community a family with a child with Down syndrome will be viewed as being exceptional in the sense that it is different from other families. At another level, the father of the child with Down syndrome is affected by the situation. For instance,
he will be in the denial stage. The relationship between the mother and the father will be affected as well.

The siblings of the child with Down syndrome will assume different roles, in order to support their brother or sister with Down syndrome. It is difficult for the siblings if the child with Down syndrome is the eldest child in the family, because African families are structured in such a way that the eldest child is the one who will look after the little brothers and sisters.

Mouton (2001:56) describes a research design by using a metaphor for research design as follows:

**FIGURE 3.2: A METAPHOR FOR RESEARCH DESIGN**
According to Mouton (2001:54) the building of the house consists of the systematic, methodical and accurate execution of the design. In the process of constructing the house, various methods and tools are used to perform different tasks (laying the foundation, bricklaying, plastering, etc). Therefore, there are similarities in building a house and doing the research.

The research design focuses on the end product: What kind of study is being planned and what kind of result is aimed at (Mouton, 2001:56). The focus of the research design should also be on; what kind of evidence is required to address the research question adequately.

A research design is also described as a plan or blueprint of how one intends conducting the research (Mouton, 2001:55). Research designs are tailored to address particular kinds of questions. Consequently, the type of design will influence the various research methods and procedures as dictated by the nature of the research problem (Babbie & Mouton, 2001:74). In the case of qualitative research, the designs … are more open, fluid and changeable, and not defined purely in technical terms" (Terre Blanche & Durrheim, 1999:3).

It is also essential to reflect the purpose of the research. The following is a representation of the dimensions of the research design decisions of this study as adapted from Miles and Huberman (1994:203-205):
3.2.2 Case study method

This case study focused on the quality of life of the learners with Down syndrome in three main areas: home, school and community.

The nature of the research problem led me to choose to do a case study. Simons (1996 in Cohen et al., 2000:183) has argued that case studies need to address certain paradoxes, namely, reject the subject-object dichotomy, regard all participants equally, and recognise the contribution that a genuine creative encounter can make to new ways of understanding education.

Case study has strengths and weaknesses. One advantage is that, a wide audience easily understands the results as they are frequently written in everyday, non-professional language.
They also capture unique features in a situation that might otherwise be lost in larger scale data. They are also strong on reality and provide insights into other, similar situations and cases and a single researcher can undertake them.

The disadvantage that is often mentioned is that the results may not be generalisable, and require that other readers/researchers see their application. They are also not easily open to crosschecking; hence they may be selective, biased, personal and subjective, and are prone to problems of observer bias; despite attempts made to address reflexivity (Nisbet & Watts, 1984 in Cohen et al., 2000:184).

A case study may be described as an intensive investigation of a single unit and most case studies involve" the investigation of multiple variables, where the interaction of the unit of study with its context is a significant part of the investigation (Babbie & Mouton, 2001:280).

3.2.3 Research Question

This study investigated the needs of the two Xhosa speaking learners with Down syndrome done in relation to examining their quality of life within their sub-systems. The question was phrased as follows: How can the quality of life of the learners with intellectual disability help to identify with the needs of Xhosa speaking learners with Down syndrome?

3.2.4 Research aim

It was mentioned in chapter one that the broad aims of the Intellectual Disability Lifespan project from the University of Stellenbosch is to identify indicators of quality of life for individuals with Down syndrome. This study, therefore, set out to investigate the needs of the Xhosa speaking learners with Down syndrome with regard to support and development.

3.2.5 Participants

Sampling must be done whenever you can gather information from only a fraction of the population of a group or a phenomenon, which you want to study (Walliman, 2001:232). In doing so, one should try to select a sample which is free from bias. Therefore, for the purpose of this study the following sampling criteria were set. The learners had to have the following characteristics:
• Down syndrome
• Xhosa speaking
• Be living in disadvantaged areas
• Be placed in a special school.

The purpose of sampling is usually to study a representative subsection of a precisely defined population in order to make inferences about the whole population (Silverman, 2000:102). For this purpose a non-probability sample was used. The non-probability sample is commonly used in qualitative research and it acknowledges that the sample may not reflect the larger population (Cohen & Manion, 1994:88) and that it may demonstrate skewness or bias (Cohen et al., 2000:172). I acknowledge the limitations of my sample and so do not attempt to generalise the results beyond the given population.

The following conditions were selected in the sampling process:

• A population of learners with Down syndrome in the Xhosa community, between the ages of 13 and 14 years had to be accessible.

• The parents of the children were single parents (mothers).

• Parents had to sign a consent form as designed by the University of Stellenbosch, permitting the researcher to conduct the research.

• The siblings of the learners with Down syndrome needed to be available.

• The neighbours of the learners with Down syndrome needed to be available.

• The educators at Nompumelelo Special school needed to be available.

• The adult with Down syndrome from Red Cross Memorial Hospital support group needed to be available.

• The four female parents of the children with Down syndrome from Red Cross Memorial Hospital support group needed to be available.
Two Xhosa speaking learners with Down Syndrome from a disadvantaged background were selected for the sample. The boy was 13 and the girl was 14 years old. They both lived the Western Cape region. The boy lived in Nyanga and the girl lived in Guguletu Township. Both learners were at the Special School in Guguletu Township.

3.2.6 Methods and techniques of data collection

3.2.6.1 Descriptive observation

One should observe the event or phenomenon in action. The critical aspect of observation is looking, and taking in as much as you can without influencing what is it that you are looking at (Tuckman, 1999:378). The researcher is given an opportunity to gather live data from live situations. The researcher is given an opportunity to look at what is taking place in situ rather than at second hand (Patton, 1990:203). The observation should enable the researcher to gather information on the physical setting, human setting, interactional setting, and the programme setting (Morrison, 1993:80). It is essential for the researcher to structure the observation in order to be aware of what he/she is observing and looking for. Therefore, for the purpose of this study the sand tray was used as the mechanism for observation due to the fact that the two learners with Down syndrome could not express themselves well.

3.2.6.2 Individual interview

The use of the interview in research marks a move away from seeing human subjects as simply manipulable and data (Kvale, 1996:11). Interviews can be seen as the interchange of views between two or more people on a topic of mutual interest. Barker and Johnson (1998:230) argue that the interview is a particular medium for enacting or displaying people's knowledge of cultural forms.

The purpose of the research interview can be defined as a two-person conversation initiated by the interviewer. The type of interview which was used for the children with Down syndrome was informal conversational. The questions were asked in context on the needs regarding the quality of life of learners with Down syndrome. The siblings were interviewed according to their circumstances.
The parents, neighbours and the educators were interviewed by using standardized open-ended interviews. The questions were planned beforehand in order to allow the interview to be structured.

The interviews included the following content:

- **Life world**: the topic of the qualitative research interview is the lived world of the participants. For example, in this study the Xhosa speaking learners with Down syndrome were observed in their life world.

- **Meaning**: the interview seeks to interpret the meaning of central themes in the life world.

- **Qualitative**: the interview seeks qualitative knowledge express in normal language.

- **Description**: the interview attempts to obtain descriptions of different aspects. The needs of the two Xhosa speaking learners with Down syndrome were described in terms of the quality of life learners of Xhosa speaking learners with Down syndrome.

- **Change**: the process of being interviewed may produce new insights and awareness (Adapted from Kvale, 1996:30).

It is important to note that at the meeting the interviewer should brief the respondent about the nature or purpose of the interview. In this study the parents of Xhosa speaking children with Down syndrome were interviewed. The interviews were conducted on monthly bases. The following are examples of the interviews conducted:

### 3.2.6.3 Document and record review

#### 3.2.6.3.1 Field notes

Field notes are a part of naturalistic observation, which the observer intends to use to observe and interpret the findings (Cohen *et al.*, 2000:141). This can be done through note taking. During this study the field notes were specifically about the interviews with the parents of the children with Down syndrome, the neighbours, the siblings and the school. The field notes were filled in two comprehensive portfolios (each case had its own portfolio).
3.2.6.3.2 Questionnaires

The key elements, indicating the main issues in designing questionnaires should be explained. It is also important to point out some problematic considerations (Cohen *et al.*, 2000:145).

- Ethical issues: the questionnaire can be seen as always an intrusion into the life of the respondent. Sometimes level of threat or sensitivity of the questions, or possible invasion of privacy. According to (Cohen *et al.*, 2000:145), "[r]espondents cannot be coerced into completing a questionnaire. They might be strongly encouraged, but the decision whether to become involved and when to withdraw from the research is entirely theirs".

- Pitfalls in question writing: One should avoid pitfalls in question writing. For instance, the researcher must avoid leading questions, complex questions, avoid irritating questions. Open-ended questions should also be avoided.

A highly structured questionnaire will ask closed questions. From example, they can be the dichotomous questions. These are questions that require a "yes" or "no" response. Finally, the appearance of the questionnaire is vitally important. It must look easy and attractive.

3.2.6.3.3 Audio tape recordings

Permission was obtained from the participants for me to record interviews on audio tape or video. De Vos (2000:304) mentions that a tape recorder allows a much fuller record than notes taken during the interview. When the researcher records the interview he/she concentrates more on how the interview is proceeding and where to go next. The tapes should be transcribed for close analysis. It is ethically important to give the participants access to the recordings (Denzin & Lincoln, 2000:829-831).

The disadvantage of the audio tape recording is that the participants may not feel happy being taped and sometimes not answer the questions as honestly as they would in normal circumstances.

3.3 CONTEXT OF THE STUDY

The study was conducted at a special school for the learners with intellectual disability ("mental handicap"). The school is situated in Guguletu area in the Western Cape. The
school, which was formed in 1983 by a Cape Mental Health Social Worker, started in the community hall in Nyanga East. When the number of learners reached 60, the Department of Education and Training took over the school. In 1988 the school moved into new premises which had been erected in partnership with the Cape Mental Health and the Department of Education and Training. The current enrolment of the school is at 220 learners. There are 110 boys and 110 girls.

All the learners get to school by bus; there are no hostel facilities. The learners come from mainly from the areas around Guguletu, namely, Nyanga; Crossroads, Philippi, but there are some learners who come from Khayelitsha. Since the establishment of the Education Management and Development Centres (EMDC) in 2003 the school has fallen under the South Metropole: EMDC.

The staff consists of one principal, one deputy, an educational therapist, one nursing sister, 17 classroom-based educators, two administrative clerks, and five general assistants. The Western Cape Education Department (WCED) employs the entire staff component.

3.4 STUDY IMPLEMENTATION

3.4.1 Procedure

It was necessary for me to set up time frames for the study, since it was part of the Intellectual Disability Quality of Life Project. I had to produce the data in 12 months, through observations made of Andiwe and Thandile and interviews with parents and siblings, the community, and educators at the school. All these interviews took me a period of four months. It was difficult at times for Andiwe's mother to attend the interviews on the set date as she was working. I had to make logistical decisions. For example, I had to interview her at separate times from my interviews with Thandisile's mother. Sometimes I had to arrange my interviews in such a way that they did not compromise my work obligations as the School Psychologist. I obtained permission to undertake research in January 2005 from the school principal and Western Cape Education Department. According to Ramazanoglu and Holland (2002:156-157) and Miller (1998:64-66 in Bleazard, 2003:68), this process is referred to as "negotiating with the gatekeepers" I did not meet with any difficulties during the process of negotiation as the principal felt that the research was long overdue. When I approached her
initially, she alluded to the fact that the school was doing their best to assist the learners with intellectual disabilities, but problems arose when they left school.

The parents of both Andiwe and Thandisile were approached for their consent and the aims and procedures of the study were outlined. The parents had to sign a consent form from the Department of Educational Psychology, which was designed by the Unit of Educational Psychology from the University of Stellenbosch. The three educators were also approached and the study was outlined to all of them. Unfortunately, it was difficult to get verbal consent from the learners due to the nature of their disability; therefore the parents gave consent on behalf of their children (Andiwe and Thandisile).

3.5 INTRODUCING THE LEARNERS

As has already been established, the study investigates the needs of the Xhosa speaking learners with Down syndrome. The two learners involved need to be described so that their background can be understood. It should be noted that there are differences between the sub-systems of the two learner's ecosystem. I intend to show how the learners with Down syndrome, their parents and the different siblings view the needs of the learners with Down syndrome differently within similar Macrosystem (the Xhosa society).

3.5.1 Thandisile

Thandisile is 14 years-old Xhosa speaking boy. He lives in Crossroads with his mother, who is a widow. His mother has four children. Two children are from the previous marriage and Thandisile and his brother are from the second marriage. Thandisile's father passed away in 1995 of natural causes. It must be explained that in the African families, terms such as "step father, half brother, half sister" do not exist. Therefore, Thandisile sees all his siblings as brothers and sisters. According to his mother she had a normal birth, and she never had any complications. When he was 3 months old, he was admitted to hospital. The diagnosis was that he had TB. The mother said, "Ogqirha bathi unentliziyo, bathi bafuna ukumenza uqhaqho, kodwa ndala" ("They said he had developed some heart problems. The doctors wanted to operate on him, but I refused"). "Bathi loo mnatwana uzakuthanda ukuphulaphula umculo xa emdala." ("The doctors said this child will like sounds, for example music, when he is older.") According to his mother, Thandisile is aggressive at times … he pushes other
children, and breaks other people's windows. His speech is not clear and he cries when he is angry. All this information was gathered in an initial research.

### 3.5.2 Andiwe

Andiwe is 13 years old Xhosa speaking girl. She lives in Nyanga with her mother and sister. Her mother is a single parent who works for a company in Cape Town. Andiwe's father left her because his child was born with a disability. Andiwe's mother later met Mandla. Their daughter Aziziphо was born in 1994.
INTERVIEWS

The interviews of the participants were divided into three categories per participant. For example the pattern for Thandisile's interview was presented as follows:

FIGURE 3.4: THANDISILE'S SUB-SYSTEMS IN AN INTERVIEW
FIGURE 3.5: ANDIWE'S SUB-SYSTEMS IN AN INTERVIEW

1. THE FAMILY
   → MOTHER
   ↓
   SISTER

2. NEIGHBOUR

3. THE SCHOOL
   → 2 EDUCATORS
   ←
   PRINCIPAL
The interviews focused on the quality of life of the learners with Down syndrome in order to establish the needs in different aspects of quality of life: personal management, recreation, future planning, work opportunities, community personal management, maintaining social relationships. The interviews were conducted over a period of four months. The examples of the translated interviews will be shown in Annexure A.

3.6 ANALYSIS OF THE DATA

According to Mauthner and Doucet (1998:38-39), "Data analysis is a critical stage in the research process, for it carries the potential to decrease or amplify the volume of our respondent's voices. It has the potential of being a deeply disempowering part of research, in which respondents have little or no control".

The data analysis aimed at establishing the needs of Xhosa-speaking learners with Down syndrome.

3.6.1 Transcription

Interviews were held with members from each of the sub-systems of the learners. Thandisile's interviews consisted out of nine interviews. Andiwe's interviews consisted out of seven interviews. Transcription was done through careful and repeated listening to recordings during which there were opportunities for repeated and detailed examination of events of interaction and the organisation of talk (Bleazard, 2003:69).

The interviews were conducted in Xhosa, and were translated into English (see Annexure A for an example of a transcribed interview).

3.7 DATA ANALYSIS

Data analysis can be seen as the essential part of research. Therefore, the analysis must be carried out in relation to the research problem. Miles and Huberman (1994:10-12), include the following concurrent flows of activity during data analysis as being data reduction, data display and conclusions drawing or verification.

The prepared researcher will need to consider the mode of data analysis to be employed. According to (Cohen et al., 2000:77), the planning of data analysis will need to consider what
needs to be done with the data when they have been collected, and how the data will be processed and analyzed. In addition, he should consider how the results of the analysis will be verified, cross-checked and validated.

The criteria for deciding which forms of data analysis to undertake are governed both by fitness for purpose and legitimacy. The form of data analysis must be appropriate for the kinds of data gathered (Cohen et al., 2000:82).

In this study the analysis strategy used was content analysis. The content of the field notes, interviews, questionnaires and documents were analyzed qualitatively to find the needs. Data were produced from the parents, the siblings and the neighbours of the learners with Down syndrome. The themes were contextualized and arranged sequentially. The result of the analysis was a synthesis in the form of themes (Cohen & Manion, 1994:101). The coding was done from the transcripts of the notes taken from the tape recordings and the individual interviews. The coding system made it easy for the data to be properly organized. The types of codes included descriptive codes and interpretive codes (Mile & Huberman, 1994:57-62 in Newmark, 2001:205). The case study data involved the organization of the findings regarding the needs of the learners with Down syndrome in the Xhosa community. The literature review, which was in line with the research problem, was also included.

A start of codes was devised to guide the analysis of the data as suggested by Mertens (1998:351) in Bleazard (2003:56). The following is the list of codes for this study that was developed from the interviews on quality of life of the Xhosa speaking learners with Down syndrome:

**Quality of life**

The aspects of quality of life as discussed by Feldman, 1998:56-101, were coded.
TABLE 3.1: CODES FOR THE ASPECTS OF THE QUALITY OF LIFE

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>PM</td>
<td>Personal Management</td>
</tr>
<tr>
<td>REC</td>
<td>Recreation</td>
</tr>
<tr>
<td>FP</td>
<td>Future Planning</td>
</tr>
<tr>
<td>WO</td>
<td>Work Opportunity</td>
</tr>
<tr>
<td>CPD</td>
<td>Community Personal Development</td>
</tr>
<tr>
<td>MSR</td>
<td>Maintaining Social Relationships</td>
</tr>
<tr>
<td>RECFAC</td>
<td>Facilities</td>
</tr>
<tr>
<td>RECLPA</td>
<td>Play</td>
</tr>
<tr>
<td>RECSWI</td>
<td>Swimming</td>
</tr>
<tr>
<td>RECSPO</td>
<td>Sport</td>
</tr>
<tr>
<td>RECCOM</td>
<td>Competitions</td>
</tr>
<tr>
<td>Pat</td>
<td>Patient</td>
</tr>
<tr>
<td>Att</td>
<td>Attention</td>
</tr>
<tr>
<td>Aggr</td>
<td>Aggressive</td>
</tr>
<tr>
<td>Disrup</td>
<td>Disruptive</td>
</tr>
<tr>
<td>Hap</td>
<td>Happy</td>
</tr>
<tr>
<td>Lang</td>
<td>Language</td>
</tr>
</tbody>
</table>

See Annexure C for the completed list of the codes used for the data analysis.

### 3.8 DATA CONSOLIDATION AND INTERPRETATION

The data was coded and categorized according to the themes within the ecosystemic theoretical framework.

A concept map of the categories of the case studies is presented below:
3.9 DATA VERIFICATION

The data produced needed to be tested using substantial evidence. According to Newmark (2001:206) "… in qualitative research credibility is achieved through prolonged and substantial engagement, persistent observation, peer debriefing, progressive subjectivity and triangulation".
3.9.1 Persistent observation

Observation is done in order to gain insight and understanding in what the researcher is studying. The observations obtained from this study were recorded. Participant observation requires that the researcher adopts dual roles and becomes an instrument of inquiry by being present in the situation, but by standing aside to observe it (Mertens, 1998:315).

3.9.2 Peer debriefing

I mentioned earlier that there were regular meetings with the multi-disciplinary team at the University of Stellenbosch, in order to discuss the research being conducted. As mentioned in Chapter One, the University of Stellenbosch in collaboration with Down syndrome South Africa formed the Intellectual Disability Quality Lifespan in 2001. The committee consisted of various professionals from the University of Stellenbosch (Department of Educational Psychology), Masters' students, parents, and representatives from special schools. The meetings, which were held monthly, provided me with ongoing support from the committee in response to my presentations on the study. The guidance I received helped me to design the interviews in as far as what to ask, and not to ask. Further support was provided by colleagues at the Mitchell's Plain Education Support Centre, and the Educational Psychologist colleague at Lentegeur Special School.

3.9.3 Triangulation

Triangulation is a process in which the researcher uses several different types of sources to provide insights into the same events or relationships. Neuman (2000:124-125) explains triangulation as follows: Surveyors and sailors measure distances between objects by making observations from multiple positions. By observing something from different angles or viewpoints, they get a fix on its true location. Triangulation allows researchers to be more confident of their results. It can also stimulate the creation of inventive methods and new ways of capturing a problem to balance with conventional data collection methods. Triangulation may also help to uncover the deviant or off-quadrant dimension of a phenomenon (Jick, 1983:145-147). In this study the process of triangulation involved descriptive observation, individual interviews and the review of documents and records.

The use of multi-methods can lead to a synthesis or integration of theories. The records and documents and the different methods of data production were used to cross check
biographical details and information on family structures (Bleazard, 2003:59). Through this I gained new insight about the situations which the children with Down syndrome experience in the Xhosa community.

According to Cohen and Manion (1997:270), the advantage of triangular techniques is that they safeguard against the risk of bias and method-boundedness and make it possible to obtain a holistic view of the research findings.

3.10 ETHICAL CONSIDERATIONS

Merriam (1998:217) suggests that in qualitative research ethical dilemmas will emerge with regard to data collection and also in dissemination of findings. The following issues are important ethical considerations: accuracy, confidentiality, deception, disclosure, honesty, informed consent (Wiseman, 1999:26-31):

- Accuracy: the researcher must consider the potential for misinterpretation of the findings.
- Confidentiality: the personal records of individuals cannot be revealed unless written permission is required from them.
- Deception: Research with human participants may involve some deception. It is therefore, important that the participants in a study do know exactly what the researcher expects them to do in particular situations.
- Disclosure: the participants should be informed accurately about the general nature of the research.
- Honesty: the facts and findings should be reported truthfully.
- Informed consent: the participants should be informed about the project, and what will happen to the findings.

All these principles were adhered together with the ethical practice guidelines for psychologists which were the guiding principle for all actions during the research study.
3.11 CHAPTER SUMMARY

This chapter recounted the research process of the study. The different components of the study were discussed, namely, the literature review, the theoretical framework, and the research methodology. Chapter Four will present the research findings on the case study of the needs of learners with Down syndrome in a specific Xhosa context.

Qualitative research is done in the natural setting with the researcher as the data-collection instrument. It attempts primarily to describe, is concerned with process, analyzes its data inductively, and is concerned with what things mean (Tuckman, 1994:385).
CHAPTER FOUR

PRESENTATION OF RESULTS
OF THE TWO CASE STUDIES

4.1 INTRODUCTION

This chapter presents an ecosystemic perspective on the experiences of the participants during this study. This study was a journey to discovery, in which the experiences of Xhosa speaking learners with Down syndrome were mirrored in juxtaposition with their needs in the community. Their parents face particular difficulties in a community that has not yet made the necessary paradigm shift.

My journey was an eye-opener. It became clear that the needs of the Xhosa speaking learners with Down syndrome were not known to the service providers.

4.2 THEMES FROM THE DATA

Ramazanoglu and Holland (2002:159-161 in Bleazard, 2003:72) state that just as data are not simply lying around to be collected, so meaning is not simply lying around in the data, waiting to be found. It is therefore, the work of the researcher to collect and decide on the meaning, categories and patterns of the data. I had to be very careful not to overinterpret displays in the sandtray, especially in view of the fact that the two learners did not verbalize a lot during the sandtray. I had to rely more on the learners' sub-systems in order to support what I had seen in the sand tray.

I had to identify the list of codes prior to the data production phase. Examples of these are mentioned in Chapter three and Annexure A. The themes had to be divided according to the learner's sub-systems. These have been mentioned in figures 4.1 to 4.10.

The themes that emerged from Thandisile were:

- **Space**: This refers to having a home.
• **Safety:** This refers to the fact that the people with intellectual disabilities are always victims of abuse in the community.

• **Love:** This refers to their need to be loved by the community.

• **Happiness:** This refers to the need to have friends who want to play with them.

• **Anger:** This refers to the fact that the community discriminates against him.

• **Resentment:** When people want him to perform difficult tasks.

Themes that emerged from Thandisile's Aunt:

• **Shock:** This refers to response of the whole family when they realised that Thandisile had a disability.

• **Care:** This depicts the need that children with intellectual disabilities have to be cared-for.

Themes that emerged from the mother:

• **Slow:** This refers to Thandisile as being slow to perform the tasks at home.

• **Distructive:** This refers to Thandisile frequently breaking the windows of the neighbours.

• **Overprotective:** This refers to the mother's tendency to be overprotective towards Thandisile.

Themes that emerged from the neighbour:

• **Naughty:** This refers to the breaking of windows.

• **Shameful:** The people feel ashamed of Thandisile.

• **Laughter:** This refers to the fact that people laugh at him.

Themes that emerged from Thandisile's sister:

• **Demanding:** This refers to the fact that Thandisile is very demanding when he wants something from his sister.

• **Chase away:** This refers to the fact that Thandisile should be placed in an institution for people with intellectual disabilities.
All the themes emerging from Thandisile's sub-systems are portrayed below:

**FIGURE 4.1: THEMES EMERGING FROM THANDISILE'S SUB-SYSTEMS**

- **THANDISILE**
  - Space
  - Safety
  - Love
  - Happiness
  - Anger
  - Resentment
  - Poverty

- **NEIGHBOUR**
  - Naughty
  - Slow
  - Same
  - Shameful
  - Disability
  - Laughs
  - Reprimand

- **MOTHER**
  - Slow
  - Destructive
  - Chase Away
  - Overprotect
  - Loving

- **SISTER**
  - Demanding
  - Observed
  - Chased Away

- **AUNT**
  - Schock
  - Disability
  - Cared
  - Educated
  - Destructive

**Themes that emerged from Andiwe**

- **Love**: This refers to the need that children with disabilities have to be loved.
- **Acceptance**: This refers to the need to be accepted by the community.
- **Inclusion**: This refers to the need to be included with the other children.
- **Sport**: This refers to the desire to participate in sport.
- **Dance**: This refers to the desire to have dance as a school activity.
- **Fear**: This refers to the fear of being abused.
- **Anger**: This refers to people who ill-treat people with disabilities.

Themes emerging from Andiwe's mother:
• **Behaves well:** This refers to her view that Andiwe is a well-mannered child.

• **Lazy:** This refers to her view that Andiwe is lazy.

• **Struggles:** This refers to her view that Andiwe struggles at school to perform some of the tasks.

• **Happy:** This refers to her view that Andiwe has always been a very happy child.

• **Aggressive:** This refers to her view that some people are aggressive towards Andiwe.

Themes that emerged from Andiwe's sister:

• **Love:** This refers to her feeling that Andiwe and the other people with disabilities need to be loved.

• **Accept:** This refers to her feeling that people with disabilities need to be accepted.

Themes emerging from the neighbour:

• **Love:** This refers to their view that children with disabilities need to be loved.

• **Treatment:** This refers to their view that children with disabilities need to be treated with respect.

• **Accept:** This refers to their view that children with disabilities need to be accepted like other people.

• **Taught:** This refers to their view that children with disabilities need to teach self-care skills, and they should be included in the community.
FIGURE 4.2: THEMES EMERGING FROM ANDIWE'S SUB-SYSTEMS

ANDIWE:
- Love
- Acceptance
- Inclusion
- Sport
- Dance
- Fear
- Anger

MOTHER:
- Behaves Well
- Lazy
- Disability
- Believe
- Beautiful
- Different
- Beaten
- Struggles
- Aggressive
- Happy
- Cruel

SISTER:
- Love
- Like
- Accept
- Sad
- Make fun of her
- Laugh
- Wrong
- Sick
- Educated/Education

NEIGHBOUR:
- Curious
- Taught
- Love
- Selfcare
- Treat
- Surprising
- Normal
- Aware
- Disability
- Possible
- Accept
- Include
- Prefers
- Capable
4.3 THEMES EMERGING FROM BOTH CASES

The themes for both cases had to be combined, because both learners are in the same school, and all the educators interviewed are responsible for them. The themes are reflected as follows:

- **Different**: This refers to their view that learners with Down syndrome are different from the other children.

- **Personality**: This refers to their view that the children with Down syndrome have such a loving personality

- **Humble**: This refers to their view that children with Down syndrome are very humble towards the people around them.

- **Loved**: This refers to their view that children with Down syndrome are easily loved, because of their personality.

- **Stubborn**: This refers to their view that children with Down syndrome can be stubborn at times

- **Lazy**: This refers to their view that some of the children with Down syndrome in the class at Nompumelelo school are seen as reluctant to do some of the duties that are too demanding.

- **Mix**: This refers to their view that children with Down syndrome mix with other children.

- **Social interaction**: This refers to their view that children with Down syndrome have very limited social interaction skills, especially when strangers are involved.

- **Accepted**: This refers to their view that children with Down syndrome want to be accepted by the community.

- **Fearful**: This refers to their view that children with Down syndrome are sometimes fearful of new environments.

- **Laugh**: This refers to their view that some members of the community laugh at children with Down syndrome.

- **Ridicule**: This refers to their view that members of the community sometimes ridicule children with Down syndrome.
- **Patient**: This refers to their view that a lot of people do not have patience when they work with children with Down syndrome.

- **Attention**: This refers to their view that children with Down syndrome have limited attention span.

- **Disruptive**: This refers to their view that children with Down syndrome disrupt the other learners when they do not know how to do tasks.

- **Creative**: This refers to their view that children with Down syndrome are very creative in class.

- **Language**: This refers to their view that children with Down syndrome have limited language ability.

**THEMES EMERGING FROM SCHOOL FOR BOTH CASES**

**FIGURE 4.3: THEMES EMERGING FROM SCHOOL**
4.4 THE THEMES EMERGING FROM THE PARENTS OF CHILDREN WITH DOWN SYNDROME

According to the parents of the children with Down syndrome, it is crucial for these children to get support from the community and the family as a whole, in order to function optimally. Secondly, they need help in as far as their personal management skills are concerned and their school work. It is very important for the children with Down syndrome to be accepted by the community. They also need to be treated in the same way as other children. The parents also voiced what their first reactions had been when they realised that their children had Down syndrome. These were feelings of disappointment, fear, denial, and worry. Finally, these parents mentioned that the parents of children with Down syndrome need a lot of information in order to help them with management of their children. The themes have been shown below:

FIGURE 4.4: THEMES EMERGING FROM THE PARENTS OF CHILDREN WITH DOWN SYNDROME
4.5 THEMES EMERGING FROM THE ADULT WITH DOWN SYNDROME

When the adult with Down syndrome was interviewed regarding the needs of the children with Down syndrome, she emphasized that **happiness and support** are the main things. These children need to be treated as "**normal**". They need to be **trained for work opportunities** in order to facilitate their placement to different work environments.

The figure below depicts these themes:

**FIGURE 4.5: THEMES EMERGING FROM THE ADULT WITH DOWN SYNDROME**

The dominant common themes related to the sub-systems of both Andiwe and Thandisile that emerged from the study were:

- **Space**: This refers to the fact that the learners with intellectual disabilities want to have their own accommodation within the family.
- **Safety**: This refers to the fact that the learners with intellectual disabilities are often victims of sexual abuse.
- **Love**: This refers to the fact that the learners with intellectual disabilities need to be loved by the community.
• **Happiness:** This refers to the fact that learners with intellectual disabilities want to be as happy as the other learners, participating in all activities.

• **Anger:** This refers to the fact that learners with intellectual disabilities become very angry when the society does not treat them like the other children.

• **Slow:** This refers to the fact that the school and parents feel that learners with intellectual disabilities are slow to perform academic modalities and household chores respectively.

• **Laughs:** This refers to the fact that the community laughs at them, because of the way they look.

• **Acceptance:** This refers to the fact that they want to be accepted by the community.

• **Fear:** This refers to the fact that the parents of these learners fear that their children might be abused by the community.

• **Education:** This refers to the fact that their children need to be educated in order for them to perform optimally in society.

### 4.6 SUMMARY OF THEMES FOR BOTH CASES

It was very clear from the interviews that the parents of learners with Down syndrome have certain concerns that were consistently presented throughout the interviews. It was a journey to discovery for me. The experiences of the individuals with Down syndrome, the parents of the children with Down syndrome, and the learners with Down syndrome were depicted as a way of portraying the needs of the learners with Down syndrome. It is clear that the Xhosa community still has a problem in accepting individuals with disabilities. This was shown by the themes that emerged from the different sub-systems in the whole system of the learners with Down syndrome.

### 4.7 DISPLAY OF ALL THE NEEDS EMERGING FOR BOTH CASES

Figure 4.8 displays needs emerging from the different sub-systems of the learners with Down syndrome from a Xhosa background. Therefore, it was important for the purpose of the study to combine the common needs that emerged in the case of each of the children in order to display the needs that had in common. For example, it was clear that the community sees the children with Down syndrome as children who need to be loved, accepted, and to be placed
in a special school and also to be able to participate in sport. The family in the case of each of these children with Down syndrome feel that the children should have access to sport; they should be protected and helped. The disability grant emerged as a problem because some parents do not receive a grant to assist them with the financial needs of their children.

The school requires health professionals like speech therapists, social workers, and physiotherapists who are Xhosa speaking. There is also a need for workshops that will provide these learners with work opportunities.

The display of these needs is shown below:

**FIGURE 4.6: DISPLAY OF ALL THE NEEDS FOR BOTH CASES**
Thandisile's sub-systems

Thandisile and Andiwe's different sub-systems have depicted the needs of Xhosa-speaking learners with Down syndrome. Their voices are portrayed in the figures below.

**FIGURE 4.7: THANDISILE'S NEEDS**
4.8 SUMMARY OF THE CHAPTER

The journey to discovery was an eye-opener. I had never before realized the pain that is experienced by people with Down syndrome. The awareness was made possible through working within an exosystemic framework. Their needs were depicted in many situations in the system, namely, family, school, community and the "self". The interviews had to be conducted in isiXhosa, in order to allow the flow of the interviews, whereby the participants would express themselves clearly.

Chapter 5 will deal with findings. The research findings will be verified and interpreted to establish an understanding of their needs.
CHAPTER FIVE

DISCUSSION OF FINDINGS AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter, I will provide a brief summary of the preceding chapters of the study before discussing the findings of the study. Next I will make recommendations, and reflect on the limitations of this study.

I shall first explore the needs that emerged from the different sub-systems of the Xhosa speaking learners with Down syndrome. In Chapter Four I showed how a focus on the quality of life needs of these two learners with Down syndrome made it possible for me to reveal the needs of Xhosa speaking learners with Down syndrome. The interpretation and discussion of these findings are of central importance in the study.

5.2 SUMMARY OF CHAPTERS

This study focused on two learners: Andiwe, a 13-year-old girl and Thandisile, a 14-year-old boy. They have the following characteristics in common:

- They are Xhosa-speaking learners with Down syndrome at Nompumelelo Special School.
- They are both in the adolescent stage of development.
- They were both raised by a single parent i.e. a mother.

Source: [Chapman, 2010] provides an introduction to the study as well as the statement of the problem, and outlines the theoretical ecosystemic perspective of the study as well as other methodological aspects. The background to the study includes a historical overview of educational transformation in South Africa, with an emphasis on the following: The Bill of Rights, The Constitution of the Republic of South Africa, the White paper on Education and Training, the White Paper on Education and Training, the White Paper 6 on Special
Education, the South Africa School Act, the report on NCSNET and NCESS, and other policies on service delivery.

In this study I worked within an ecosystemic framework.

In Chapter Two I reviewed the literature that provided an African perspective on disabilities.

In Chapter Three I discussed the research methodology.

Chapter Four was the zenith of this study, because it contained the fieldwork, the observation of the participants in real situations and settings. In this chapter I described the implementation of the study. The participants and I went side-by-side on a journey to discover the needs of Xhosa-speaking learners with Down syndrome. This was a demanding chapter, because I had to conduct most of the interviews in isiXhosa, and then interpret them in English. The interviews were shown to be an important means of understanding the needs of the learners with Down syndrome.

5.3 NEEDS OF THE LEARNERS WITH DOWN SYNDROME

For the purposes of the discussion, the needs of both of these learners will be divided according to the particular quality of life within a sub-system of society, and later a synopsis of the needs will be presented to show what this revealed about the needs of the Xhosa speaking learners with Down syndrome.

- Macrosystem: Xhosa society: The community in Gugulethu and Nyanga.
- Exosystem: The African family (the families of the Xhosa speaking learners with Down syndrome).
- Mesosystem: The school, Down Syndrome Support group in Red Cross Memorial Hospital, and the adult with Down syndrome.
- Microsystem: The learners with Down syndrome, namely, Thandisile and Andiwe.
FIGURE 5.1: THE EXOSYSTEM
(The family of the Xhosa speaking learners with Down syndrome)

EXOSYSTEM
- Support System – family
- Support Services: Social Workers, Speech Therapists, Hospitals etc
- Help from the support services
- Education
- Acceptance

As it was mentioned in Chapter 4, it is clear that parents of Xhosa-speaking learners with Down syndrome see the need for a support system, for instance social workers, speech therapists, and hospitals. Learners with Down syndrome should be accepted by the community. The figure above reflects the needs of Xhosa-speaking learners with Down syndrome as seen by the parents of the two children with Down syndrome.

FIGURE 5.2: MESOSYSTEM
(The school, support group from Red Cross Memorial Hospital etc)

- Information
- Support
- Education: Special Education
- Sport
- Recreation
- Future Planning
- Career Path
- Work opportunities
- Independence

The figure above shows the broader needs of the Xhosa speaking learners as seen by an adult with Down syndrome, for instance education at a special school, supportive neighbours and a Down syndrome support group. It also identifies the need for information to be given to the parents of the children with Down syndrome as well as to the community at large.
The family needs a lot of support from the support services and the wider community. For instance, children with Down syndrome need to be placed in an environment conducive to learning, such as a special school. Recreation facilities are essential for these children in order for them to develop holistically. Provision for a career path is also necessary to ensure that placement in the workplace can happen as soon as they have finished normal schooling. It is important to encourage the children with Down syndrome to be independent in certain modalities.

**FIGURE 5.3: MACROSYSTEM** (The neighbours of the learners with Down syndrome)

- Love
- Acceptance
- Institution
- Sport

The neighbours in Nyanga and in Gugulethu felt that these learners should be **loved and accepted by the community at large**. They also felt it would be good if they could be placed in **institutions** like special schools where they could be equipped with the skills they need to deal with challenges of society.

**FIGURE 5.4: MICROSYSTEM**

According to the voices of both cases, they have a need to be loved and accepted. Participation in sport is seen as an important factor as it allows them to interact with other learners. They also see the school as a place where these needs can be met. In addition, there is a need for recreation facilities to give them exposure to certain sporting codes, and work opportunities as the eventual way of being independent and being able to manage their own resources. These needs are reflected below:

- Sports
- Acceptance
- Work
- Love
- Recreation
- School
- Dance
5.4 A SYNOPSIS OF THE NEEDS OF THE TWO XHOSA SPEAKING LEARNERS WITH DOWN SYNDROME

It is clear that the earlier the parents of the learners with Down syndrome get support from the different support services, the better the child will be equipped to function optimally in the community. It is difficult when the parents are in a disadvantaged area, because of the lack of support services in these areas. The other problem faced by the children with Down syndrome in the Xhosa culture is the lack of acceptance by the community. When the learners with Down syndrome complete their tuition at Nompumelelo, there is no future planning for them. Some of them do go to the workshops in Heideveld, Manneberg, Athlone etc, but there language becomes a barrier to accessing the services that could provide them with the necessary skills. Some of the other needs of the Xhosa speaking learners with Down syndrome are love, health services, work opportunities, career path, independence, and safety. Another factor, which is often not provided in a disadvantaged community, is sport and recreation. There are no swimming pools for these learners. If one compares the services offered in other special schools in places like, Claremont, Bellville, Cape Town etc, a discrepancy in the provision of services becomes evident. This is why there are few learners with Down syndrome who are swimmers. The sporting codes offered in a country reflect the different classes in society. Black learners in special schools are offered the sporting codes that are available generally in their environment, like soccer. However, sporting codes like swimming, hockey, tennis are not offered because of the lack of facilities.

5.5 QUALITY OF LIFE INDICATORS

The following table will depict the Quality of life Indicators categorised by Schalock (2000:122) that emerged during the study. It should be noted that there were no differences between these and the needs of the Xhosa speaking learners with Down syndrome. This table may be viewed as a reflection of the needs of learners with Down syndrome:
<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>EXEMPLARY INDICATORS</th>
</tr>
</thead>
</table>
| Emotional well-being | • Safety  
• Spirituality  
• Happiness  
• Freedom from stress  
• Self-concept  
• Contentment |
| Interpersonal relations | • Intimacy  
• Affection  
• Family  
• Interactions  
• Friendships  
• Supports |
| Material well-being  | • Ownership  
• Financial  
• Security  
• Food  
• Employment  
• Possessions  
• Socio-economic status  
• Shelter |
| Personal development | • Education  
• Skills Fulfillment  
• Personal competence  
• Purposeful activity  
• Advancement |
| Physical well-being  | • Health  
• Nutrition  
• Recreation  
• Mobility  
• Health care  
• Leisure  
• Activities of daily living |
| Self-determination   | • Autonomy  
• Choices  
• Decisions  
• Personal control  
• Self-direction  
• Personal goals |
| Rights               | • Privacy  
• Voting  
• Access  
• Due process  
• Civic responsibilities |
| Social inclusion     | • Acceptance  
• Status  
• Work environment |

(Schalock, 2000:122)
It is also important to show how the indicators of quality of life of the Xhosa-speaking that emerged from this study are similar to the exemplary indicators as portrayed by Schalock (2000). The connection will be reflected in the following section:

<table>
<thead>
<tr>
<th>QUALITY OF LIFE INDICATORS</th>
<th>NEEDS OF THE XHOSA SPEAKING LEARNERS WITH DOWN SYNDROME</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Emotional well-being</td>
<td>Safety and happiness</td>
</tr>
<tr>
<td>• Interpersonal relations</td>
<td>Support</td>
</tr>
<tr>
<td>• Material well-being</td>
<td>Safety, Protection, space and work</td>
</tr>
<tr>
<td>• Personal development</td>
<td>Education</td>
</tr>
<tr>
<td>• Physical well-being</td>
<td>Recreation</td>
</tr>
<tr>
<td>• Self-determination</td>
<td>Personal development</td>
</tr>
<tr>
<td>• Social inclusion</td>
<td>Acceptance</td>
</tr>
</tbody>
</table>

The link between the needs of the Xhosa-speaking learners with Down syndrome and the general quality of life indicators shows that these indicators can be used to reveal the needs of Xhosa-speaking learners as well. It can be mentioned that the community integration and a sense of belonging for the learners with Down syndrome has proved to be one of the most important factors influencing their quality of life. Therefore, a sense of belonging through interdependence is needed.

5.6 LIMITATIONS OF THE STUDY

One of the limitations of the study was that there is little literature on the African perspective on disabilities. Only very limited research has been done in this area within an African context. The other limitation was that the two learners with Down syndrome in the case study had only limited ability to express themselves. It was therefore difficult to find out the needs of learners with Down syndrome from Xhosa background from the learners themselves. Communication had to be done through their parents. A sand tray was used, but that could have limited their ability to express their needs clearly.

Due to poverty that affects disadvantaged communities, the parents of the learners with Down syndrome had a tendency to mention the material things that would benefit them as well. They did not really reveal the needs of their children. One of the problems for that is a question of language. The Xhosa language has limited vocabulary in as far as explaining the
word "needs". The respondent might read it as needing to give only one response. This also limited the amount of information produced on the needs of the learners with Down syndrome in general. Another reason for the limited response is that the community sees hope when they see the outsider. They view him as someone who can help them overcome the problems of poverty.

5.7 RECOMMENDATIONS

The recommendations will be divided into two sections, namely, recommendations for future research and recommendations on how service providers can meet the need of learners with Down syndrome.

5.7.1 Recommendations for future research

The study focused on the needs of Xhosa-speaking learners with Down syndrome. The area that was difficult to produce data was the views of the fathers of the children with Down syndrome. It would therefore be a challenge to focus the research on the fathers of the children with Down syndrome in the Xhosa culture, as it is still very patriarchal society in as far as care giving is concerned. The mothers are still regarded as the people who can provide assistance to the people with disabilities. One needs to ask oneself why the most accommodating people are the mothers in the Xhosa community.

Another area that needs attention is the role that could be played by the different departments, such as Health and Social Services, in enhancing the quality of life of learners with Down syndrome. Research could be done on the role of local government in Gugulethu could play in providing sport and recreation for people with disabilities.

Research could also be done on the role of special schools in facilitating future planning for learners with Down syndrome. The other area that needs to be given attention is the career path for the learners with Down syndrome. A possible line of enquiry is whether there is a psychometric tool that could be used to help identify an appropriate career path for people with Down syndrome.

5.7.2 Recommendations for the service providers

When discussing the findings, I mentioned that there are no workshops in Gugulethu and the surrounding areas where learners with Down syndrome can gain workplace skills. These
learners have to go "over the bridge" in order to reach these workshops. A further problem for some of these learners is that the language used is a barrier. Therefore, service providers need to think of establishing workshops in Gugulethu.

Secondly, learners with Down syndrome need to be included in the world of work. This refers to the fact that, placement for job shadowing in different shops, firms and working places is essential. These learners can do jobs like packing or cleaning the shelves.

The special schools in Gugulethu need to become resource centres so that learners in these schools will have more opportunities. For example, sport is still an area that exposes the divisions in societies. In Gugulethu, for instance, the sports facilities at the special school are very limited. I feel that all special schools should be treated equally. At present many parents are reluctant to enrol their children in the special schools in Gugulethu. They all want to enrol them at special schools in places like central Cape Town, Claremont or Bellville, because of the discrepancy in the services offered. The gap needs to be closed. A child who comes from Bel Porto Training Centre and a child who comes from Nompumelelo or Lentegeur ELSEN are being offered equal education. When Professor Sibusiso Bhengu was Minister of Education, he instituted a commission of inquiry into all of the support services. I feel that the current Minister of Education, Ms Naledi Pandor, needs to institute the commission of inquiry into how equitable the provision of services and facilities is at special schools.

5.8 REFLECTION

During this journey I saw for the first time some of the realities of the world of children with Down syndrome. Through the voices of the children themselves, their parents, the educators from the special school, the neighbours, the siblings, and the adult with Down syndrome I arrived at a number of insights into their lives. Coming from the Xhosa community myself, it had never really struck me that after ten years of democracy in South Africa people with disabilities are still marginalised. The Xhosa community has not yet reached the point where it readily accepts people with disabilities. The families of people with disabilities therefore prefer to send them to the schools where the community will not see them all the time.

It was a very disturbing factor to find out that there are no workshops in Gugulethu for Xhosa-speaking people with disabilities. I mentioned in Chapter 2 that I come from the Eastern Cape. In the community I come from, people with disabilities are not considered as
people who can participate optimally in the community. The same is true of Gugulethu. When one compares the two communities, Gugulethu can be seen as an urban area, whereas the community in the Eastern Cape is a rural area. One would assume that in an urban area like Gugulethu people would be more accepting towards the people with disabilities, but that is not the case. The reality is that, we Xhosas are still discriminating against people with disabilities. The only sector of the population that shows signs of acceptance is the "mothers". I think the time has come for us the Xhosa population to transcend the barriers of discrimination, and accept people with disabilities. They are not going to disappear or to be abandoned in the forests – they are here to stay. We must include them in all aspects of life. We as a community must show Ubuntu (Humanity). It is now the time to stand up, and say enough is enough. Our brothers and sisters deserve better treatment than this! The government departments need to help bridge the gaps between the special schools in disadvantaged areas and those in privileged areas. The special schools in Gugulethu and similar areas cannot be compared to the special schools in Claremont, Bellville, Stellenbosch, Cape Town, Wynberg and Houtbay. There is a serious discrepancy in the facilities available.

At the time of writing this research, Lentegeur ELSEN had just started a project involving children with disabilities in job shadowing. Children are placed in different shops, firms, filling stations etc. This aims to equip children with disabilities with work skills. This is what should be done in communities like Gugulethu.

I close my reflection with this poem dedicated to all the people with disabilities in all communities:
TO THEM AND OTHERS

Let me remember the days of darkness, when the clouds gathered to bring rain.
Let me remember the thunderstorms roaring in the far distance.
Let me wipe the warm tears streaming down the cheeks like the Crocodile River.
The road to emancipation is like Table Mountain.
I will use the old weapons of freedom ... the pen and paper to voice out my dissatisfaction!
I will not pretend, when the names of the people with disabilities are spewed on the community walls. Ridiculed and rejected.
Where are they?
The storm is coming very fast ... ready to fall on those helpless bodies.
The cries of the hungry bodies, like the dying Zebra killed by the Lion.
Where are they?
Are we ashamed of them? Yes! People see me with this body ... they laugh.
When I'm drooling they do not want to eat in front of me. People, what have I done to you? I was born by the people like you ... I feel pain ... I cry ... I laugh too. I have blood.
Why give me what you do not want?
I shall not mince my words anymore ... Give me dignity.
I will not mince my words, when the people still ridicule me!

I am talking about the people with Down syndrome, the people with intellectual disabilities, and the people with disabilities.
South Africa wake-up, before we lose our community.
They do not get enough services ... schools they go to are called special schools.
Are we treating them as being special!
Why therefore, buy time when we should give them services they deserve?
Why marginalise them? Why we call ourselves free, when the other section of our population is not free!

The time is now.
Let us stand up and open our hands to our brothers and sisters.
Together we shall sing a song of victory. We shall sing a song of happiness. When we laugh together, eat the same food.
We shall sing!

(A poem written by BHEKI SKOTA dedicated to people with disabilities)
REFERENCES


KWAZULU-NATAL, DEPARTMENT OF HEALTH. Batho Pele Principles.


WESTERN CAPE EDUCATION DEPARTMENT (2004)  


## ANNEXURE A

### THE TRANSLATED INTERVIEW:
**EXAMPLES OF CODED TRANSCRIPTS FOR DATA ANALYSIS**

#### INTERVIEW 1: THANDISILE'S MOTHER

<table>
<thead>
<tr>
<th>INTERVIEWER</th>
<th>RESPONDENT</th>
<th>QUALITY OF LIFE</th>
<th>ASPECTS OF QUALITY OF LIFE</th>
<th>THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>How are you, mam?</td>
<td>I am fine.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which hospital did you attend for Thandisile's birth?</td>
<td>I gave birth to Thandisile in 1990. I had him at the Bishop Lavis hospital.</td>
<td>Cpd</td>
<td>Cpdhos</td>
<td></td>
</tr>
<tr>
<td>How many children do you have?</td>
<td>There are four, two girls and two boys.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When he passed away, was he still staying with you?</td>
<td>Yes, we were staying together.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How did Thandisile's father react when he realized that his son has a disability?</td>
<td>He loved him so much. He used to pick him up, and go out with him.</td>
<td></td>
<td>Love</td>
<td></td>
</tr>
<tr>
<td>When he is at home does he play?</td>
<td>When he is here at home?</td>
<td>Rec</td>
<td>Repla</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>He does the things they did at school. Maybe he will count, and say &quot;1.2.3.4.&quot;</td>
<td>Cpd</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does he play with other children?</td>
<td>He does, but he does not play with them properly. When he plays with them, he pushes them very hard. Or he will pick up a big stone and hit them. He throws stones at the windows as well.</td>
<td>Rec Rec Msr</td>
<td>Repla Repla</td>
<td>Aggr Aggr</td>
</tr>
<tr>
<td>Does he know money?</td>
<td>He does not know money, but if he sees it, he just takes it. Sometimes I send</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Answer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does he know how to relieve himself?</td>
<td>Yes, he can</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does he know how to dress himself?</td>
<td>He doesn't know how to dress himself. If he tries, he puts the trousers the wrong way round. He does not know how to wash himself as well. I must wash him everytime.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What do you mean?</td>
<td>I can see him here at home Sometimes I ask both him and his brother to wash their school clothes. He will refuse.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You are rearing a child with a disability… how does the community behave towards the family?</td>
<td>No, they do love him…they love him. But the community do not all love him, because he is very destructive in other people's houses. Then they just chase him away.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How does the Xhosa community view people with disabilities?</td>
<td>They handle them like small children, who know nothing. They also overprotect them.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How are his siblings towards him?</td>
<td>You mean in terms of loving him?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ANNEXURE B

THEMES GENERATED IN THE QUALITY OF LIFE

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>THEMES IN QUALITY OF LIFE</strong></td>
<td><strong>CODES</strong></td>
</tr>
<tr>
<td>Patient</td>
<td>Pat</td>
</tr>
<tr>
<td>Attention</td>
<td>Att</td>
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<td>Aggressive</td>
<td>Aggr</td>
</tr>
<tr>
<td>Disrupting</td>
<td>Disrup</td>
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<td>Life situations</td>
<td>Lifsit</td>
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<td>Moments</td>
<td>Memo</td>
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<td>Activities</td>
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<td>Equip</td>
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<td>Creative</td>
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<td>Preparation</td>
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<td>Happy</td>
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<td>Dealing</td>
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<td>Required</td>
<td>Req</td>
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<td>Problems</td>
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<td>Language</td>
<td>Lang</td>
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<td>Understand</td>
<td>Under</td>
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<td>Dropping out</td>
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<td>Continue</td>
<td>Cont</td>
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<td>Difficult</td>
<td>Diff</td>
</tr>
<tr>
<td>Different</td>
<td>Differ</td>
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<td>Personality</td>
<td>Perso</td>
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<td>Humble</td>
<td>Hum</td>
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<tr>
<td>Loved</td>
<td>Love</td>
</tr>
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<td>Stubborn</td>
<td>Stub</td>
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<td>Lazy</td>
<td>Lazy</td>
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<td>Amazed</td>
<td>Amaz</td>
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<tr>
<td>Inactive</td>
<td>Inact</td>
</tr>
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<td>Experience</td>
<td>Expe</td>
</tr>
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<td>Fearful</td>
<td>Fear</td>
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<td>Accepted</td>
<td>Acce</td>
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<td>Unaccepted</td>
<td>Unacce</td>
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<td>Embarrassed</td>
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</tr>
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<td>Laugh</td>
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<td>Discriminates</td>
<td>Discri</td>
</tr>
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<td>Quiet</td>
<td>Qui</td>
</tr>
<tr>
<td>A</td>
<td>B</td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>THEMES IN QUALITY OF LIFE</td>
<td>CODES</td>
</tr>
<tr>
<td>Participate</td>
<td>Part</td>
</tr>
<tr>
<td>Represent</td>
<td>Repre</td>
</tr>
<tr>
<td>Sh</td>
<td>Shy</td>
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<td>Good</td>
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<td>Naughty</td>
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<td>Shameful</td>
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<td>Chase</td>
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</table>
## ANNEXURE C

### COMPLETE LIST OF CODES USED IN DATA ANALYSIS

<table>
<thead>
<tr>
<th>Quality of life</th>
<th>Codes on quality of life</th>
<th>Sub-systems</th>
<th>Codes on sub-systems</th>
<th>Aspects of quality of life</th>
<th>Subsequent codes</th>
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</thead>
<tbody>
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<td>Personal Management</td>
<td>PM</td>
<td>Family</td>
<td>FM</td>
<td>Eating</td>
<td>PMET</td>
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</tr>
<tr>
<td>School</td>
<td>SCH</td>
<td>Sweeps</td>
<td>PMSPS</td>
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</tr>
<tr>
<td>Community</td>
<td>COM</td>
<td>Dressing</td>
<td>PMDR</td>
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<td>The learner with Down Syndrome</td>
<td>LDS</td>
<td>Washing</td>
<td>PMWAS</td>
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<td>Play</td>
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<td>Swimming</td>
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<td>Sport</td>
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<td>Practical work</td>
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<td>Sorting buttons</td>
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<td></td>
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<td>Remove cotton</td>
<td>WOREMC</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sorting hangers</td>
<td>WOSTH</td>
<td></td>
<td></td>
</tr>
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