THE HIGH SCHOOL EXPERIENCE OF A LEARNER WITH DOWN SYNDROME: A CASE STUDY

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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 at any university for a degree.

LMMorrison

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Signature

27 February 2008

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Date

SUMMARY

The inclusion policy which is currently being implemented according to White Paper 6 (July 2001) has raised many questions and debates. In South Africa at the moment there is a focus on the implementation of inclusion policies in primary schools. Although many studies have been conducted on Down syndrome, there seems to have been little focus on the adolescent. Specifically their experiences in the high school context appear to have received little attention.

This paper focused on the experiences of an adolescent with Down syndrome who has been mainstreamed into a high school. The experiences are discussed within identified indicators of quality of life namely; peer relationships, experiences of academic, general school and extra-mural activities. In addition the effects of Down syndrome on areas such as adolescence, inclusion strategies, behaviour and social skills are also investigated.

The findings of this paper were that of adolescents with Down syndrome can be successfully mainstreamed if their individual needs are catered for. These needs include opportunities to spend time with learners with the same abilities as their own. Satisfaction was experienced by the participant and her parents regarding her academic placement and scholastic achievements. A factor that played a role in her successful placement was the supportive environment she was in. Although satisfaction was experienced with regards to the process of inclusion there were parental concerns regarding her future independence.

OPSOMMING

Die inklusiewe beleid wat tans volgens die Wit Skrif 6 van Julie 2001 geïmplimenteer word, het gelei tot baie vrae en debattte. In Suid-Afrika is daar 'n fokus op die instelling van die inklusie proses in laerskole. Alhoewel baie studies oor Down sindroom gedoen is kom dit voor asof min aandag aan die adolessent gegee word. Dit geld veral ten opsigte van hul ervarings in die konteks van die hoërskool.

Hierdie studie fokus op die ervarings van 'n adolessent met Down sindroom wat tot die hoërskool toegetree het. Die ervarings word bespreek binne gespesifiseerde areas van die kwaliteit van lewe naamlik; ervarings van akademiese aktiwiteite, algemene skool aktiwiteite en buitemuurse bedrywighede. Daarbenewens word die effek van Down sindroom op areas soos adolessensie, inklusiewe strategieë, gedrag en sosiale vaardighede ook nagevors.

Die bevindinge van hierdie navorsing het daarop gedui dat dit wel moontlik is om adolessente met Down sindroom in hoofstroom in te sluit, mits daar aan hul individuele behoeftes voorsien word. Beide die deelnemer en haar ma het tevredenheid ervaar ten opsigte van haar akademiese plasing en skolastiese prestasies. 'n Ondersteunende omgewing was 'n faktor wat 'n besliste bydrae gelewer het tot hierdie sukses. Alhoewel beide ouer en kind hoofsaaklik tevredenheid ten opsigte van die proses van inklusie ervaar het, was haar ma tog bekommerd oor haar onafhanklikheid in die toekoms.

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TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1

INTRODUCTION

1.1   INTRODUCTION

This chapter states my personal motivation for doing this study. A brief explanation of the following aspects are included, the research problem and research question. The aims of the study, research design and methodology are also included. The chapter concludes with a brief explanation of the structure of the report.

1.2   PERSONAL MOTIVATION AND RELEVANCE

The inclusion policy which is currently being implemented in South Africa according to White Paper 6 (2001) has raised many questions and debates. There is currently a focus on the implementation of inclusion policies in primary schools. As a result of this focus my research is concerned with the way in which learners with disabilities are included in South African high schools. The choice to focus on a learner with Down syndrome is due to a personal interest with individuals with Down syndrome.

During my search for literature it became clear that there is a gap in the research with regards to adolescent Down syndrome learners' personal experiences, especially their school experiences. Although many studies have been done on Down syndrome it appears that there has been little focus on the adolescent with Down syndrome.

To fill some of the research gaps regarding Down syndrome, Stellenbosch University together with Down Syndrome South Africa started the *Intellectual Disability: Quality Life-Span Development (DSSA/US)* project in 2000 (Le Grange & Newmark 2002:88). The project's aims were to develop and implement support programs in order to establish quality life-span development for individuals with intellectual disabilities. In order for quality research to be produced, on a national and international level, collaborative relationships were to be built with other universities and organizations.

The first phase of this project focused on the following aims;

- *Establish the needs of an adult with Down syndrome in the transition from a sheltered work environment to a corporate work environment.*

- *Establish the needs of intellectually disabled adolescents during career directed training in the transition from school to work.*

- *Ascertain the needs of mothers in coping with young children with an intellectual disability.*

- *Establish the needs of educators in the process of including learners with intellectual disabilities into mainstream schooling.*

- *Establish the communication needs of parents of learners with intellectual disabilities who have been institutionalized.*

These studies indicate that further research, specifically in the adolescent developmental phase need to be done if the project is to meet its aim of "establish[ing] quality life-span development of learners (from birth to adulthood) with intellectual disability through the development and implementation of support programs" (Le Grange & Newmark 2002:88). As my study falls within the aims of this project I will work from a quality-of-life perspective.

There is an increase in awareness and concern in the perceived well-being of individuals, especially those with intellectual disabilities, such as Down syndrome. The focus of quality-of-life work is on the social and psychological dynamics of well-being. Quality-of-life work has been given many definitions. The definition by Schalock (2000:118) encompassed dimensions that can be placed in a hierarchal order as follows (from bottom to top); physical well-being, material well-being, rights, social inclusion, interpersonal relations, self-determination, personal development and emotional well-being. This study will investigate some of these areas within this definition as it relates to the participants' lives and experiences and in particular the inclusive school experience.

White Paper 6 (2001:25) stated that the "inclusion of learners … with impaired intellectual development will require curriculum adaptation rather than major structural adjustment or sophisticated equipment." It is one of White Paper 6's medium-term goals to have "transform(ed) further education and training and higher education institutions to recognize and address the diverse range of learning needs of

learners, especially disabled learners" (White Paper 6, 2001:22). At present little attention has been given to the learner with Down syndrome who successfully completes his/her primary school education in a mainstream school and has to move on to a mainstream high school. It is because of this gap in the literature that I have focused my research on a high school learner.

During my literature search I could not find research that had focused on how the adolescent learner with Down syndrome experiences high school in South Africa. Many resources including Landsberg, Kruger and Nel (2005) provided guidelines on how to accommodate learners with disabilities, empowering the teacher and including the child in the peer group in primary school. There is however a dearth of literature on how to include adolescent learners and I had to rely on international resources. Lorenz (1998:14), provided information on the difficulties learners with Down syndrome may experience, for example their possible struggle to adapt to the high school environment. Many internet sites are dedicated to Down syndrome but even there the adolescent sections were often incomplete. I did, however, find an internet site created specifically for adolescents with Down syndrome, containing information on a variety of topics; interviews with celebrities and tips on safety, health and relationships (www.ndss.org). It therefore appeared that there is little research regarding the inclusion of adolescents with Down syndrome in national or international sources readily available.

It would be ideal if further research can be conducted in the field of adolescent experiences, which may influence education policy and improve support programs.

1.3   RESEARCH PROBLEM

This research project is an investigation into how a sixteen year old learner with Down syndrome experiences being included in a private high school. As individuals with Down syndrome typically have an intellectual disability, which negatively impacts their scholastic progress, many parents decide to remove their children from mainstream schooling once primary school has been completed (Lorenz, 1998:12). The school that the participant had been included in has a special inclusion class of which she is a member. This class is the school's first attempt at inclusion.

Inclusion is a world-wide movement where active attempts have to be made by schools to include learners who used to be excluded from mainstream classrooms and

schools as a result of their disabilities (Swart & Pettipher in Landsberg, Kruger & Nel, 2005:4).

Learners from the school's inclusion class participate in the mainstream classes for subjects such as technology, art, music, physical education, and more formal learning areas where appropriate. The vision of the special needs facility is to support and flexibly integrate learners with special needs into the life of the school.

The research problem is therefore to explore how the participant perceived her school experience. The participant's mother will assist in providing information in order for a more comprehensive picture of her experiences to be drawn.

1.4   RESEARCH QUESTION

The purpose of this study was to answer the question: How does an adolescent learner with Down syndrome experience high school?

1.5   RESEARCH AIMS

Learners with Down syndrome who are included in mainstream schools in South Africa need research attention. As stated earlier, during my literature review I did not find research done in South Africa, more focus was on British and American inclusion practices. Even in these international sources adolescents who are included in mainstream schools was not area that had received much attention. The focus of much of the literature appeared to be on the medical condition of the individual with Down syndrome. The central aim of this study will therefore be to explore the adolescent's experiences as a learner with Down syndrome being included or mainstreamed into a mainstream high school in South Africa.

The further aims of this study are to examine an adolescent with Down syndrome's experiences within high school in the context of:

- Peer relationships

- Experience of academic activities

- Experience of general school activities

- Experience of extra-mural activities

These areas have been chosen so that a comprehensive understanding of an adolescent's experiences can be made. As there is a dearth in the literature regarding adolescents with Down syndrome this study will add to the current knowledge base and can be further expanded on in later research studies.

1.6   THE THEORETICAL APPROACH OF THIS STUDY

Yin (1993:4) stated that the role of theory in research is to establish expectations for analyzing the case study under investigation. This study, of investigating an adolescent with Down syndrome's high school experiences, was done through an interpretative paradigm. This paradigm was chosen as the purpose of the study was an attempt to understand an individual's perception of their context.

Interpretative research is necessary according to Merriam (1988:165), as it brings to light new perspectives on everyday situations. This is done through documenting actual experiences in order to gain an understanding of them. The understanding should be based on the meaning individuals place on their experiences and on the social settings in which they take place. As a person can not be removed from their context, the social setting events take place in as well as the broader context should be taken into account when formulating an understanding of the individual's experiences.

Qualitative research methods are best suited to the task of trying to comprehend another's reality. The underlying principle of interpretative research according to Terre Blanche and Durrheim (1999:124) is that researchers want to study individuals and groups as they go about their daily lives, rather than under artificially, created conditions. Terre Blanche and Durrheim (1999:6) stated that interpretative research assumes that people's subjective experiences are real and should be taken seriously. In addition we can understand others' experiences by interacting with them and listening to what they have to tell us. Interpretative research relies on the first hand accounts of people's experiences and attempts to describe what is observed in rich, descriptive detail.

Bleicher in Terre Blanche and Durrheim (1999:125) further defined interpretative research as "the meaning of human creations, words, actions and experiences that can only be ascertained in relation to the contexts in which they occur". This includes personal and societal contexts. The implication is that interpretative researchers

usually work with material that is richly inter-related and would lose its meaning if attempts were made to separate it from the social context it takes place in.

Social action is as Neumann (2000:71) explained action onto which people place subjective meaning. The social world exists because people experience and give meaning to it through interacting with others in an ongoing process of communication and negotiation. Social action can not be isolated from the context in which it takes place or the meanings given to it. There are two levels by which the social world can be interpreted. The first level is the one constructed by the people who were involved and their reasons or motives for their actions. The second level of interpretation is the researchers' discovery and reconstruction of the first level of interpretation. The interpretative researcher sees value and meaning infused everywhere and in everything.

It is clear from the above definitions that interpretative research is the relevant method for the proposed research, as my particular interest lies in the participants' own experiences and meanings associated with the context she found herself in. The following section will contain a brief discussion of the research design and the methods used to do this study.

1.7   RESEARCH DESIGN AND METHODOLOGY

1.7.1   Research design

As Terre Blanche and Durrheim (1999:29) stated the purpose of a research design is to provide a plan that spells out how the proposed research is going to be implemented so that it answers the research question. Berg (1989:283) explained that qualitative research is best suited to the kind of study proposed. This is because it is a search for answers by examining the settings in which people find themselves as well as the people themselves and how they make sense of their contexts.

The aim of this study was to investigate the experiences that a learner with Down's syndrome had in high school. The qualitative single case study was a suitable method to execute this study. A case study is a thorough description of a person or larger unit such as an institution (Merriam, 1988:9). Content analysis of the produced data was carried out. The data gathering techniques will be discussed in brief here and in more detail in chapter three.

1.7.2   Research method

1.7.2.1   Data collection techniques

Data for this study was collected through interviews with the participant and her mother. Merriam (1988:72) stated that the interview is the best method to gather information when doing a case study. Secondary corroborative evidence was collected through a telephonic interview with Hanlie Swanepoel, Head of Down Syndrome South Africa.

The interview guide was chiefly compiled by combining questions from the "Quality-of-Life" questionnaire (Cummins, 1997:20; 2004:24) and the article; Educational Challenges Inclusion Study (Wolpert, 1996). The areas covered by the questions were compared with those used in an interview conducted for a newspaper that interviewed an adolescent with Down syndrome (Ashworth, 2002:16). The participants were given the opportunity before the interview to go through the questions and make adjustments to them if they thought it necessary. (See Annexure 2)

1.7.2.2   Data analysis

Babbie and Mouton (2001:493-494) maintained that a research study depends on the interest and perspective the researcher has on the gathered information. The researcher decides on whether a piece of information becomes data or not.

The method of analysis was content analysis, this is where relevant examples and themes are identified in the data. The analysis of data for this study was through the transcription of the tape-recorded interviews. The transcriptions as well as the process notes made while interviewing were organized to determine themes. The themes were coded and a data display made in order to build a comprehensive understanding of the case.

1.7.2.3   Validity and reliability

The issue of internal validity will be addressed by including multiple sources of data in the form of an interview with the mother of the participant and the information received from Hanlie Swanepoel. Triangulating data according to Babbie and Mouton (2001:275-276) is effective when trying to gather information about different constructions of the same phenomenon. This is done through asking questions from different sources and using different methods to gather information. External validity

will be addressed by providing a thick description of the procedures and findings (Merriam, 1988:177).

1.7.2.4   *Ethical considerations*

Consent to participate in the study was achieved by verbally explaining the study in full to the parents of the participant. The parents and the participant (see annexure one) were also provided with an information sheet explaining the purposes of the research. A consent form was given for them to sign, an example of which was sent to them before the interview. The participating adolescent received an adapted consent form. It was made clear to the participants that they were welcome to view the documents or data at any stage. Fictitious names were given to all participants to protect their identity. This process of informing the participants at all stages was to ensure that there was transparency between myself and the participants.

1.8   CLARIFICATION OF KEY CONCEPTS

A brief description of the key concepts used in this report will be given below:

Down syndrome – According to the Massachusetts General Hospital, Down syndrome is a disorder that can be distinguished by certain physical as well as functional features. Adolescents with Down syndrome are usually shorter than typically developing adolescents by two standard deviations. Their heads are usually small and round while the back of the head may be flat as a result of incomplete skeletal growth. This also affects the size of the nose and ears which are smaller than the typical size. The neck may also be shorter. Often the individual with Down syndrome's will have slanted eyes. Many adolescents with Down syndrome have poor muscle tone and strength. The physical features and the intellectual disability are caused by a chromosomal abnormality, a result of extra genetic material. The chromosomal abnormality is caused by an additional chromosome-trisomy 21, in each cell instead of two chromosomes. In 95% of individuals with Down syndrome they have forty-seven chromosomes instead of the typical forty-six.

Quality of life – In the field of intellectual disabilities quality-of-life issues have been receiving attention since the 1970s (Brown & Brown, 2005:718). The focus on current quality-of-life work is centred on the individual with an intellectual disability, such as Down syndrome. It is based on the individual's perceptions of themselves, their understanding of their role in their social contexts and their attempts to reach their

goals and dreams. Quality-of-life involves material well-being, rights, social inclusion, interpersonal relations, self-determination, personal development and emotional well-being (Shalock, 2000:119).

Adolescence – In Smith, Cowie and Blades (2005:281) adolescence is defined as the transition between childhood and adulthood. It is marked by biological changes due to the onset of puberty. Changes in the adolescent's social skills and needs are also noticed, as more time is spent with their peers than with their families. There is an increase in attempts to reach independence.

Inclusion – Is a broad philosophical position that is being promoted on an international as well as national level (Donald, Lazarus & Lolwana, 2002:23). It aims for all children to have the same educational rights and to not be discriminated against due to differences in ability, race, gender, language, religion or social class. This policy presents South Africa with some unique as well as universal challenges. The unique challenges include the effects of the past political policies where education policies discriminated against children not only on the basis of race but also on the basis of disability. This resulted in a many fragmented and unequal system, where certain populations received more assistance and support than others. The effects of the past policies are still felt today in the attitudes individuals have towards inclusion as well as the availability of resources in many schools to assist learners with disabilities. The universal challenges that inclusive education face can be based on the attitudes of individuals, schools, teachers and principles as well as the wider society towards inclusion. These attitudes influence how and whether learners with disabilities are included into our schools as well as the success of the inclusion as a philosophy.

Experience – Thoughts, feelings and feelings are activated and refined according to Dewey's theory of learning. An experience embraces all the human senses (LeCompte, Millroy & Preissle 1992:39, 111).

High School – In the South African school system, high school stretches from grade eight to grade twelve. A national exam is written by all grade nine learners after which learners may choose to continue to grade twelve (known as Further Education and Training – FET) or leave the schooling system or attend a college or other training institution (Education Department).

1.9   STRUCTURE OF THE PRESENTATION

This study will be reported as follows:

Chapter 2 – Literature review

The literature review will address Down syndrome broadly, the adolescent phase and the issues surrounding being in high school. A brief overview of Quality-of-life research will also be given.

Chapter 3 – Research Design and Methodology

The rationale for choosing a qualitative case study and all the relevant aspects relating to data production, organization and analysis as well as ethical issues will be discussed. The context in which the study took place will also be explained.

Chapter 4 – Implementation of the study

The results of the interviews will be reported in this chapter.

Chapter 5 – Discussion of findings, Limitations, Recommendations and Reflections

The findings are discussed in this chapter. This chapter also includes a discussion on the limitations of the study, recommendations for this study as well as future research.

1.10 REFLECTION

The reason for conducting this study was a combination of personal and professional motives. The search for literature on adolescents and their inclusion into schools left me interested in the well-being of adolescents with Down syndrome. The adolescents' lack of voice not only with regards to their education but also in other areas of their development and lives left me considering the ethical aspects of making decisions and choices for people without knowing what their opinions and feelings on the matter were.

Most research concerning adolescents with Down syndrome has been conducted internationally. In South Africa limited research in this regard has been done. I therefore hope to contribute to the expansion of knowledge of what it means to be an adolescent with Down syndrome being integrated into a mainstream high school.

Beside the motivation and relevance of this study, this chapter also included a brief description of the research process. This study was approached from a pro-inclusion

theoretical standpoint and was influenced by the Quality-of-Life paradigm. The research aims were to explore how an adolescent with Down syndrome experienced being included in a mainstream high school. The research design was qualitative. The techniques for data production and analysis as well as issues of validity, reliability and ethics were briefly described. The literature consulted for this study will be reviewed in Chapter 2.

CHAPTER 2

REVIEW OF THE LITERATURE

2.1 INTRODUCTION

The purpose of this study is not to focus on what Down syndrome is but rather on how it influences individuals' lives. This chapter will give a short description of the syndrome; its effects on adolescence and inclusion. The study's overall aim is to improve the adolescent with Down syndrome's well-being and therefore an overview of Quality-of-Life research is included.

2.2 QUALITY-OF-LIFE

Quality-of-life issues have become steadily more prominent since 1948, when the World Health Organization defined health as being the presence of physical, mental and social wellness and the absence of disease and infirmity (Testa & Simonson 1996). Since 1973, there has been an increase in the amount of interest in quality-of-life practice and research.

Interest in quality-of-life has historically come from four sources (Shalock 2004:204). These sources are; a shift in belief and focus that technology and medicine can solely result in an improved quality of life. There is also a move to not only including individuals with disabilities in the community but also to assess the outcomes of being included on the individual's wellbeing. In addition the past few years have seen an increase in the individual's rights as consumers and users of services, which have had a positive impact on service delivery. Lastly awareness in quality of life aspects has been raised.

A framework for understanding can be built around the quality of life concepts in order to improve the individual's quality of life within their environments. This is as a result of the quality of life concept according to Shalock (2004:204) at present being applied as a way in which to become more sensitive towards the individual's perspective and fit with their environment.

The dimensions that are included in the Quality-of-Life framework are the physical, spiritual, social, emotional, intellectual and occupational according to Simmons (2007). In addition Shalock (2000:118) defined quality-of-life as concerned with the individual's emotional, physical and material well-being, their interpersonal relations, personal development, self-determination, social inclusion and their civil rights. These distinct areas are Testa and Simonson (1996) reported influenced by an individual's experiences, beliefs, expectations, and perceptions. Simmons (2007) regarded the socio-economic variables; gender, age, education, ethnicity, and income level, all aspects to consider when examining quality of life. In this study I focus on an individual's quality of life, as opposed to a family's or health-related quality of life.

The above mentioned dimensions can be measured according to two criteria: the objective assessment of functioning or health status and the more subjective perceptions of health. Testa and Simonson (1996) explained that although the objective aspects are important when defining an individual's degree of health, it is the subjective perceptions and expectations that translate the objective assessment into the actual quality of life experienced. Individuals with the same health status may have different qualities of life. The reason for this difference is that we each have our own expectations regarding our ability to cope with limitations and disability. This expectation may have an influence on our own perception of health and satisfaction with life.

A purpose of quality-of-life measures is to assess whether there has been any changes in the human and financial costs and benefits of new programs and interventions, specifically for individuals with intellectual disabilities. In order for a significant impact to be made on public policy, service delivery principles and practice on a micro-, meso- and macro-system level, an understanding of the impact of quality of life measures needs to be made (Shalock 2004:204). This purpose has been formulated as a result of the potential exclusion of individuals with intellectual disability and their families from participation in society.

In this study I combine elements of Shalock and Simmon's definitions as aspects such as education, emotional well-being and interpersonal relations are investigated.

2.3   DESCRIPTION OF DOWN'S SYNDROME

2.3.1   Prevalence

Any couple from any racial, social or cultural background has the potential of having a baby with Down syndrome (Lorenz 1998:1). Different authors cite a variety of statistics when determining the incidence of Down syndrome. Smith, Cowie and Blades (2003:32) stated that approximately one in every 800 babies is born with Down syndrome. The reason Down syndrome occurs is still not certain. What is known is that it is a chromosomal abnormality that usually causes damage to the ovum before conception (Massachusetts General Hospital 2007). A chromosomal abnormality may occur when there is a chromosomal translocation. Translocations are a section of one chromosome that is placed into another chromosome. This translocation can happen spontaneously or when the parents have a translocation in their own genetic makeup.

2.3.2   Physical characteristics

The specific physical characteristics associated with Down syndrome are a flat appearance to the face, with a low bridge to the nose, high cheekbones and outward slanting eyes with a conspicuous eye-lid fold (Smith, Cowie & Blades 2005:32). The muscles tend to be limp which contributes to difficulties with motor coordination. Many of the physical characteristics typical of individuals with Down syndrome are as a result of the incomplete growth of the skull and skeleton. According to Lorenz (1998:3) there appeared to be no connection between the degree of "obviousness" of the physical characteristics and the degree to which development was delayed. Difficulties are often experienced with language development and expression. This can in part be attributed to a small mouth cavity. Vision and hearing may also be affected (Down Syndrome South Africa).

2.3.3   Medical implications

Medical advances have according to Wishart (1998), helped to ease the concerns of that having a child with Down syndrome may bring. Paying proper attention to the effects diet and lifestyle has on development and health is important when looking after one's well-being.

Most children with Down syndrome have relatively healthy childhoods, although many can have hearing and visual problems (Buckley & Sacks 2002). There are children with Down syndrome who experience other difficulties unrelated to Down syndrome such as epilepsy or autism. These disorders can have a profound impact on the child's functioning level. In adulthood the problems individuals with Down syndrome experience appear to have to do with an accelerated growth process (Wishart 1998). It seems as if individuals with Down syndrome are susceptible to premature aging. Chen (2007) identified the following signs of premature aging; as a decreased skin tone, early greying or loss of hair, hypogonadism, cataracts, hearing loss, age-related increase in hypothyroidism, seizures, neoplasms, degenerative vascular disease, loss of adaptive abilities, and increased risk for early-onset Alzheimer.

Although it appears as if individuals with Down syndrome may experience premature ageing the life expectancy of individuals with Down syndrome has increased from an average of nine years of age in 1921 to the current 60 years of age.

Most medical conditions can be successfully treated, for example infections involving immune response (Chen 2007). Obstructions, such as choanal stenosis can affect the upper airway which can cause amongst other things, cerebral hypoxia, may be experienced. Some medical conditions appear to arise from having a less than average ability to take the normal precautionary measures, such as skin infections from inadequate hygiene procedures and burn wounds from accidents with irons or stoves (Wishart 1998).

2.3.4 Personality

As with many disorders and syndromes stereotypical personality types have risen. The stereotypical personality of an individual with Down syndrome include characteristics according to Wishart (1998) such as that they are happy, affectionate, musical, good mimics and have a well developed sense of fun. Chen (2007) included in his definition that they have a natural spontaneity and are warm, gentle, patient and tolerant. Both authors mentioned that individuals with Down syndrome may exhibit stubbornness. It must be emphasized that the above is a stereotype and every individual with Down syndrome has a unique personality.

2.3.5 Intellectual development

Down syndrome is associated with a degree of intellectual disability. Chen (2007) stated that the IQ range for individuals with Down syndrome can lie between 20 and 85 with a mean of 50. On starting school at age five, according to Lorenz (1998:5) many children with Down syndrome are on the same functioning level as most of their age-group. However developmental progress in mental age or academic advancement does not usually progress at the same rate as it does for their typically developing peers.

It is important Lorenz (1998:12) explained to note that an individual with Down syndrome's test performance on intelligence measurements is often erratic. This may be due to their often clumsy finger movements. Practical, matching tasks and verbal tasks that have a time limit are usually performed poorly because of their slow reaction time. These factors do not consider the child's potential ability to complete the task successfully if they were given enough time to do so.

The measured IQ claimed Lorenz (1998:6) of an individual with Down syndrome decreases with age. The rate and degree that it diminishes varies from individual to individual. Lorenz (1998:6) maintained there is as yet no evidence to suggest that overall development reaches a plateau in adolescence. Dykens in Chadwick, Cuddy, Kusel and Taylor's (2005:878) research findings contradict the above statement as they claimed that it appears adaptive behaviour skills do reach a plateau in adolescence. Conclusive evidence on this point still needs to be found.

2.3.6 Social development

Lorenz (1998:61) explained that children with Down syndrome appear to have relatively competent social and social language skills. Like all their skills, social behaviour is learnt more slowly. Most children with Down syndrome learn the unwritten rules of conversation and how to adapt them to effectively communicate with their peers. The social behaviour that is important for children with Down syndrome (and everyone else) to learn according to Lorenz (1998:61) is; taking turns, cooperating and sharing. The development of these skills however needs continual practice and encouragement. In a study by MacDonald (2006) he reported that even in adolescence many individuals with Down syndrome needed assistance with the unspoken rules of conversation.

Just as it is important to encourage age appropriate desired behaviour so it is important to discourage inappropriate social behaviour. Most adolescents with Down syndrome Buckley and Sacks (2002) explained are socially sensitive and understand the non-verbal cues to emotions such as body language and facial expressions. Many adolescents are able to show good empathy and understanding of social behaviours but struggle to express how they feel as a result of their limited language abilities.

Although social competence has determinants other than a high cognitive functioning level the connection between the two is strong enough to be included when investigating social skills. According to Sigman and Ruskin (1999:1) the extent to which individuals with Down syndrome are able to lead independent or semi-independent lives, in terms of their career and/or living set-up depends a great deal on their social skills. The degree to which individuals with Down syndrome can live independently depends as much on their cognitive abilities as on their social skills. The ability to communicate is necessary for social interaction and therefore can pay a significant role in the individual's ability to live independently.

It has been suggested by Chadwick, Cuddy, Kusel and Taylor (2005:885) that there is a limit to the social development of individuals with Down syndrome as a result of their intellectual and communication disabilities. Wishart (1998) reported that there are many adults with Down syndrome who do not acquire the skills needed to live a largely independent life. Chadwick et al. (2005:885) argue that because of the limitations on their social development individuals with severe intellectual disabilities tend to be more dependent on their families and do not build many relationships outside of them. They may stay dependant on their parents or other carers for their entire lives and these relationships are then more important than relationships with peers.

2.3.7   Emotional development

As Wishart (1998) explained the needs of individuals with Down syndrome are not very different from those of us without Down syndrome. Individuals with Down syndrome also have needs regarding their education, family, friends, employment and self-esteem. These requirements, excepting employment do not change significantly with increasing age.

The need for employment increases with age but employment is often difficult to achieve, leaving many individuals and their families frustrated and depressed. The inability to find a suitable job can contribute to some individuals losing their previous enthusiasm for life and retreating into themselves. The result of this retreat may be few friends outside of the family circle and a limited life-style with few 'outsider' interactions. This isolation is an area of concern, as a meaningful social life may often help to be a substitute for a successful career.

Individuals with Down syndrome who isolate themselves may have Pepi and Alesi (2005:420) explained a personal history with little success and much frustration which tends to leave individuals feeling worthless about them-selves. This as Sala in Pepi and Alesi (2005:420) stated may influence the quality of performance on cognitive tasks. Individuals who repeatedly experience failure, including individuals with Down syndrome are likely to develop a negative attribution bias and are unlikely to have expectations of future success.

Lorenz (1998:61) argued the above view by stating that if the individual with Down syndrome has an increased level of activity and participation, should there be the opportunities to do so, an increased confidence and self-esteem may follow.

Although individuals with Down syndrome may have appropriate social skills factors such as unemployment may lead them to isolate themselves from others and the skills they have learnt will not be utilised.

2.3.8   Skill development

A great deal of difficulty is experienced reported Wishart (1998) by children with Down syndrome in learning basic childhood skills. Most individuals with Down syndrome experience difficulties taking in visual, auditory and other sensory information quickly, which results in slow reaction times. A contributing factor according to Smith et al. (2003:33) to problems with speech comprehension, pronunciation and number ability is a poor memory for heard speech. Individuals with Down syndrome sometimes use behavioural strategies that weaken their progress in learning, especially when they find tasks too challenging. These strategies may include social behaviour such as distracting adults' attention or acting stubborn to avoid tasks that are too difficult, too easy or too much effort.

There is evidence to suggest according to Wishart in Lorenz (1998:5) that children with Down syndrome do not make use of all the skills that they have acquired. The conclusion that some individuals with Down syndrome are less motivated than many other individuals with similar intellectual functioning ability had been made. This behaviour may lead to difficulties as discussed below.

2.3.9   Behaviour

Behaviour difficulties such as tantrums may result when children with Down's syndrome who have been successful at avoiding work by smiling or changing the subject, are confronted by a teacher or other individual, who realizes that they are more competent than they have been making out to be and insists that they complete a task (Lorenz, 1998:5).

Frustration and inappropriate behaviour may also occur when individuals with Down syndrome feel that they are not being listened to or understood (Lorenz, 1998:63). If situations are not handled correctly, the individual with Down syndrome may become isolated and negative self-stimulatory behaviour, such as thumb-sucking, rocking or genital stimulation may occur. Should inappropriate behaviour occur the learner should be treated firmly and the cause of the behaviour determined.

Overall individuals with Down syndrome are at less of a risk for developing problems including psychiatric disorders than other individuals with intellectual disabilities. Although according to Dykens, Shah, Sagun, Beck and King (2002:484) children with intellectual disabilities are at an increased risk, relative to their normal developing peers for emotional and behavioural problems, especially depressive disorders. The more frequent problems that they encounter are associated with externalizing, stubbornness and inattention.

When the child with Down syndrome is successfully integrated in the home or school environment, Lorenz (1998:61) reported and where the balance between challenge and support is maintained, inappropriate behaviour should rarely occur. Pueschel (1990) reported that the family environment may be an important factor in the type of behavioural symptoms displayed. Individuals with Down syndrome who come from more dependent family environments tend to have emotional and mood disorders, whereas those from homes where there is conflict may be at a greater risk for antisocial behaviour. Supportive families have the best outcome regarding behaviour

and overcoming barriers in adolescents with Down syndrome. A family environment that is not supportive may be, amongst others factors a barrier to development.

2.3.10 Barriers to development

Acquiring basic childhood skills is a major developmental obstacle to most children with Down syndrome. Wishart (1998) stated it is important to be realistic about the difficulties that children with Down syndrome face. However there is no proof as yet that those with few problems as well as those with severe problems do not have the potential to develop their skills and abilities further.

Communication is often an area that individuals with Down syndrome struggle in as mastering language skills is often a challenge. As a result of the struggle it can take to be vocal, many individuals with Down syndrome, Lorenz (1998:61) explained don't assert themselves vocally. This may have a negative impact on their ability to be included in a mainstream school, as the school environment often requires that one expresses oneself verbally.

Other difficulties learners with Down syndrome tend to experience in school are the deficits in their short term, auditory and sequential memory. Their strengths lie in their visual processing ability. According to Caycho in Lorenz (1998:56) despite the delay in acquiring skills, most children with Down syndrome appeared to develop their mathematical concepts in the same way that typically developing children do.

Wishart (1998) stated that current education models do not take into account that learners with Down syndrome may have diverse learning styles. Some of the teaching methods may be based on incorrect assumptions about the developmental processes of individuals with Down syndrome. The specific nature of the problems children with Down syndrome experience in the classroom can change. This may be as a result of being confronted with a variety of teaching approaches from different teachers. Teachers will therefore need to adapt their teaching styles to meet the needs of the Down syndrome learner.

It is the individuals with Down syndrome who do respond to intervention of their cognitive and language skills, not those that do not respond to intervention, according to Wishart (1998) that need further study. These exceptions can provide evidence and clues on how to break the performance ceiling for others. The upper limit to the

development for individuals with Down syndrome is not known and it is an area that needs further research.

The current focus in research is on a 'whole-child' approach (Ziegler in Pepi & Alesi 2005:419). This approach places the emphasis on the reciprocal relationship between the cognitive and motivational factors that characterize development (Pepi & Alesi 2005:419). Research on this relationship appeared to prove that increases in abilities are possible. The education context can therefore have a profound impact on development as it can encourage or discourage interaction with individuals other than those associated with the family.

2.3.11 Effect on family

As Wilks (1974) demonstrated the news that one's child has Down syndrome can cause distress to the new parents. Garthy et al. in Wishart (1998) have found that although there are many difficulties raising a child with Down syndrome it is not the burden that it is commonly thought to be. Most families are able to continue, according to Buckley and Sacks (2002) to live normal family lives if they are able to find the resources they need to cope with their child with Down syndrome.

2.4 ADOLESCENCE

Adolescence can be a turbulent life stage. This turbulence is as a result of rapid changes in the physical, emotional and sexual self. According to Smith, Cowie and Blakes (2003:289) hormones have a direct effect on psychological as well as physical functioning.

All growth is linked to biological changes in the body. These changes are controlled by the hypothalamus, which controls the pituitary gland that produces hormones (Smith et al. 2003:283). On a physical level the development of the reproductive organs take place as a result of the release of hormones. There are changes such as the development of body hair, sweat glands that become more active as well as a deepening voice and breast development in girls. These changes are linked to the reproductive system but are not directly part of it. A growth spurt is experienced by both girls and boys during the adolescent phase.

Cognitively, adolescence is the stage when individuals reach the period of formal, operational thought (Smith et al. 2003:289). This stage marks the adolescent's

increasing ability to think about abstract issues and hypothetical situations. This ability brings its own pressures as the adolescent has to make decisions regarding e.g. career choice, who to vote for, learning to drive, whether to participate in activities such as underage smoking and drinking and how to spend their recreational time.

Activities such as spending recreation time with media products like cell phones and computers (see research by Larson & Verma in Smith et al. 2003:296) can play an important role in identity formation as these products are part of the so-called youth culture (Arnett in Smith et al. 2003:296). Most adolescents according to Smith et al. (2003:296) can spend as much as half of their waking hours in recreation. Adolescents also spend significantly more time than when younger socializing with their peers.

As adolescents become more independent they often tend to spend more time with their peers than with their families. Peers play a role in identity formation as well as being a source of emotional support for the adolescent. The relationship with peers can often differ from the relationship they have with their family. Smith et al. (2003:305) explained that in childhood the relationship with one's parents is often unilateral while in adolescence it develops into a mutually reciprocal relationship. Younnis in Smith et al. (2003:309) explained that although the relationship with parents in adolescence does become more mutually reciprocal than it was in childhood it is not on the same level as the mutually reciprocal relationship adolescents have with their peers.

When typically developing adolescents become more independent, Buckley and Sacks (2004) explained, it influences not only their lives but also the lives of their parents. Parents often have more time to themselves as they are no longer kept as busy with the everyday care of their child. Everyday care needs in adolescence include skills such as being able to maintain personal hygiene and the ability to dress appropriately. Many should also be able to make simple meals, handle money for their everyday needs and be able to stay alone at home, at least during the day.

It is clear that adolescence brings many challenges to each individual as there are many changes in physical, emotional and cognitive development to adapt to. The differences and similarities between individuals with Down syndrome and their typically developing peers will now be discussed.

2.5   ADOLESCENCE AND DOWN SYNDROME

How do adolescents with Down syndrome differ from their typically developing peers? Buckley and Sacks (2004) concluded that they differ in various ways although each adolescent has varying patterns of skills and may function on different developmental levels.

2.5.1   Physical development

Although all adolescents with Down syndrome, according to Buckley and Sacks (2002) experience delays in all areas of their development the extent of the delay is not the same across all areas. Therefore every individual with Down syndrome can make significant progress in most areas of their development.

Just as it does for typically developing adolescents, the onset of puberty for the adolescent with Down syndrome brings about bodily changes such as menstruation, wet dreams, increasing sexuality and issues surrounding contraception. Adolescents with Down syndrome also have a sexual drive, therefore contraception and sexually transmitted diseases need to be discussed with them. The complex issues surrounding parenthood also need to be worked through as it is possible for women with Down syndrome to fall pregnant. It is more difficult for men with Down syndrome to impregnate a woman due to their lower sperm count, but not impossible. These issues need to be dealt with by the adolescent as well as their families. It is clear that regarding sexual development there are more similarities with their typically developing peers than differences, however this is not as true for all of their physical development.

A diminished pubertal growth in comparison with their typically developing peers is experienced according to Pueschel (1996:91). Physically adolescents with Down syndrome are shorter than their typically developing peers by two standard deviations. Research by Cronk, Crocker, Pueschel, Shea, Zakai, Pickens and Reed (1988:102) has demonstrated this. A diminished growth pattern is experienced throughout the child's life, except during middle childhood where growth patterns appear to be similar to those of typically developing peers.

Many adolescents with Down syndrome gain a large amount of weight during adolescence. This gain may be due to the following factors according to Pueschl (1990); increased food intake, reduced activity level, and a decreased intracellular

metabolic rate. In some samples congenital heart disease played a role in weight gain in childhood but there was inconclusive evidence as to what role it played in weight gain during adolescence (Cronk et al. 1988:109). Adolescents with Down syndrome, especially when overweight, may develop skin infections in the peri-genital area, their buttocks and thighs. These skin infections may make the adolescent with Down syndrome self-conscious about their physical appearance.

Adolescence is a time when physical appearance can play an important role in being socially accepted. Individuals who do not have weight problems tend to be better socially accepted and may have a significantly improved self image in contrast with those with weight problems. If adolescents are significantly overweight they may not, according to Pueschel (1996:92) want to participate in physical and other recreational activities. Participation and exposure to experiences can enhance general development and assist in areas such as motor development where there may be delays.

Delays in motor development may slow progress in mastering self-help skills such as writing and the ability to use equipment such as kitchen appliances (Lorenz 1998:12). Motor developmental delays may have a subtle effect on social involvement as delays might hamper their ability to play games on the playground or board games where small pieces are involved. Although motor development may hinder participation in activities, it is in the area of language development that there is often significant difficulty experienced.

The area that experiences the most delay is speech and language development as well as learning from listening (Lorenz 1998:12).Working memory development is delayed relative to non-verbal abilities. Working memory is involved in thinking, problem-solving and reasoning.

Adolescents with Down syndrome have in common with their typically developing peers, changes in body image. Adolescents with Down syndrome have strengths in visual and spatial processing and while their weaknesses lie in auditory processing and motor skills. The similarities between typically developing adolescents and adolescents with Down syndrome include the need to be socially accepted by ones peers. In contrast many typically developing adolescents do not have the same medical needs that adolescents with Down syndrome have.

2.5.2 Medical implications

According to the Massachusetts General Hospital for Children's website there are a number of medical problems that adolescents with Down syndrome may have to cope with. Approximately 33% - 50% of adolescents with Down syndrome have congenital heart disease. Up to 25% of adolescents with Down syndrome could have instability of the upper cervical spine where it connects to the skull. There is an increased chance for leukemia, hypothyroidism and intestinal difficulties (celiac disease). Individuals with celiac disease are intolerant to the gluten in wheat, oats, barley and rye. This has implications for their dietary needs. Complex dietary needs may have an indirect impact on their social lives as they may be hindered by their dietary requirements to participate in typical activities such as going out to eat.

From the above it can be concluded that the possible medical needs of an adolescent with Down syndrome may have an impact on their physical well-being as well as their social development.

2.5.3 Social development

Adolescents with Down syndrome are unique individuals and all vary in their rates of development. There is however a common trend of strengths and weaknesses in all areas of their development, social development included, as explained by Buckley and Sacks (2002).

Social development, as already mentioned is seen as a relative strength (Buckley & Sacks 2002). Adolescents appear to enjoy learning from social interaction with adults as well as their peers. Age appropriate behaviour will develop if adolescents are able to interact with their peers and the appropriate social behaviour is encouraged and expected from them.

A difficulty adolescents with Down syndrome may experience that can have a negative impact on their social lives is the frequent inability to verbally express their feelings. Consequently their distress will, according to Buckley and Sacks (2002) be expressed in their behaviour. They may use their knowledge of human behaviour to their advantage by being uncooperative when they don't want to do something, negative behaviour may reduce the opportunities to be included by others in social activities.

The social development of adolescents with Down syndrome depend on a variety of psychological factors according to Pueschel (1996:94). It is stated by Buckley and Sacks (2002) that during adolescence it is important for adolescents with Down syndrome to receive support from their parents and teachers. Adolescence is the time when an understanding of what it means to have Down syndrome should be developed. Self-esteem, personal identity and other adjustments will have to be made to fit this understanding.

Aspects that need to be encouraged in the adolescent with Down syndrome are independence and the skills to exercise control over their lives. The presence or lack of a sense of competence and the ability to do things independently may also influence self-esteem.

Independence according to Pueschel (1996:94) is the ability to complete tasks without assistance and successfully separate emotionally from parents, family members and other caregivers. The ability to live unsupervised, work and be integrated with non-disabled peers can only take place if individuals with Down syndrome are given the same opportunities to learn as individuals without Down syndrome.

In a study by Buckley and Sacks' (2004) it was found that most adolescents were able to independently maintain their personal care and hygiene. These skills developed later in many cases than their typically developing peers. It was argued that this may not have been a reflection of their ability but what they were allowed to do by their parents e.g. washing their hair by themselves.

The adolescent phase is also difficult for parents according to Cuckle and Wilson (2002:69) as they have concerns regarding their children, especially in terms of their independence. These concerns include:

1. Being 'over-friendly' and indiscriminate in talking to strangers

2. Forming inappropriate relationships with members of the opposite sex

3. Personal and road safety including independent travel

4. The effects of lack of energy and stamina because of health problems

Independence is according to Glenn and Cunningham (2001:163) an area the individual with Down's syndrome support structures, such as family members will have to deal with as more individuals with Down syndrome become integrated into

'mainstream society'. Independence is just one of the challenges individuals with Down syndrome have to overcome.

Fackler (2005) highlights further difficulties that may emerge with adolescence. These include aspects such as maintaining good personal hygiene, sexual activities or being the victim of sexual abuse. There may also be psychological problems such as depression as the individual with Down syndrome tries to define his/her place in their communities.

According to Pueschel (1996:94) some adolescents with Down syndrome may experience obstacles in developing and maintaining a healthy self-esteem. These obstacles may be present as a result of various factors that can include frustration with their abilities, being discriminated against or pitied because of being seen by others as different. It can be challenging to adolescents with Down syndrome to define themselves because of the above mentioned factors.

When adolescents with Down syndrome are asked to give descriptions of them-selves, core attributes tend to be positively rated and peripheral attributes negatively. "Most individuals have positive views of self and negative comparisons only effect feelings of self-worth if they involve attributes important to the person" (Harter & Monsour in Glenn & Cunningham 2001:164). Part of development is to compare oneself to others and make relative assessments of one's competence. Adolescents, according to Glenn and Cunningham (2001:175), including adolescents with Down syndrome tend to attach their feelings of self-worth to their physical appearance and social acceptance above their academic achievements. The way in which we define ourselves can influence who we make friends with and why we do so.

The connotations adolescents with Down syndrome make to friendship were according to Cuckle and Wilson (2002:66), the discussion of experiences with one another and participating in group activities where emotional support was offered. A component of learning from others through role-play and skills training was added into the adolescents' definition. This definition of friendship differs somewhat from the one that typically developing peers give. According Smith et al. (2005:309) typical adolescent friendship is defined as a period where intimacy and commitment as well as discussion of opinions are important.

According to Pueschel (1996:93-94) the move from childhood to adulthood is not only meaningful for the individuals themselves but also for their families and even their community. Individuals with Down syndrome may find this transition particularly difficult. They may find it challenging to free themselves from the role of the child. This might be as a result of being inadequately equipped to deal with the responsibilities that being an adult brings.

Pueschel (1996:90) explained that most adolescents with Down syndrome will have the same physical characteristics as typically developing adolescents. They may however lack the cognitive and behavioural skills necessary to cope with their environment or their own need for independence. The National Down Syndrome Society (USA) had set out a timeline of activities from middle childhood to adulthood (22 years old) with what they regarded as the essential activities for successful transition. These activities included investigating one's interests and strengths in view of a future career. They also emphasized inclusion into community activities from an early age. The transition to independence has become one of the top priorities for individuals with developmental delays such as Down syndrome.

2.5.4   Behaviour

All adolescents, including those with Down's syndrome can, according to Lorenz (1998:63) at times present with inappropriate behaviour. The reasons for misbehaviour by adolescents with Down syndrome are similar to those displayed by their typically developing peers. These behaviours can include frustration with feelings of incompetence or feeling that one's needs are not being heard.

Certain behaviour is inappropriate at school whether it is a typically developing adolescent or one with Down syndrome who is exhibiting the behaviour. This inappropriate behaviour includes according to Lorenz (1998:63) actions that;

1. Cause harm to one's self or others

2. Upset or annoy others

3. Interfere with the learning of the child or classmates

4. Disrupt the smooth running of the organization

Adolescents with Down syndrome who have significantly difficult behaviour may cause stress for their teachers and families, reported Buckley (2006). Difficult

behaviour can also have a negative impact on the adolescent's learning and social opportunities. Adolescents who can behave in a socially acceptable manner are more likely to have friends, have more active social lives and more successful working lives. Behaviour does tend to improve with maturity and many of the inappropriate behaviours reported in early adolescence may be linked to general cognitive delays and immaturity.

In summary according to Pueschel (1996:90-95) the same variables have to be considered for adolescents with Down syndrome as for their typically developing peers. The variables include biological development, education, recreation and independence. Individuals with Down syndrome tend to have a different schooling experience from their typically developing peers. This difference is also affected by whether the learner has been included into a mainstream school or whether a special school is attended.

2.6   INCLUSION

A complex and dynamic relationship exists between the learner, the center of learning, the broader education system and the social, political and economic context of which we are all part. These components all play an important part in ensuring that effective learning and development takes place (Department of Education 2002:130). The responsibility of the education system to develop and sustain learning is based on the recognition that education is a fundamental right which extends equally to all learners. Exercising this responsibility involves ensuring that the education system creates equal opportunities for effective learning for all learners. The inclusion or exclusion from education was defined as a process rather than an event by Booth, Ainscow and Dyson (1997:337). Their differentiation is based on either increasing or decreasing the participation of learners in the curriculum, curricula and communities of local mainstream schools.

According to Booth et al. (1997:338) inclusive education concerns a group of students who could be excluded from mainstream education as a result of their special needs. Exclusion usually refers to those students who could be removed from the mainstream as a result of disciplinary procedures. The purpose of inclusive education is an attempt to reduce all exclusionary pressures and devaluations of students based on disability, race, gender, class, family structure, lifestyle or sexuality. Every school according to

Booth et al. (1997:338) has its own system of inclusion and exclusion through responding to the different needs of its students. This can include the way students are categorized, grouped or disciplined, how resources are used or how teaching and learning are organized to maintain students who need extra support as well as those who do not.

Swart (in Eloff & Ebersöhn 2004:231) defined inclusion as the practice and process of involving and meeting the diverse needs of all learners. Regardless of age, ability, socio-economic background, talent, gender, language, HIV status and cultural, classrooms and schools need to support them. In the process of accommodating diversity, the education system develops ways of making the same curriculum accessible to all learners. However there are still many negative attitudes to overcome before many schools adopt inclusion as a philosophy.

Negative and harmful attitudes towards differences in our society remain a critical barrier to learning and development (Department Education 2002:136). These attitudes often result in the labelling of learners. The most serious consequence of labelling is linked to placement and exclusion. Placement may be inappropriate to the learner's needs and might result in the learner being marginalized in the school context. Negative attitudes or pessimistic views about what individuals with disabilities are capable of, can undermine successful inclusion according to Gilmore, Campbell and Cuskelly (2003:65).

Teachers may experience concerns surrounding inclusion as they are the ones who have to successfully include the learner with the special need into their classrooms. Zollers, Ramanathan and Yu (1999:164) stated that within a democratic and empowering culture, teachers have the opportunity to contribute to the implementation of inclusion and will therefore invest in the complex process of making inclusion successful. The opportunity to contribute to the implementation process would assist in alleviating the teachers' concerns.

Villa and Thousand (2004) defined inclusion as a philosophy where diverse academic and social learning needs are supported by valuing, welcoming and empowering them. The goal of inclusion is still being pursued in the South African context.

2.6.1   Inclusion in the South African context

Inclusion in South Africa has been influenced not only by the world-wide shift in philosophy towards inclusion but also by our political past (Lomofsky & Lazarus 2001:303). Prior to the democratization of the country in 1994, the education departments were splintered and resources were unequally distributed. To rectify the inequalities of the past, South Africa's 1996 Constitution states that all learners have a right to education. The South African Schools Act (1996) supports this by legislating that all children, including those with special education needs must attend school from the year they turn seven until they are fifteen years of age or they have completed grade nine – whichever comes first. In addition the National Qualifications Framework (NQF) consists of eight qualification levels (Lomofsky & Lazarus 2001:304). A learner who has completed the compulsory schooling phase (grade one to nine) is awarded with a level one qualification as will adults who complete Adult Basic Education and Training. Further levels are awarded depending on the training institution and the years of study successfully completed. The purpose of the NQF was to end segregation between education and training. By integrating the education system, learners who because of disabilities or other barriers to their learning were excluded from mainstream education can now have their special education needs met.

Inclusion in the South African context is explained in the Education White Paper 6: Special needs education (2001) where the commitment is made to build an inclusive education and training system. This document accepts and acknowledges the diversity of needs learners have and aims to include and empower these learners, as well as those who have to educate them. Lomofsky and Lazarus (2001:308) differentiate between the policy developments on a national and an international level. On an international level the greatest influences on the inclusion movement were the *Universal Declaration of Human Rights*, the *United Nations Convention on the Rights of the Child*, the *Standard Rules of the Equalisation of Opportunities for Disabled Persons* and the *World Conference on 'Education for All by the year 2000'*. In South Africa the inclusion policy's values were additionally influenced by the *Report of the National Commission on Special Needs in education and Training* and the *National Committee for Education Support Services*. Government initiatives such as the *White Paper on Education and Training in a Democratic South Africa*, *The South African Schools Act* and the *Paper on an Integrated National Disability Strategy* all lead to

our current inclusive policy as laid out in the *White Paper 6: Building an Inclusive Education and Training System.*

Shifts in policy as outlined by White Paper 6 (Department of Education 2002:214) are to:

- *Systematically move away from using segregation according to categories of disabilities as an organizing principle for institutions;*

- *Base the provision of education for learners with disabilities on the intensity of support needed to overcome the debilitating impact of those disabilities;*

- *Place emphasis on supporting learners through full service schools that will have a bias towards particular disabilities, depending on need and support;*

- *Direct how the initial facilities will be set up and how the additional resources required will be accessed;*

- *Indicate how learners with disabilities will be identified, assessed and incorporated into special, full-service and ordinary schools in an incremental manner;*

- *Introduce strategies and interventions that will assist educators to cope with a diversity of learning and teaching needs to ensure that temporary learning difficulties are improved;*

- *Give direction for the Education Support System needed;*

- *Provide clear signals on how current special schools will serve identified disabled learners on site, and also serve as a resource to educators and schools in the area.*

The inclusion policy has meant the redefinition of special schools. According to White Paper 6 (Department of Education 2001:22-23) special schools will still be provided for those learners whose needs are too intense to be catered for by a mainstream school. However the role of most special schools will change. They will become resource centres for mainstream schools by providing expertise and support so that successful inclusion of learners at schools will take place. In addition schools and colleges will be established that are equipped and supported to provide for all the learning needs.

Statistics regarding the amount of adolescents with Down syndrome included in South African schools were not available at the time of completing this study. Through personal correspondence with Hanlie Swanepoel, Chairperson: Down Syndrome Association Pretoria/Tshwane, it appeared as if there were small numbers of adolescents included into mainstream high schools. According to her these placements were for the most part successful, although many parents chose to remove their children from the mainstream school in order to place them in a school of skills or other alternative once they had completed grade nine. It appeared as if most adolescents with Down syndrome do not continue with mainstream schooling once they have completed primary school. The parents of these learners have to find alternative placements for their children in the form of special schools or schools of skill.

2.6.2   Distinction between mainstreaming and inclusion

It is important to differentiate between inclusion and mainstreaming. Mainstreaming implies that a learner from a separate special education class visits the regular classroom for specific, usually non-academic, subjects. Inclusion is an educational process by which all students, including those with disabilities, are educated together for most of the school day. Integration is a term that is often used in conjunction with or as a synonym for mainstreaming. Swart et al. in Eloff and Ebersöhn (2004:236) described integration as a limited attempt to create access to mainstream schools. Integration is supporting diverse learning needs through additional inputs or facilities in essentially unchanged mainstream classrooms and schools.

Table 2.1: **Differences between inclusion and mainstreaming** (Department of Education 2001:17).

Inclusion	Mainstreaming
Differences are valued and similarities built on	Learners are required to adjust or adapt to a particular system
Support is provided to all learners, educators and the system as a whole	Learners receive additional support so that they are able to integrate
Minimizing and eliminating barriers to learning.	Changes in the learners needed to take place to enable them to fit into the system

2.7   INCLUSION AND DOWN SYNDROME

Cuckle and Wilson (2002:66) reported that there had been a steady increase of learners with Down syndrome into mainstream schools overall. However research by Lorenz (1998:14) indicated that there is a decrease in the numbers of children with Down syndrome included in mainstream schools the older the child becomes.

The principles of inclusion as applicable to individuals with Down syndrome are described by Swart and Pettipher in Landsberg, Kruger and Nel (2005:18) as a focus to acknowledging and respecting that all people can learn, that all people learn differently and have different learning needs that should be valued equally. Down Syndrome South Africa further defined an inclusive school as one that views differences as an ordinary part of human experience that are to be valued and organised for. All children benefit when all learners feel they belong and the education is sensitive and responsive to their individual differences.

Inclusion for children with Down syndrome has for Lorenz (1998:18) three purposes, these are:

1. *To foster learning by the provision of appropriate and challenging education programs.*

2. *To help establish age appropriate patterns of behaviour. Although just the presence of age appropriate behaviour does not guarantee that age appropriate behaviour will be modelled.*

3. *To encourage the development of meaningful relationships with peers, that will extend beyond the school day.*

In conjunction with Lorenz's findings research by Buckley (2006) has shown that if a learner with Down syndrome is included there is progress in a number of areas. These areas of progress include speech and language, literacy, communication, and behaviour. In the areas of socialization and daily living skills however there were no significant differences between being educated in an inclusive school or in a special needs school, according to Buckley's (2006) findings. Villa and Thousand (2005) reported evidence that learners who are included in mainstream schools have better employment success.

In a study done by Rynders, Johnson, R.T., Johnson, D.W. and Schmidt (1980) it was found that there were significantly more positive interactions and more interpersonal attraction between learners with Down syndrome and their typically developing peers when cooperation was developed in the classroom rather than a competitive and individualistic atmosphere. This may be difficult to achieve as there is an inclination for learners with Down syndrome to be treated differently, even when prejudice has disappeared.

The difficulties surrounding finding mainstream placement may be related to the existence of prejudice and the effects of ignorance which can not be ignored. Many parents will struggle to find a placement for their child especially when the child is ready to go to high school. Once placement has been found Rondal et al. (1996:215) stated that learners with Down syndrome may have to deal with stigmatization e.g. name calling. However being made to feel inferior by one's peers is not limited to learners with Down syndrome. Other learners who receive extra support also have to deal with the effects of labelling by their peers.

Other difficulties may hinder the individual with Down syndrome's scholastic progress, as reported by Down Syndrome South Africa (DSSA). Challenges may include visual and hearing impairment, delayed fine and gross motor skills, speech and language difficulties and a shorter concentration span. Other difficulties include poor auditory short term memory and auditory skills, impaired thinking and reasoning skills, difficulties with consolidation and retention and sequencing difficulties. It is possible to accommodate these needs in a mainstream classroom by limiting the

amount of verbal instructions, giving shorter instructions, using a variety of methods to teach a concept and giving the learner more time to process information and answer questions. A complete guide to accommodating learners can be found on the DSSA website.

As Rondal et al. (1996:208) explained, even though learners with Down syndrome may present the school with specific challenges they are not the only learners with special learning problems or needs. Schools can therefore no longer exclude learners with Down syndrome on the basis of their learning difficulties. This does not mean that the school will not have to examine its system of education and consider how best to integrate the learner with Down syndrome. Integrating and changing the school system is in most instances a difficult process as it requires the collaboration of the various systems such as the primary school and other support networks. Successful integration is reliant on a motivated teaching staff and headmaster who are willing to put in extra effort. This is also vital when considering a mainstream high school placement.

2.8   HIGH SCHOOL AND DOWN SYNDROME

It is argued by Buckley and Sacks (2002) that the biggest influence on any adolescent, including the adolescent with Down syndrome is their school experience. High school brings many changes and challenges for all learners as they adjust to a new school environment and the biological changes adolescence brings.

Mainstream high school may initially be as Lorenz (1998:74) reported a confusing place for adolescents with Down syndrome as there are new rules and ways of doing things that may be different from the ones they are used to. Tralli in Carrington and Elkins (2002) explained that the more traditional culture in a high school emphasizes subject content rather than student needs. The needs and accommodations for learners with special needs are therefore often not a priority amongst high school staff and administrators. Other challenges may include as Lorenz (1998:14) pointed out an increasingly complex curriculum, which is taught by a variety of teachers with their own style of teaching and a more challenging task differentiation. Being withdrawn from the class for focused teaching may become necessary. It is therefore important that the curriculum program of teaching and support is coordinated.

The withdrawal system was described by Carrington and Elkins (2002) as the more traditional model of support where learners who needed additional academic input were removed from the class by special education teachers. Some schools have part-time special classes for students with significant learning or adjustment problems and some schools have full-time special education classes. Using volunteer helpers, teacher aides and peer tutors are also ways of supporting students with special learning needs. Some schools use ability grouping in some subjects, particularly in mathematics. Other schools provide specialist teaching support for students and teachers in the regular classroom. Frequently, it is a combination of these types of programs that provide learning support for learners. This and factors such as social acceptance that the adolescent with Down syndrome has to contend with results in their parents having to be more involved and take more responsibility for their child's education than parents of typically developing adolescents.

The move to high school brings many changes reported Cuckle and Wilson (1997:66), not the least of these being the changes in social life as peer relationships become more important. The move to high school for an individual with Down syndrome can have a negative impact on their social lives. Socialization in mainstream primary schools is easier than it appears to be in high school. Lorenz (1998:15) explained that this happens as normally developing peers grow away from their class mates with Down syndrome and these learners become more isolated.

Typically developing learners reported Lorenz (1998:74) may not approach learners with Down syndrome especially if there is an adult minder nearby. They may also not want to get involved with the learner with Down syndrome because they fear being constantly relied on to support the learner with Down syndrome and that this will interfere with their own school work. It is important to have friendships with typically developing peers to learn age-appropriate behaviour and how to interact with people not in ones' immediate circle of support. Buckley and Sacks (2002) described the friendships with disabled peers as less fun orientated and mutually supportive to being more helping in nature.

Friendships with those experiencing the same or similar difficulties as oneself is also important as it shows that there are others who are facing similar challenges to one's own (Buckley & Sacks 2002). This is especially important as adolescents with Down syndrome may appear less mature than their peers and not be as independent from

their parents as other adolescents their age. Younger, mainstream friends are also not always appropriate as although emotional maturity and language skills may seem the same, interests may not be similar. Although mainstream peer relationships should still be encouraged adolescents with Down syndrome need the opportunity to have access to friends with similar needs, whose level of maturity and interests may be more evenly matched to their own (Cuckle & Wilson 2002:68). To have typically developing friends may help to make the transition from primary to high school easier as they may adjust quicker to the new environment with its new rules.

The context of the school needs to be understood as there are, as already mentioned a number of rules that learners have to learn. These rules have to be remembered over a long period of time and they are usually given verbally without the use of visual aids (Lorenz 1998:74). The ability to remember the rules is often a difficult task for learners with Down syndrome; typically developing learners sometimes exploit this inability. Lorenz (1998:64) reported that while learners with Down syndrome are often 'set-up' in schools as the butt of practical jokes, they are not often bullied. Being seen as the class clown is sometimes a successful way to get attention for learners with Down syndrome however it may also be that they have not been told that this behaviour is inappropriate.

Although children with Down syndrome are according to Lorenz (1998:39) unlikely to function on the same level of the curriculum as most of their peers, the education needs of an adolescent with Down syndrome stay the same whether they are in a special school or in the mainstream (Buckley & Sacks 2002). Individuals with Down syndrome's learning problems may be as a result of a different learning style rather than a learning barrier according to Wolpert (1996). Even though successful inclusion may take place the gap between what an adolescent with Down syndrome is able to accomplish and what his/her peers are able to do will increase with age.

2.9   REFLECTION

The literature review focused on areas such as Down syndrome, adolescence and what it means to be an adolescent with Down syndrome. A brief explanation and history of inclusion was given and ways in which learners with Down syndrome can be included into mainstream classrooms. Information regarding quality of life was also provided. From this is it can be seen that the child with Down syndrome has very specific

education needs. More research is needed according to Wishart (1998) on the difficulties experienced in the classroom. This research is necessary as the difficulties may not, as is presumed by many, be due to developmental delays but may be specific to Down syndrome. The goal of any school or family based research should be to expand the abilities they do have. It was also clear that children with Down syndrome can successfully be included into mainstream schools even in high school. The necessary support does need to be in place for inclusion to be successful and the attitude of the teacher may play an important role in the success of the inclusion effort.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

This study explored the experiences of an adolescent with Down syndrome in high school. The research was conducted by means of a qualitative case study. This chapter will address the context of the study, the research paradigms and the methods used to implement the study.

3.2 CONTEXT OF THIS STUDY

The participant is a 16 year old girl who attends a private school in a Cape Town suburb. The school caters for mainstream learners and has a special inclusion class (the school's term) for learners with special needs.

The school's vision is that learners from the inclusion class are supported by meeting and encouraging their educational, social and vocational training growth within the school. There are currently five adolescents with Down syndrome who attend the school. These learners are included to varying degrees in mainstream classes and activities. The mainstream classes that the learners from the inclusion class attend are; design technology, art, music, physical education and more formal learning areas where appropriate. The special inclusion classes follow a life-skills based curriculum that focuses on functional literacy, theme work, general knowledge, computer skills, art and craftwork as well as physical education. To meet the learning and skill needs of the learners a variety of role players are needed.

The special inclusion unit has a team that consists of the parents, home-based teachers, an occupational therapist, a learning support teacher, the school principal, members of the school board and members of the wider community. The collaboration of the parents is regarded as an important component to the success of each learner's participation and inclusion into the school.

An example of how the school makes use of the various role players is an active life-skills and vocational training program which is run by a former teacher of the inclusion class. This program consists of skills assessment, job-sampling, self-advocacy skills, relationship building, awareness of difference between work and leisure and community membership. The participant in the study is currently part of the program.

A discussion of the research design that was used to explore the experiences of one child in the inclusion class of the school will follow.

3.3   RESEARCH QUESTION

When a research problem has been identified there is a move from general interest in a subject area to a detailed statement of the research problem. The answers to the research problem can be found in the context of the research question (Freebody 2003; Merriam 1988).

In terms of this definition the research question, mentioned in chapter one can be formulated in the following way: How does an adolescent with Down syndrome experience high school?

3.4   RESEARCH AIMS

As discussed in chapter one, including learners with Down syndrome in mainstream schools in South Africa is an area that requires research attention. During my literature review I did not find much research done from a South African perspective. To gather information on this topic I corresponded with Hanlie Swanepoel, who is experienced in the field of including learners with Down syndrome into South African mainstream schools. As there was not much literature available from South African sources I investigated international sources.

In international literature, including adolescent learners with Down syndrome was not an area that had received much attention either. The focus appeared to be on the medical condition of the individual with Down syndrome. Literature on how the learning difficulties e.g. short term auditory memory affected individuals with Down syndrome however was available (the work of Lorenz, 1998 can be consulted in this regard).

The central aim of this study will be to explore the adolescent's experiences as a learner with Down syndrome who is mainstreamed into a private Western Cape high school.

The further aims of this study are to examine an adolescent with Down syndrome's experiences in high school in the context of:

- Peer relationships

- Experience of academic activities

- Experience of general school activities

- Experience of extra-mural activities

The above mentioned areas have been chosen in order to gain an understanding of an adolescent's experiences in high school. As there is a dearth in the literature regarding adolescents with Down syndrome this will add to the current knowledge base and can be further expanded on in future research studies.

3.5 RESEARCH DESIGN

Merriam (1988:124) stated that a research design is decided on through investigation of what type of end result is required. The research question also helps shape the problem under investigation and influences the design chosen. A research design should be a plan that sets out how the research question is going to be answered (Terre Blanche & Durrheim 1999:29).

According to Yin (1993:45) a good research design should meet certain requirements. These requirements are, to clearly state the question that is to be researched and how the chosen research method will answer the research question. The research method will also influence how the data will be gathered.

3.6 RESEARCH METHOD

Answers are sought in qualitative research by examining the settings in which people find themselves, the people to be found there and how they make sense of their settings (Berg 1998:8). As Merriam (1988:3) explained, it is assumed that meaning is to be found in how people experience their lives and these experiences are mediated through the researcher's own understanding of the world.

Merriam (1988:10) further defined qualitative research as:

1.   Holistic and inductive

2.   Natural settings are the data source

3.   Descriptive

4.   Reporting all valuable perspectives available

5.   Placing an emphasis on validity by regarding all settings and people as being worthy of study.

The goal of qualitative research is to describe and understand human behaviour before trying to explain and predict this behaviour (Babbie & Mouton 2001:53). When one works from this perspective the implication is that the world is made up of multiple realities. Experiences are subjective and can be interpreted but not measured. This is due to beliefs rather than facts forming the basis of perception (Merriam 1988:10).

In light of the above definition, a single, interpretative qualitative case study was decided on as the best method to meet the research aims, as it focuses on a single phenomenon. The underlying principle of interpretative research according to Terre Blanche and Durrheim (1999:70) is that researchers want to study individuals and groups as they go about their daily lives, rather than under artificially, created conditions. Social action is as Neumann (2000:148) explained action onto which people place subjective meaning.

Neumann (2000:148) further explained that the social world exists as and because people experience and give meaning to it. The social world is maintained by interacting with others in an ongoing process of communication and negotiation. Of interest to the researcher are the reasons that motivate actions. Social action can not be isolated from the context in which it takes place or the meanings given to it.

The interpretative researcher sees value and meaning infused everywhere and in everything. This leads to two levels of interpretation, the first one being the one constructed by the people who were involved in the action and what their reasons or motives were for their actions. The second level of interpretation is the researchers' discovery and reconstruction of the first level of interpretation. A case study consists of both levels of interpretation.

The following descriptions of a case study were considered when making a choice. Yin (1993:xi) stated that case studies are appropriate to use when topics are broadly defined, the study is to cover a phenomenon as well as contextual conditions and there are a number of sources of evidence to ask for their insights. Patton in Merriam (1988:68) explained "that depth and quality data can only be obtained by "getting close" physically and psychologically to the phenomenon under study". The researcher therefore takes a holistic view of the situation under study (Shaw in Merriam 1988:11). Merriam (1988:68) also stated that the uniqueness of the case study lies in the questions asked and the relationship between researcher and participant, more than in the methods used.

Case study knowledge can be compared to other methods as having the following characteristics according to Merriam (1988:15):

1. More concrete

2. More contextual

3. More developed by reader interpretation

4. Based more on reference populations determined by the reader

Case studies are not the full picture of a person's life, context they live in or all the aspects of their lives, but merely an in depth glimpse into one aspect of their lives (Merriam 1988:9).

3.7   PARTICIPANT

The selection of the participant for the study was through identifying a school that included learners with Down syndrome to some extent. After a school that mainstreamed learners from an inclusion class was identified and contacted, information was sent to the parents regarding the study. From the parents who responded a participant was selected at random. Once the participant had been identified and initial contact was made, interaction took place through telephonic conversations and e-mails. A face to face interview was arranged where the participant and her mother were interviewed. The participant in this study was a 16 year old girl who was in an inclusion class but mainstreamed for certain subject areas and activities. She met the criteria set out for the study.

These criteria are listed below:

- The person should be 13 years old or older

- Be included in a mainstream school at some level.

- Be able to express him/herself verbally

The setting for the interview was Stellenbosch University's Education department. The interviews took place in a room that is used by students at the Unit for Educational Psychology for therapy clients.

3.8   DATA PRODUCTION TECHNIQUES

3.8.1   The researcher as primary instrument of data production

Various authors give different perspectives on what the role of a researcher in a qualitative research is. I try to position myself with the following views.

Denzh in Merriam (1988:76) viewed the interviewer as the expert in asking the questions but the subject is the expert on his/her life and therefore on the answers he/she supplies. Walker (1980:176) in Merriam further defined the role of the researcher in a qualitative case study as "… constantly attempt[ing] to capture and portray the world as it appears to the people in it. What seems to be true is more important than what is true … the internal judgments made by those [the researcher] studies or who are close to the situation are more significant than the judgments of outsiders."

The qualitative researcher according to Merriam (1988:16-21) plays a key role in data collection and should therefore be sensitive to what effects the researcher has on interpretation, be interested in the subject's point of view and have a humanistic attitude towards participants. The researcher's role in a qualitative case study is to attempt to gather enough information systematically so that the researcher can understand how the subject under study functions (Merriam 1988:6). Hamel et al. in Berg (1993:212) summarized the definition by stating that a case study is not a data gathering technique but a collection of data gathering techniques that constitute a methodological approach.

Furthermore the qualitative researcher is interested in the participant's perspectives rather than the factual truth. This implies that it is the researcher's obligation to

present "a more or less honest rendering of how informants actually view themselves and their experiences" (Taylor & Bogdan in Merriam 1988:168). The researcher is more interested in trying to understand and describe the process than behavioural outcomes.

3.8.2 Interviews

In a case study, some and often all the information is gathered through interviews (Babbie & Mouton 2001:289). Kane (1985:63) recommended using any approach that brings across to the subject under study "the sense and meaning of what you want". Merriam (1988:72) stated that the best method for gathering information when doing a case study is by interview. However an interview is not a mere conversation, complexity and subjectivity is a natural part of interviewing.

To ensure that the interview was not a mere conversation an interview guide was compiled to ensure that all relevant topics were covered (Patton 1987:111). Interview guides allow the interviewer to adapt the wording and the sequence of the questions to the subject in the context of the actual interview.

As mentioned in chapter one the interview guide for this study was compiled by combining questions from the "Quality-of-Life" questionnaire (Cummins 1997:24; 2004:20) with the questions derived from the article; Educational Challenges Inclusion Study (Wolpert 1996). The areas covered by the questions were compared with those used in an interview conducted for a newspaper that interviewed an adolescent with Down syndrome (Ashworth 2002:16).

INTERVIEW GUIDE

Parents:

- **BIRTH AND DEVELOPMENT**

1. *When did you first find out that Sarah had Down syndrome? (While pregnant, immediately after birth, or much later?)*

2. *Did you know at the time what Down syndrome was?*

3. *How did the news that your daughter has Down syndrome affect your family? (nuclear and extended)*

4. *What type (if any) support structures were there in place? Did you find the support they offer meet your needs? Are there current support structures in your life that offer you support?*

5. *Can you tell me what type of challenges you have faced? (frustration with professionals, anxiety about the future, motional wellbeing of parents and marriage, social relations in family, lack of moral and social support)*

- **ADOLESCENCE**

1. *What has you experience been regarding Sarah's schooling?*

2. *Can you tell me more about your involvement with the school?*

3. *Tell me more about Sarah's adjustment to the school.*

4. *What (if any) behavioural changes have you noticed.*

5. *How successful do you think inclusion has been for your child, regarding:*

   - *academic gains*

   - *socialization*

   - *independence*

   - *language*

   - *self-esteem*

   - *development of friendships*

6. *Five word description of your child.*

7. *Can you tell me about some of your child's abilities and interests?*

8. *What are your hopes and dreams for your child?*

9. *What about your child makes you proud?*

10. *What do you see as indicators of quality-of-life? (emotional, social, spiritual and physical aspects)*

11. *How do you see Sarah's quality-of-life? What do you think could promote her quality of life?*

12. *What advice would you give to parents who are considering putting their child in mainstream education?*

Participant:

1. *Do you have friends at school? Can you tell me what you do together?*

2. *Do you have friends at home? Can you tell me what you do together?*

3. *Are your friends at home the same as at school or are they different?*

4. *Have you ever slept over at a friend's house? Has one of your friends ever slept over at your house? Is sleeping over something you'd like to do?*

5. *What schoolwork do you like doing the most? Can you tell me why?*

6. *What schoolwork don't you like? Can you tell me why?*

7. *What schoolwork do you find the easiest to do?*

8. *What schoolwork do you find the most difficult to do?*

9. *Where do you spend break times? What do you do at break?*

10. *Do you have assemblies? What happens there?*

11. *Does your school ever have school plays? Have you ever taken part?*

12. *Do you ever use the school library?*

13. *Do you play sport? What sport do you play? Where do you play?*

14. *What do you enjoy doing?*

15. *What would you like to do when you have finished school?*

16. *What was makes you sad / happy / angry at school/home?*

17. *Is there anything else about you, you would like me to know?*

Taylor and Bogdan in Merriam (1988:77) reported the following issues that need to be addressed before the start of any interview.

1. *The researcher's motives and intentions as well as the purpose of the research.*

2. *Participants' identities are protected by the use of pseudonyms.*

3. *The decision of who has the final say over what is included in the research document has been finalized.*

4.   Any issues of payment have been resolved.

5.   All logistics regarding the interview process have been sorted out.

3.8.3   Audio tapes

The accuracy of the interviews can be improved by the use of a tape recorder (Patton 1987:137). They also allow the researcher to pay close attention to the interviewee as his/her attention is not distracted by having to write down what is being said. This also aids the relationship between the interviewer and the subject as the interviewer can focus on the cues and needs of the subject. Tape recorders should be used judiciously so that they do not become interfering or inhibit social processes or participant responses (Patton 1987:96). The quality of the recorder should be checked before the interview as a poor recording may mean the loss of valuable data (Patton 1987:138).

3.8.4   Data analysis

Merriam (1988:123) described the process of data collection and analysis as recursive and dynamic. Data analysis in a qualitative case study is an ongoing activity but it becomes more intensive once all the data have been collected. The analysis of data includes the following aspects, organizing the findings, determining whether generalization is appropriate to the study and developing theory. Babbie and Mouton (2001:493-494) maintained that a research study depends on the interest and perspective the researcher has on the gathered information. The researcher decides on whether a piece of information becomes data.

Multiple data collecting techniques which allow researchers to compare and contrast interpretations, investigate and develop unexpected findings and allow for findings that contradict what one was expecting to find are recommended (Freebody 2003; Terre Blanche & Durrheim 1999). Triangulating data enhances the validity thereof and can be used in conjunction with multiple data collecting techniques to thicken the data.

Triangulation is according to Babbie and Mouton (2001:275-276) the most effective way to extract the various and differing constructions of reality that exist within the context of a study. This is accomplished by collecting information about different events and relationships from different points of view. In this study, data was gathered

from the participant, her mother and Hanlie Swanepoel through recorded correspondence and interviews.

In this study the recorded findings were transcribed. The transcribed data was coded in order to identify themes. Content analysis was the method chosen to analyze the themes. Coding occurs when themes are identified in the text and identified by using highlighters to colour text, physically cut text out or using computer software (Terre Blanche & Durrheim 1999:143). While coding, data is broken down into meaningful pieces in order for it to be clustered together and labelled. Open coding was used to identify themes (Neumann 2000:406); codes in the form of abbreviations were assigned to the emerging themes. The themes were placed in a table; on the left hand side was the transcribed interview and on the right hand side the codes (see annexure two).

3.9   RELIABILITY AND VALIDITY

3.9.1   Validity

Objectivity and thoroughness are important in determining validity. Lincoln and Guba in Merriam (1988:168) stated that the ability to evaluate the validity of a study is reliant upon the researcher demonstrating that the various understandings of the phenomenon in its context have been sufficiently represented.

According to Merriam (1988:69) thoroughness in a qualitative research study comes from the researcher's presence as well as the nature of the interaction between the researcher and the participants. The triangulation of data, the interpretation of perceptions and rich, thick description are used.

3.9.2   Internal validity

Qualitative case studies tend to have high internal validity (Merriam 1988:168). According to Merriam (1988:166-170) one achieves internal validity by specifying the units of analysis, developing rival theories and analyzing already published work to test one's own theories.

Merriam (1988:166-170) stated that qualitative case study data can be generalized when the following aspects receive attention; providing a thick, rich description, establishing the typicality of a case and doing a cross case analysis. Merriam's (1988:169) strategies to ensure internal validity, include triangulation, member checks

and peer examinations. It is important that internal validity is assessed in terms of interpreting the researcher's experience, rather than in terms of reality itself.

To achieve internal validity in this study I plan to use the strategy of triangulation by consulting the participant's mother and Hanlie Swanepoel.

3.9.3 External validity

Terre Blanche and Durrheim (1999:313) stated that external validity is when findings from studies can be generalized "beyond the confines of the design and study setting".

As this study is a single interpretative case study the generalizability of the findings will not be high.

3.9.4 Reliability

Merriam (1988:170) defined reliability as the extent to which one's findings can be replicated. The phenomenon studied in fields such as education and psychology are assumed to be dynamic and to have impacting factors that are forever changing. It is therefore impossible to achieve reliability as it is understood in other fields. The emphasis in a qualitative case study is as Walker in Merriam (1988:172) stated on "collecting definitions and the presentation of material in a form where it is open to multiple interpretations". The above is true for this study as each individual involved has his/her own understanding of their context.

3.10 ETHICAL ISSUES

3.10.1 Ethics

In order to prevent possible ethical dilemmas the researcher should set up an ethical framework in which to work.

An ethical framework should consist of the following aspects (Fraser et al. 2005:98):

1.   Principles of respect and justice

2.   Rights-based research

3.   Best-outcomes ethics

Relevant to this study is the understanding that children have views and motives that the researcher can not take for granted. Therefore as Fraser (2005:104) stated, an

ethical researcher who does research with children needs sensitive methods for discovering children's own views and the meaning they attribute to their experiences.

The above mentioned are included in the ethical considerations I needed to take into account before doing this study. My main concern was receiving informed consent from my participant. This was of particular importance as she has Down syndrome, which limits intellectual functioning. In order to achieve this I used Stellenbosch University's letters of consent to achieve consent from the parents and an adapted version to achieve consent from the participant. The participant and her parents received information regarding the purpose of the study before they were given the opportunity to consent to the research.

3.10.2 Consent

Deschenes and Vogel in Berg (2005:42) defined active consent as the "formal written permission by an informed parent or legal guardian that allows the child to participate in the research project". Berg (2005:47) further defined informed consent by stating that it is; *"knowing consent of individuals to participate as an exercise of their choice, free from any element of fraud, deceit, duress or similar unfair inducement or manipulation. In the case of minors or mentally impaired individuals whose exercise of choice is legally governed, consent must be obtained from the person legally authorized to represent the interests of the individual".*

In order to obtain informed consent Fraser (2005:50) recommended that one must always explain in full; the purpose, process and intended outcomes of the proposed research. When doing research with children a high level of understanding is needed by them before valid consent can be obtained. This could potentially exclude doing research with children. Therefore the full understanding and consent is required by the parent/guardian. It is especially important when working with children that explanations are clear and understandable.

3.10.3 Confidentiality

Berg (1989:79) defined confidentiality as purposefully removing from the research records any information that might indicate the participants' identity. When information is disclosed it should according to Fraser (2005:50) only be done in such a way that the identity of those involved will be protected.

3.11 REFLECTION

The research design and methodology were discussed in this chapter. This study was conducted within a qualitative research framework. It took the form of a qualitative case study with the aim of exploring an adolescent's experiences within a mainstream high school. Data was generated through semi-structured interviews. Developing themes and codes reduced the data. Issues of validity, reliability and ethics were also addressed. The implementation of the study will be discussed in chapter 4.

CHAPTER 4

IMPLEMENTATION OF THE STUDY

4.1 INTRODUCTION

This chapter will place the study in context and sketch the background of the case in terms of a description of the participant, the participant's mother, the setting and the procedure leading up to the interviews and the interviews themselves. Lastly the themes that emerged from the interview are identified.

4.2 THE PARTICPANT

4.2.1 Identifying a participant

The selection of the participant for the study was through identifying a school that included learners with Down syndrome. After a school that mainstreamed learners with Down syndrome was identified and contacted, information was sent to the parents regarding the study. From the parents who responded a participant was randomly selected. Once the participant had been identified and initial contact made, interaction took place through telephonic conversations and e-mails. The participant met the criteria for inclusion in the study as she was over thirteen years old, verbal and mainstreamed into a high school. To facilitate reporting, I will use the pseudonym 'Sarah' to refer to the participant. Pseudonyms for her mother and sister are 'Bronwyn' and 'Jane' respectively.

4.2.2 Preparation for the interview

After the participants had been identified I sent them information regarding the purpose of my study, the larger project that I was involved in, the ethical as well as the consent forms. To ensure that Sarah was included, information regarding my study and a consent form were sent to her. These were simplified in order for her to understand them. Her mother did inform me that Sarah could on occasion become reserved and sometimes found it difficult to speak to strangers. In order to overcome this potential problem I compiled a pamphlet for Sarah in which it was explained who

I was and why she was coming to speak to me. A photo of my-self and the room in which the interview was to take place were included. I e-mailed the pamphlet to her a few days before the interview. In case Sarah was reserved in the interview set up I prepared documents with faces indicating different emotions, yes/no flash cards and adapted some of the Quality-of-Life answer sheets (see annexure three). The purpose of these was that she could point to the appropriate answer if she was not comfortable with giving verbal responses. Closer to the interview date the interview guide was sent to Sarah and Bronwyn so that they could read through the questions and have time to comment on any questions they were not comfortable with. Bronwyn kindly offered to come to Stellenbosch University so that I could interview her and Sarah. The interviews took place in the Education Department in a room that is used by students from the Unit of Educational Psychology for therapy.

4.2.3   Background information on the participant

The participant was a sixteen-year-old, English speaking girl with Down syndrome. The family composition is nuclear and they live in a Northern suburb of Cape Town. The family is originally from Pretoria, they moved to Cape Town when Sarah started pre-school. Sarah has an older sister, Jane, who is in her first year of tertiary education. Bronwyn reported that Sarah and her older sister generally have a good relationship. Jane has played an important role in Sarah's life as protector and mentor. According to her mother, Sarah idolizes her father and they spend much time together, for example Sarah supports him when he plays water-polo. Extended family members have played an important role in Sarah's development and have been a source of support to the family. The family has recently lost members of this support group due to illness and age.

Sarah attends a private school in one of the wealthy Southern suburbs. She commutes to school in a daily lift club. The school that Sarah attends is a private Roman Catholic school that has a special inclusion unit that caters for learners with special needs, up to the age of nineteen. The Unit is on the same grounds but, physically removed from the rest of the school. There are two classes in the Unit that have been divided into a junior and a senior section. Altogether there are eleven learners in the unit. Sarah is currently a member of the senior class. It is planned that she will remain at the school until she is nineteen years of age. The learners from the inclusion class join the mainstream classes for subjects such as art and technology. They also attend

school assemblies every Monday and Chapel on Fridays with the rest of the school. In other activities such as sport there are separate categories for the learners from the inclusion class. Should they wish to do so, learners from the inclusion class may participate in (sport) activities with the mainstream learners, as Sarah has done.

4.2.4   Impressions of the participant

Sarah arrived at the University with her mother, Bronwyn. She was dressed in a fashionable outfit, her long hair worn loose and wearing glasses. Sarah is shorter than average and quite slim. It later emerged that dressing well is something that is important to her. Jane assists her to choose clothes that will suit her. An overall impression of well-being was made.

Sarah greeted me with a handshake and appeared at ease. In the room where the interview was to take place Sarah and her mother chose their seats, leaving me to sit in between them. The room we sat in was supplied with a sand tray and activities, such as drawing should Sarah want to use these materials. It was decided that I would interview Bronwyn first so that Sarah had time to settle into the new surroundings.

During her mother's interview Sarah occasionally stood up to adjust her clothing and she went over to investigate the sand tray once. The micro-cassette recorder was of great interest to her. She inspected it and the micro-cassettes periodically throughout the interview. About midway through the interview with her mother I asked her to watch the micro-cassette recorder for me as I was concerned that the tape would finish without my noticing. She willingly took the recorder and held it up for us throughout the rest of the interview. Occasionally her mother would ask for confirmation of a fact or request information from Sarah, this she gave without hesitation.

It appeared from their interactions with one another that there is a good relationship between mother and daughter. Sarah showed signs of "typical teenage behaviour". For example when her mother made a remark about the soap opera Sarah watches, Sarah gave an exaggerated sigh and said "mom". Bronwyn allowed Sarah to answer the questions by herself and only on two occasions did she attempt to draw more information from Sarah.

4.2.5   Interviewing the participant

The questions I asked Sarah were divided into three topics namely; friendships, school and certain aspects about her self. There were a total of seventeen questions. I

adapted some of the questions from the information I had from the interview with her mother. When I interviewed Sarah it appeared as though she gave her full attention to what was being asked. She was able to answer all the questions verbally. When she needed to, she asked that I repeat the question. Most of her answers were given in short sentences or one word answers. It seemed as if Sarah was relatively relaxed in the interview situation.

4.2.6   Interviewing the participant's mother

In order to get a comprehensive understanding of Sarah's development and school life I interviewed Sarah's mother. She answered the questions as set out in the interview guide and verbally completed an anamnesis questionnaire. The interview guide consisted of seventeen questions which investigated birth, development, adolescence and schooling. Sarah's mother gave thick, rich descriptions for the questions asked of her. She radiated a positive attitude towards Sarah and laughed frequently. When she spoke about the recent loss of her mother due to illness, she began to cry, Sarah also had tears in her eyes. Bronwyn was able to continue with the interview after a short period in which she collected herself. The interview with Bronwyn was characterized by an easy-flowing dialogue interspersed with many anecdotal examples.

4.3   DATA ANALYSIS

The analysis of data includes; organizing the findings, determining whether generalization is appropriate to the study and developing theory. Babbie and Mouton (2001:493-494) maintained that a research study depends on the interest and perspective the researcher has on the gathered information. The researcher decides whether a piece of information becomes data.

In this study the material was recorded onto audio tapes. The records were transcribed and coded in order to identify themes. Content analysis (Neumann 2000:406) was the method chosen to analyze the gathered data. Open coding was used to locate themes; codes in the form of abbreviations were assigned to the emerging themes. The data was placed in a table; on the left hand side was the transcribed interview and on the right hand side the codes.

An excerpt from the analysis is included here, a more complete analysis can be found in annexure two. Here **PA** stands for parents' attitude, **WELBE/PHYS** is physical

wellbeing and **EFFFAM** is the effect of having a child with Down syndrome on the family.

Table 4.1:   Data analysis

What are your hopes and dreams for your child? I'm hoping that she will be able to live an <u>independent life</u> from my husband and I. We … they are working on something at the moment, the parents of the children who have finished. They are buying a home where they can come home to live and go out to work. They have actually got a house like that in at the moment called the Vineyards up in Constantia. <u>They've got a house mom and everyday these children or young adults go out to work. So one of the parents are now looking into buying a place and obviously we'd all come in. So I'm hoping she'd be able to do that or something like that because I'm not going to be around for ever and I don't feel that it'll be fair on my eldest daughter if she's left with the burden and responsibility although I have no doubt that if something happened she'd gladly take over.</u>	**PA** **WELBE/PHYS** **EFFFAM**
Participant: **Do you have friends at school? Can you tell me what you do together?** *Ja…what was the question again?* **What type of things do you do with your friends at break time?** *Um <u>we have break, we play cricket...</u>***Do you like batting or bowling more?** *<u>Batting.</u>* **I must attempt I can never hit that ball. Do they have a special place for you to play?** Ja. …………… **So are your friends a little bit important to you or lots important to you?** *<u>Lots</u>* …………… **What schoolwork do you like doing the most? Can you tell me why?** *<u>Maths…um it's my favourite</u>.* **What schoolwork don't you like? Can you tell me why?** *<u>Spelling...it's difficult</u>* **What schoolwork do you find the easiest to do?** *<u>Languages</u>* **What schoolwork do you find the most difficult to do?**	**INT** **FRISHIP** **SCH**

4.4   EMERGING THEMES

From the interview the following themes emerged:

Table 4.2:   Themes identified from interviews

THEMES THAT EMERGED AS BACKGROUND INFORMATION	
Support:	▪ Absence of ▪ Present ▪ Individuals who were meant to provide support but had a negative impact ▪ Networking
Parent's outlook on having a child with Down syndrome:	▪ Positive attitude ▪ Treating her no differently than their other child ▪ Not settling for what was available ▪ Learning from their child ▪ Creating and giving opportunities
Influence of having a child with Down syndrome	▪ May be stressful on the family and can make or break a marriage ▪ Impact on the sibling
Society's views	▪ Old –fashioned views ▪ Accepting
Themes that emerged dealing with adolescence and schooling	
Schooling	▪ Positive attitude from all three schools ▪ Attended schools that had experience with inclusion ▪ Influence of principals' attitudes ▪ Teachers ▪ Other learners
Adolescence	▪ Concerns ▪ Behaviour ▪ Independence
Future dreams	▪ To be independent ▪ To work
Themes that emerged in the interview with Sarah	
Academics	▪ Attitude towards
Recreation	▪ Various activities; shopping, movies, sport
Friends	▪ Mainly from class at school ▪ Personality clash with classmate
Future	▪ Plans to work at a hair salon or as a messenger
The school	▪ Playground rules ▪ Participation

Each theme will be elaborated on and the sub-sections for each will be discussed as they emerged from the interview.

4.4.1 Themes that emerged from the interview with the participant's mother

Support: The role support plays in the first months and years of the child being born has a significant role on the emotional well-being of the parents. The impact of having support structures was mentioned frequently until Sarah started to go to school. Initially there was a lack of support from the Down syndrome association due to Bronwyn's understanding of their contact policy. The policy at the time according to Bronwyn was that the association would not contact the parents with a newborn baby with Down syndrome but wait until the parents were ready to connect with them. The role of the association in their lives changed as the family became increasingly involved with it. The intense involvement with the association ended when the family moved from Pretoria to Cape Town. Bronwyn mentioned her gratitude towards the association for supplying her with relevant information regarding Down syndrome.

The information that was available to Bronwyn at the time of Sarah's birth was, in her terms, 'archaic'. Not only was the literature that was available out-of-date but the information that individuals gave her too, was outdated. Bronwyn stated that before she had more relevant information, the support her family offered her was of critical importance to her emotional well-being.

Positive sources of support came from family members. This support was mostly in the form of time and emotional support. Examples were the time her mother and father-in-law especially, spent with Bronwyn and Sarah, whether it was taking them to doctors and therapists or sitting with them at home.

Different sources of support emerged when Bronwyn started to network with other mothers who had children with Down syndrome. This support network dispelled Bronwyn's feelings of isolation. It also provided resources in the form of therapists and materials to stimulate Sarah's development.

A source of support that had a negative impact on the family was a genetic counsellor that came to speak to the family. The genetic counsellor held the view that children with Down syndrome should be placed in a home or institution. Bronwyn and her husband were opposed to this view and found her visit to their home upsetting.

Bronwyn stated that what you need when you hear you have a child with Down syndrome is "*support and positive people around you to build you up*".

The Parent's outlook on having a child with Down syndrome:

Bronwyn mentioned on three different occasions during the interview that having a positive attitude towards Sarah and her abilities had a constructive effect on Sarah's development. In addition to her positive attitude Bronwyn reported that she did not accept the information that was initially given to her regarding Down syndrome. She became involved in the South African Down Syndrome Association (DSSA) which provided her with more relevant information. Being able to network with other parents also proved to be a valuable source of information and advice regarding the potential of a child with Down syndrome.

A central belief Bronwyn holds is that Sarah is to be treated just the same as her typically developing child. Her view of Sarah is that she is "*a normal child, same as all of us*". She stated that it was important for her to be involved with Jane's schooling as much as she was with Sarah's. The ability to give Sarah the opportunities to learn and develop was a theme that Bronwyn emphasized throughout the interview. She stated that "*I always feel you won't know what their potential is unless you give them the chance*". As a member of the family Sarah is able to contribute to the family's knowledge. She has learnt skills at school namely sign language and beading. These are unique skills within her family and she is encouraged by them to teach them these skills. It was emphasized that Sarah was to be brought up as a member of their family and to be included in all of their activities.

The effect on the family: Having a child with a disability does place stress on the family reported Bronwyn. She stated that she had observed during the time that she worked at the DSSA how the birth of a child with a disability could "make or break" a marriage. She also had concerns about the possible influence having a child with a disability could have on the other siblings. Bronwyn did experience some feelings of guilt as she felt that Jane did not have a carefree childhood. This was due to the time that was spent taking Sarah to various therapists and doctors. However having a sibling with a disability did not, according to her, have a negative effect on Jane, Sarah's older sister.

Society's views on Down syndrome: From the moment the family found out that Sarah had Down syndrome they have had to listen and interact with members of society who have various opinions on Down syndrome. The information that

Bronwyn initially received in the form of literature and others' opinions regarding the abilities of individuals with Down syndrome was, in her words 'archaic'. It was only when Bronwyn joined a support group for mothers with children with Down syndrome and the DSSA that she was exposed to more relevant material. Having the opportunity to interact with other parents played an important role in shaping her views about children with Down syndrome and their capabilities. It gave her encouragement and a feeling of belonging as she was with others who were going through a similar experience to her own. The positive attitude that the support group offered was very important to her.

In the broader society there are still mixed reactions to Sarah. Bronwyn stated that she thinks that she is more sensitive to people staring at Sarah or not knowing how to react to her than Sarah is. The impression her description of the family gave is that Down syndrome is discussed openly. Bronwyn mentioned examples of her husband and elder daughter reacting to other people's insensitive actions by going up to them and offering to explain to them what Down syndrome is, whether they wanted the information or not. Fortunately Sarah has been met with positive attitudes at the schools she has attended.

Schooling: Sarah's initial school experience was in a Montessori school in Pretoria. The school was run by a friend of the family. Bronwyn reported that Sarah was happy during her time at this school.

When the family moved to Cape Town they heard that a large mainstream primary school had accepted a boy with Down syndrome who was a year or two older than Sarah. They moved into the suburb the school was located in so that they would be in the school's feeder area. The school accepted Sarah in pre-primary and she continued there until the end of her grade five year.

During her time at the primary school her class friends supported her by assisting her with homework and making sure that she was not left out of classroom activities. Her scholastic progress was assisted by a facilitator that the school hired. The school facilitator came three times a week and removed all the learners in Sarah's class who needed extra learning support for an hour. Towards the end of grade five Sarah began experiencing a great deal of frustration. This frustration according to Bronwyn was as a result of the faster development and progress her peers were making when

compared to her. As a result of Sarah's frustration and unhappiness it was decided that she should leave a fulltime mainstream placement.

Sarah's high school was chosen based on its already existing special inclusion unit. The learner with Down syndrome that had preceded them at the primary school was already at this school. This learner's successful placement encouraged them to place Sarah into this school. As already explained, the school has a special inclusion unit that consists of two classes namely a junior and a senior class. These classes have fulltime special education teachers and classroom aides. Sarah is a member of the senior class. In addition the school has involved members of the community and past teaching staff to teach the learners skills and assist them in finding employment once they leave the school.

Sarah's high school experience has also been one of acceptance. Although Sarah is in an inclusion class she is mainstreamed into some of the school activities and classes. Bronwyn reported that the teachers and children in the mainstream school were very accepting of her and the other learners from the inclusion class. Active attempts were made to include Sarah and the other children from the inclusion class as much as possible in school activities. On a social level however Sarah interacts only with the children from the inclusion class and with other children with disabilities.

The schools that Sarah has attended have all had positive attitudes towards her. Bronwyn reported accepting and welcoming attitudes from the teachers and principles. In the primary school where Sarah was completely included, her classmates were very accepting of her and she was part of a group of friends from her class. These friends were concerned with Sarah's well-being and assisted her with her homework. Bronwyn initially had concerns about the other parents' attitudes towards Sarah but she found that these were for the most part accepting.

At all three schools that Sarah has attended, Bronwyn had only positive experiences with regards to the schools' attitudes towards Sarah. This positive attitude she attributes to the principals whose welcoming and accepting attitudes filtered through to Sarah's teachers and the other learners. Bronwyn reported that not only did she encounter positive attitudes at the school but that the schools showed a willingness to support Sarah in ways beyond that expected of them.

Regarding Sarah's academic progress, the school follows a policy of having an Individual Education Plan (IEP) for each learner. The IEP sets out the individual goals that each learner has to achieve in the year. This is reviewed every year in November. According to Bronwyn, Sarah is achieving her academic goals with more ease than many of the other learners in her class, because she is more intelligent than some of them. Bronwyn stated that she has observed how Sarah's participation in mainstream classes such as technology and art has motivated her to work harder and to stretch herself in these subjects. This level of inclusion does not frustrate her as the classes are not academically based so it is easier for her to stay closer to the mainstream learners' achievement level.

The future: The future dreams that Bronwyn has for Sarah are that she will live an independent and fulfilled life. This implies living in a house she should regard as home with a housemother and other independent individuals with Down syndrome. Having a job was also mentioned as important. Bronwyn sees Sarah's strong fingers as an asset she can use in her future career. The possibility of washing people's hair at a hairdresser was mentioned, another alternative was to work as a messenger. These possibilities will be explored closer to the time that Sarah has to leave school. Bronwyn stated that should Sarah find a romantic partner and want to get married then she could, however she did not support her having children.

Adolescence: 'A typical teenager' is the way Bronwyn described Sarah's behaviour. The most significant behaviour that was mentioned throughout Sarah's development was the frustration and subsequent aggression displayed towards her family at the end of Sarah's grade five year. This ended as soon as she started to attend her current school. Bronwyn stated that as Sarah was her second child she was more relaxed in dealing with difficult behaviour. She also stated that Sarah presented with very few behavioural difficulties except for her stubbornness. All other behaviour was viewed as what one would expect from a typically developing teenager attempting to become independent.

Sarah's attempts at independence include her trying to be authoritative. This consists of her trying to assert her authority over her mother, which Bronwyn does not allow. Sarah has also attempted to force her will over a younger boy who also has Down syndrome who is in a lift club with Sarah. It has been explained to Sarah that her

behaviour is unacceptable if it hurts the feelings of others. Consequently Sarah has developed an imaginary friend who she can control.

Bronwyn's main concern when Sarah was approaching adolescence was not her behaviour but the start of her menstrual cycle. The cause of her concern was as a result of a discussion with another mother who had a daughter with Down syndrome. The consulted mother found this stage to be extremely stressful for herself, her daughter and the rest of the family. However Bronwyn's concerns proved to be unfounded as the move to this new phase of Sarah's development was smooth.

As adolescence is a period when there is a striving towards independence, Sarah has also expressed her desire to become more independent. There is a measure of independence granted to Sarah by her family. Other than waking Sarah up in the mornings Bronwyn does not need to assist her in getting ready for school, this includes Sarah making her own sandwiches and caring for herself of hygienically. Sarah also packs her own suitcase when the family goes away together on holiday.

With regards to recreation and independence, Sarah and her friends are always under parental supervision when they go to watch movies together or take part in an activity such as ten pin bowling. Although Sarah does not visit shops completely alone she is allowed to make purchases for the family by herself when instructed to do so e.g. when going to the local Seven-Eleven, Sarah's family will wait in the car while she makes the purchases for them. Safety has a significant impact on Sarah's ability to be independent and Bronwyn reported that many of the precautions she takes with Sarah she also took with her other daughter.

Quality-of-life: Bronwyn felt that Sarah had a high quality of life in the areas of her physical, social and spiritual well-being. It was in the area of Sarah's emotional well-being that she felt there was room for development. Her rationale is that Sarah still needs to learn how to fend for herself if she is going to lead a successful independent life. She felt that it was important that Sarah learn how to successfully handle other people's possible negative perceptions of her.

4.4.2   Themes that emerged from the interview with Sarah

Recreation: Sarah enjoys a variety of recreational activities. These include singing and dancing. She loves to listen to CDs of which she has a variety and she enjoys singing along with them. Her other interests include watching DVDs and going to the

movies. Her favourite movies at the moment are teenage romances. Sarah also enjoys going shopping especially for clothes.

Sarah plays a variety of sport, she mentioned cricket as her favourite sport where she enjoys batting more than bowling. On Fridays they play cricket at school. She is also a very good swimmer and has competed in the school swimming gala with the mainstream learners and not in the category for the inclusion class learners. In her last race she came third. Sarah also enjoys playing hide-and-seek with her friends at school.

Her friendship group has changed with the move from primary school to high school. In primary school she made friends with her typically developing peers. She no longer sees them on a social level although they greet one another if they see one another in the shops. She is currently friends with the other members of her class and other children with disabilities. Every second weekend there is a social where the members of the inclusion class get together and watch a movie, go ten-pin bowling or have a party. On the playground Sarah and the other members of her class, when they are not playing cricket or hide-and-seek, sit together and talk. They have a place on the playground that they enjoy sitting in and try to sit there most breaks.

With regards to her relationships with others, Sarah has had a personality clash with another member of her class. This girl is leaving at the end of the year as she will have turned nineteen. Sarah expressed her relief that this girl will no longer be a member of her class. Her other relationships were noted as being trouble free.

School: Sarah's favourite activity at school is going to Chapel. Every Friday the entire school goes Chapel, here they pray, sing and receive blessing.

The subject at school that Sarah enjoys is mathematics, "*because it is her favourite*". She dislikes reading and has a number of ways to get out of having to do her reading homework e.g. brings the assignment but not the book it is based on home. Sarah's least favourite subject at school is spelling. She said "*it was fine*" to join in with the other children for art and technology.

Future plans: Sarah's future plans include becoming someone who works at a hairdresser. This interests her as she enjoys making people pretty.

4.4.3 Information gathered from the anamnesis form

The anamnesis form provided additional information not gathered in the interview. This included further details concerning Sarah's development and family interactions.

Table 4.3: Themes identified from anamnesis form

Development	▪ Motoric ▪ Speech and language ▪ Medical difficulties
Personality	▪ Emotional characteristics ▪ Description of
Relationships	▪ Friends ▪ Discipline ▪ Family
Recreation	▪ Family activities
Schooling	▪ Adjustment

The identified themes above will be discussed in more detail.

Bronwyn reported that Sarah would have reached all her motoric developmental milestones within the normal limits had it not been for the operation done to correct her club left foot. She was however able to sit within the normal time limit. Bronwyn attributes this to the physiotherapist working with Sarah. Sarah wears glasses as she does not have good vision. No problems were identified with her hearing. With regards to her language and speech development, Sarah developed within the normal limits. Bronwyn mentioned that Sarah's good language development was due to her own interactions with her. She also reported that Sarah received speech therapy at the local university from eight months of age until she was three years old.

Early in Sarah's development she experienced many medical difficulties. These included a hole in her heart, epileptic fits, a left club foot and a displaced right foot. Sarah under went operations to correct the hole in her heart and the problems with her feet. She took medication for her epileptic fits but no longer does as she outgrew the fits.

Even though Sarah's early development had many medical difficulties Bronwyn did not report any further difficulties other than normal childhood illness such as chicken pox throughout the rest of her development. She mentioned that Sarah has a high pain threshold and does not complain when she is in pain, so it is difficult to know when something is physically wrong with her. In 2006 Sarah started to take medication for

an under-active thyroid. Bronwyn reported fewer mood swings and significant weight loss since she has been on the medication.

The following description of Sarah's emotional characteristics were given; an average self-confidence, reasonable independence and that she cries easily especially when her father shouts at her (which is not often) and she hates to upset people. Her personality was further described as being shy, independent, obedient, exceptionally tidy, quiet, loving, cheerful, humorous, responsible, self-controlled, sympathetic, helpful and honest. She also enjoys socializing and her friends are important to her. She prefers to spend time with friends rather than to be on her own. In terms of Sarah's relationships with the other members of her family she has a good relationship with her nuclear and extended family members. She had a special relationship with her late maternal grandmother. Her maternal grandmother and her grandfathers on both sides of the family, although specifically her paternal grandfather played an important role in her upbringing. A less satisfactory relationship with her paternal grandmother was reported. Her play is also imaginative and as mentioned earlier she has an imaginary friend who appears to assist her to overcome potential behavioural difficulties.

No behaviour problems were mentioned and according to Bronwyn, Sarah accepts discipline well from herself and her husband. The forms of discipline they use are talking to her and taking away privileges, especially watching television.

The family enjoys walking on the beach together. As Sarah does not like walking for long distances she and her sister will meet their parents at a designated meeting place for a picnic or shorter walk. The family also enjoys playing various board games together. Sarah will frequently go with her father to support him when he plays water-polo. She also accompanies her mother to watch her play squash.

Additional information regarding Sarah's schooling is that she adjusted reasonably well to her new school environments. Except for the end of grade five Sarah has had a positive attitude towards school and her teachers.

4.5 ADDITIONAL SUPPORT

Table 4.4

School	▪ Successful inclusion ▪ Attitudes of teachers
Recreation	▪ Age appropriate interests

Additional support regarding the themes that emerged from the interviews was provided through correspondence with Hanlie Swanepoel Chairperson Down syndrome Association Pretoria/Tshwane. Her opinion is that for inclusion to be successful, children with disabilities such as Down syndrome should be included in a mainstream school from the start of their school careers. This early inclusion makes the high school inclusion experience easier. Her opinion on providing a facilitator is that they are often not necessary. It is her experience that if the teachers are sufficiently prepared for including a learner with a disability then a facilitator is not needed. It is also her opinion that teachers will accept a child with a disability sometimes more readily than they will a child who presents as a challenge to discipline and respect.

Further support was provided by a newspaper article (Ashworth, Eastern Daily Press, 1 June 2002:16) where a learner with Down syndrome was included into mainstream high school in England. This article confirmed that learners with Down syndrome can be successfully included into mainstream high schools. The interviewed learner had a facilitator to assist her on a part-time basis. Her friends were mainly from the mainstream classes. She also made friends with learners from her private extra-mural activities such as drama class. It was also clear from the interview that age appropriate recreational activities were enjoyed such as listening to popular music.

4.6 SUMMARY

The interviews revealed data that correlated with the literature. The most important themes were, according to the participant's mother the support she and her daughter had received especially during the early childhood years. She also emphasized the importance (to her) of treating Sarah as a member of their family who is just like the other members who needs assistance with certain areas of her life. She maintained

that treating Sarah as a unique individual in terms of her schooling needs had contributed to her successful school experience.

The interview with Sarah revealed typical teenage interests in friends, music and sport. Just like many typically developing adolescents she also has plans for the future.

In conclusion, the interviews painted a success story, where a family had accepted the limitations that a child with Down syndrome has. These limitations have however not stopped them from having dreams for their child or the belief in her potential.

4.7   REFLECTION

This chapter contained the implementation of the interviews conducted for this study. The process leading up to the interviews was also described. My meeting with the participants of the study is given as well as the contents of the interview session.

This chapter therefore serves to explain the interview experience. The contents of the interviews were given before the themes that emerged were discussed. Producing and analyzing data was an exciting and challenging task. The validity and reliability of the data was addressed through triangulation. The themes that I arrived at were confirmed by sending a copy to the participants for verification. These findings, as well as the limitations of the study, recommendations and reflections will be discussed in Chapter 5.

CHAPTER 5

DISCUSSION OF FINDINGS, LIMITATIONS, RECOMMENDATIONS AND REFLECTIONS

5.1   INTRODUCTION

The main focus of this chapter is a discussion of the findings from the interviews with the study's participants. This chapter starts with a brief summary of the previous chapters. A discussion of the findings will follow. The last section of this chapter will centre on the limitations of this study, recommendations for further study and reflecting remarks.

5.2   SUMMARY OF CHAPTERS 1, 2, 3 AND 4

Chapter one contained a brief description of the personal motivation for and the relevance of this study. The research problem, research aims, theoretical approach of the study, the research design and methodology as well as the structure of the presentation was also included. The aim of this study was to investigate the high school experience of an adolescent learner with Down syndrome through an interpretative case study. The following issues were investigated; peer relationships, experience of academic activities, general school activities and extra-mural activities.

The literature on Down syndrome, adolescence and associated topics was discussed in chapter 2. The theoretical approach that informed this study was based on promoting quality of life. Quality of life issues include the physical, spiritual, social, emotional, intellectual and occupational according to Simmons (2007). These are some of the aspects that were explored through the interviews with the participant and her mother.

The research design and methodology were discussed in Chapter 3. The type of case study that was chosen was a qualitative interpretative case study. This was seen as the best method to collect data as it focuses on a single phenomenon. Data was collected by means of interviews with the participant and her mother, as well as an anamnesis

form that was completed by the mother. Supporting data was gathered through personal correspondence with Hanlie Swanepoel – Director of the Down syndrome South Africa. Themes from the gathered data were coded through the process of open coding.

The findings from the interviews were reported on in Chapter 4. These findings will be interpreted and discussed in the following section.

5.3   SUMMARY OF DATA

The produced data covered the following areas – early development, adolescence and schooling. Numerous sub-themes such as support, parent's attitudes towards having a child with Down syndrome, the influence of having a child with Down syndrome on the rest of the family and society's views on Down syndrome emerged. Sarah's school experiences, adolescence and sub-themes such as behaviour and the future were also discussed. In the interviews held with Sarah the questions fell within three categories namely school, friends and her self. From these, sub-themes such as recreation, academics and the future came forward.

The relevant themes will be discussed further in the section below and linked with the literature.

5.4   ANALYSIS OF INTERVIEW CONTENT

This research was done via a single, interpretative qualitative case study as it focused on a single phenomenon. The underlying principle of interpretative research according to Terre Blanche and Durrheim (1999:70) is to study individuals as they go about their daily lives, rather than under artificially, created conditions. The themes that emerged will now be discussed.

Wishart (1998) suggested that if proper attention is paid to diet and lifestyle then children with Down syndrome should lead healthy childhoods. This appears to be true for Sarah. Although she experienced medical difficulties as a young child, the rest of her development has been healthy. Her medical difficulties were those often associated with children with Down syndrome namely epilepsy and heart problems (Wishart 1998). Sarah has however outgrown the epileptic fits. Her heart problem was corrected when she was three and a half years old. Sarah also wears glasses as she

does not have good vision, which is also typical of individuals with Down syndrome (Down Syndrome South Africa).

With regards to Sarah's physical development it seemed as if other than her early medical challenges, she was able to meet all her developmental milestones within the normal time limits. Sexuality is a topic that many adolescents explore as their bodies physically change (Smith et al. 2003:281). As Sarah currently an adolescent this is an area that had to be explored as she has had to adapt to her changing body.

Although there appears to be some contradiction in the research as to whether individuals with Down syndrome reach a developmental plateau in adolescence or not (Dykens in Chadwick et al. 2005; Lorenz 1998) Bronwyn is of the opinion that Sarah has reached such a plateau with regards to her intellectual development. It appeared that the transition into adolescence was smooth.

Sarah does, as many other adolescents do, spend a significant amount of time with friends as well as media products *("I watch DVD's").* This according to Smith et al. (2003:296) reported is typical of the adolescent phase. It appears as if Sarah has other age-appropriate interests (Buckley & Sacks 2002). These interests include watching DVD's (mostly teenage romances), listening to music, going to the movies and spending time with her friends. The majority of her friends are children in her age group who also experience some form of disability. Having friends who experience barriers similar to one's own is important as they provide a source of support according to Cuckle and Wilson (2002:68). Sarah reported her friends as being very important to her ("*Talk to my friends")* and just as with a typically developing adolescent the time that she wants to spend with them can lead to disputes. "*There's actually one [a social] tomorrow night that's causing a major bug-bear in our household*". Sarah reported that she found it easy to make friends especially when new children joined their class. Although Sarah has boys as friends she has not taken the step of having a boyfriend. She enjoys shopping with her older sister for clothes as she has an interest in wearing fashionable clothes and "*looking pretty."*

During adolescence physical appearance often becomes important (Pueschel 1990) and Sarah appears to have strong interest in her appearance. Pueschel (1996:92) reported that many teenagers with Down syndrome gain significant amounts of weight due to a variety of factors. As of 2006 she has been taking medication for an

under-active thyroid. Bronwyn reported that since Sarah has been taking medication and following a healthier lifestyle program she has lost weight. The weight loss had a positive impact on her self-esteem as she feels more confident in her clothes and wants to wear fashionable clothing. According to Bronwyn the medication not only reduced Sarah's weight but also the amount of mood swings she experienced. Although mood swings can be seen as a normal part of development if not handled appropriately they may have negative impact on behaviour.

Although Dykens et al. (2002:484) reported that individuals with Down syndrome are at a higher risk than the general population for behavioural difficulties, this has up to this point not been Bronwyn's experience with Sarah. She describes Sarah's current behaviour as that of a typical teenager, not very different from her other daughter's behaviour as a teenager. From the description given of Sarah's family and how she is included and supported as a member of the family, it appears as if the balance and support that Pueschel (1990) reported was necessary for appropriate behaviour had been achieved. This appeared true with regards to most of her social behaviour.

Although Sarah has many well-developed social skills it appeared as if certain of Sarah's social skills do, as MacDonald (2006) found in his research need to be practiced. Inappropriate behaviour, for example her domineering behaviour towards another child with Down syndrome has had to be actively discouraged by explaining to her why her behaviour is inappropriate. Bronwyn's reported manner of dealing with inappropriate behaviour appears to be in line with Buckley and Sacks (2002) suggestion that inappropriate behaviour should be dealt with firmly.

As already mentioned, social skills are seen as a relative strength in individuals with Down syndrome (Lorenz 1998:61). It appears as if Sarah possesses the skills to respond appropriately to social situations and people's emotions. This was seen during the interview in her reactions to information her mother was sharing and her own expression of emotion e.g. her sadness at her grandmother's passing. Sarah is able to respond with empathy towards others, her mother reported that Sarah showed concern when her sister was ill. Empathy is a skill that individuals with Down syndrome usually have report Buckley and Sacks (2002).

Even though Bronwyn's mother emphasized Sarah's uniqueness, she also stated that Sarah has the same emotional needs as individuals without Down syndrome. Her view

is supported by Wishart's (1998) statement that individuals with Down syndrome have the same emotional needs as typically developed individuals.

Sarah's personality was described as shy, independent, obedient, exceptionally tidy, quiet, loving, cheerful, humorous, responsible, self-controlled, sympathetic, helpful, stubborn and honest. As can be seen this description is wider than the stereotypical description of individuals with Down syndrome as happy, affectionate, musical, good mimics, with a well developed sense of fun (Wishart 1998; Chen 2007). It appears as though Sarah's personality has made it easier for her to adjust to the school environment.

Sarah has had to adapt to different school environments, from being a member of a mainstream class to her current placement in a special class. As the research has shown there is a decrease in learners in mainstream high-schools (Lorenz 1998:14). Sarah herself is an example of a learner with Down syndrome leaving the mainstream schooling system. In primary school Sarah was withdrawn from class three times a week to spend an hour with other learners with learning difficulties. This system of being withdrawn was described by Carrington and Elkins (2002) as a method of dealing with learners who experienced learning difficulties.

Her parent's reason for removing her from the inclusive placement was as a result of their perception that she was unable to keep up with her peers academically and socially. Research by Lorenz (1998:14) has found that as children become older there is an ever widening gap between what individuals with Down syndrome can do versus those who don't have Down syndrome.

According to Bronwyn, Sarah's inclusion met Lorenz's (1998:18) three purposes for including learners with Down syndrome into mainstream schools, while she was in primary school. The purposes were that scholastic learning was encouraged, age appropriate patterns of behaviour were learnt and (up until grade five) she built meaningful relationships with her mainstream peers.

It was Sarah's experience that she found it easier to make friends with the mainstream children in primary school than in high school. This correlates with research done by Lorenz (1998:15) who found that primary school relationships were made and sustained better than in high school. Her friendships in primary school were also described as being more helping and less fun orientated which is what Buckley and

Sacks (2002) found in their research. "*I mean they actually had fights about who was going to help her, I mean some of these kids went home and even made workbooks for [Sarah] out of their own, you know, it was absolutely beautiful to see and they'd give her stars and well-done [Sarah] and you know mark her work*".

It appears as if Sarah has not had to deal with stigmatization and prejudice at school as reported by Rondal et al. (1996:215). At all three schools she attended she has been welcomed and accepted according to her mother. This acceptance and welcome was according to Bronwyn as a result of the attitude the headmasters and teachers at the school had towards inclusion. The attitudes of the other parents towards Sarah and the family's involvement in the school were also reported as positive.

Lorenz (1998:68) reported the importance of parental involvement in the child with Down syndrome's education. Bronwyn reported that she was very involved in the primary school that Sarah attended but not on an academic basis. She trusted that the teachers and facilitators knew what Sarah needed to know. *"... with regards to me telling her [the teacher] what I think Sarah needs to do I left that entirely up to her, I mean she's got the training, she's got the knowledge, she needs to tell me where she needs my help. And it's the same now Sarah purely brings home what the teachers tell her what to do ..."*

Since Sarah has been in high school Bronwyn's involvement with the school has decreased. The reasons that she gave were that they live further away from the school and since Sarah is older there is less of a need for her to be intensely involved in the school. She supports the school by going to their fêtes and assisting them if they need someone to transport the learners.

Although Sarah has experienced successful school placements her learning needs are still significant. Individuals with Down syndrome experience various barriers to learning. These include, amongst others, difficulties with short term memory and expressive language. Wishart (1998) postulated that some of the learning difficulties that individuals with Down syndrome experience may not have so much to do with their abilities but with an unmet learning style. If Sarah's grade five experiences, where she was in a mainstream classroom, are examined it can be speculated that some of her frustration may have been due to her learning needs not being adequately met. In grade five when the class work got too complicated for her she was given

worksheets to complete and was not involved in the work in any other way. "*So every time they would progress onto something new she couldn't cope with they would put a worksheet under her nose and the poor thing got so tired of those worksheets*".

The other alternative to the above-mentioned argument is as with most children with Down syndrome Sarah has intellectual delays. She, as many children with Down syndrome who have been included before her, saw how her friends and peers started progressing much faster than she was able to. The jump in progress speed and ability of her typically developing peers (Lorenz 1998:5) was experienced by Sarah when she was in grade five, when the average class age is eleven. This resulted in a great deal of frustration (according to her mother) being experienced as Sarah saw her friends able to do things that she was unable to do. It was at this stage that her parents decided to remove her from a fulltime inclusion placement and place her in her current situation of being mainstreamed. The change in placement had a positive effect on her frustration levels. Bronwyn reported Sarah as being much happier at her current school. This positive change in her behaviour her mother attributes to her being in a class where she is on the same ability level as her peers.

As can be seen in Sarah's case, children with Down syndrome experience various barriers to learning and development and it is important to be realistic about the barriers that they experience (Wishart 1998). It appeared as if Bronwyn was realistic about the future goals that Sarah could achieve e.g. working at a hairdresser washing people's hair or as a messenger. It is important to Bronwyn that Sarah will have a job that she will be good at and enjoy. She was also aware of the areas that may hinder Sarah in her work such as her difficulties with her short term memory. "*... she can work in a hair dresser, wash and shampoo people's hair and give them a massage when she puts the conditioner in. But the only thing is the concentration is very short so we'll have to work on that one".*

Sarah's limitations have not prevented her from continuing to develop and learn new skills. This is demonstrated in her improved performance in the art and technology class "*... it's definitely a motivation because she's pretty bright in comparison with her class and so she's the king-pin in her class and doesn't think she has to try any harder but when she goes in with other children and she sees what they are achieving it encourages her to try harder".* Sarah's efforts to improve her performance and her ability to do so correlate with Wishart's (1998) view; individuals with Down

syndrome have the potential to develop their skills and abilities further. Although they have the ability to further develop their skills there are still difficulties to overcome, which need support.

Children with Down syndrome are not the only ones in need of support as the news that one has a child with a disability can be very distressing in Bronwyn's opinion. The importance of support to the family is significant. Buckley and Sacks (2002) explained that having a support structure can make it easier for families to cope. Bronwyn reported that her family and extended family were initially an important source of support. Later on in Sarah's development, networking with other mothers who had children with disabilities also made the issues surrounding having a child with Down syndrome easier to deal with; "*I met all these other ladies who had Down syndrome children and I just saw crikey it's not as bad as we thought …*"

From the above it can be seen that having a child with a disability does affect the family unit, as amongst other issues the child's future has to be provided for on a practical level. This can place stress on siblings who may feel that they have to take responsibility for their disabled sibling when their parents are no longer able to do so. "*… any child that is born with a disability, it is very stressful on the family and that can either make or break the marriage*". It is apparent that from the time the child with Down syndrome is born one has to deal with a different dynamic than with a typically developing child.

Bronwyn reported that it was very important to her that Sarah was included and treated as a member of their family. The family was described by her as one that enjoys participating in sport, going to the gym and living a generally healthy lifestyle. Sarah is included in this healthy lifestyle as she plays cricket, swims and occasionally goes to the gym with her mother. They also enjoy doing activities together such as playing board games and going to the beach.

It does not appear that having a child with Down syndrome has had a negative influence on the family's recreational activities or time that they spend together. This attitude of togetherness correlates with the description by Wilks and Wilks (1974) of including a child with Down syndrome into the family. Bronwyn emphasized that Sarah has unique characteristics and problems just as they all have. "*… so there's a little bit of a wobbly here and there but you correct it and carry on. You have a*

wobbly with normal children anyway. Just give them good grounding and obviously lots and lots of love".

Independence is an important issue for Bronwyn "… *I always feel you won't know what their potential is unless you give them the chance*". She reported that is important that Sarah is able to take care of herself. In order for Sarah to develop the skills necessary for independence she is given opportunities to practice these skills. An example of an opportunity to practice these skills is when the family goes away together on holiday Sarah is responsible for packing her own suitcase. Sarah is also able to maintain her personal hygiene and everyday needs such as making her lunch sandwiches. These abilities correlate with Buckley and Sack's (2004) research findings show that adolescents with Down syndrome were able to maintain personal care and hygiene.

Bronwyn and her husband are taking steps to ensure that Sarah has a degree of independence in the future. Their future vision for Sarah is that she will live in a group home with other individuals with Down syndrome and a house mother. From here Sarah will be able to get to work. In order to reach this goal they are investigating buying into a group home where individuals with Down syndrome will live. The reasoning behind this goal is that Bronwyn and her husband will not always be around to help Sarah and they do not want to place the responsibility of looking after her on their other daughter. *"I'm not going to be around for ever and I don't feel that it'll be fair on my eldest daughter if she's left with the burden and responsibility ... But you also want to provide, you know".* Although Bronwyn has concerns regarding Sarah's future, she is taking an active role in ensuring that her daughter will be well provided for. The parent's attitude of providing opportunities for Sarah to develop independence correlates with Pueschel's (1996:94) that independence will develop if the individual with Down syndrome has a chance to do so.

As mentioned in chapter 2, quality of life issues are subjective perceptions of health (Testa & Simonson 1996). Bronwyn's perceptions of Sarah's quality of life were that her spiritual, physical and social well-being needs were met. Her emotional, occupational, independence and romantic partner needs had a lower perceived level than the other needs. Her mother expressed concerns regarding whether the mentioned needs would be met in the future. These concerns correlated with Wishart's (1998) explanation that it is often difficult for individuals with Down syndrome to have

satisfying careers, which in turn can have a negative effect on their emotional wellbeing. Although she is concerned about Sarah's need for a career, Bronwyn is hoping that they will not be an issue. This is because Sarah is involved in a program at the school that tries to place individuals with Down syndrome into jobs.

Bronwyn summarised the experience of having a child with Down syndrome as the following;

"*Look when you're pregnant with a child and you have all these dreams for that child and when you don't know during your pregnancy that your child has Down's syndrome and you only find out at birth. Don't shelve those dreams, don't change them because there is a problem, pursue those dreams and you'll be amazed at what you can achieve. I didn't for once think that I was going to change anything and I think that's why she has achieved what she has.*"

5.5   SUMMARY OF ANALYSED DATA

The processed data revealed that in many ways Sarah is not only a typical adolescent with Down syndrome but also a typical adolescent.

As a young child she had many of the medical difficulties such as an under-active thyroid and epileptic fits, reported in the literature. Most of her earlier difficulties she has outgrown or they have been surgically corrected.

Sarah's schooling experiences have been relatively easy. Her parents did not have to fight to have her accepted into the school of their choice, but were fortunate to meet headmasters at mainstream schools who were willing to include their daughter. Sarah's academic progress is not the main focus of her attending a mainstream school, although her mother claims that she has learnt many skills. Her parents wanted to see what she could learn but also to encourage her to socialize with her typically developing peers, especially at the primary school level.

Hanlie Swanepoel provided corroborative evidence with regards to successful school placements. She also emphasized the important role the attitude of the headmaster and teachers can have on the success or failure of an inclusive placement.

Currently Sarah's group of friends consists mainly of other individuals who experience disabilities of some sort. There appeared to be satisfaction with her current group of friends and Bronwyn did not express concerns with Sarah's ability to interact

with others. She felt that the interaction that Sarah had with typically developing individuals such as her sister and family friends would equip her with enough skills to interact successfully on her own.

Sarah's parents appear to want her to have as much independence as she is able to. They are looking into the future and are considering investing in a group home that Sarah will one day be able to call home. It appeared as if it is important for the family that Sarah has gainful employment especially if she can work in a field that she is skilled in and enjoys.

Sarah herself appeared to be a typical teenager in many ways. She had age appropriate interests in recreational activities such as visiting with her friends, listening to music and watching movies. She did not seem to place much emphasis on school, although she did mention that there are subjects such as spelling that she does not enjoy. She appeared to be happy and satisfied with her school experience. There did not appear to be any areas where dissatisfaction was experienced.

There were many correlations between the processed data and the literature. Of especial interest to me was the development of friendships with mainstream peers, or the lack there of. Also of interest was Sarah's grade five mainstream classroom experience and the questions it raised as to whether she was frustrated because her learning needs were not being met or because she saw her classmates progressing at a much faster rate than she was.

5.6   LIMITATIONS OF THE STUDY

The limitations of this study were the following:

- Only one case was used, this has a significant impact on the external validity and generalizability of the findings.

- I would have liked to have interviewed Sarah's father to find out what his perspective was on Sarah and her schooling experiences.

- My inexperience of interviewing an individual with Down syndrome left me wondering how much more I could have probed for answers.

- A visit to the school would have helped get an understanding of the practicalities surrounding the inclusion class and their participation in other school activities.

- I also wondered whether other information regarding the same issues would have come to light had I had more time to spend with the participants.

5.7   RECOMMENDATIONS

- Further research into what teaching methods are best suited for learners with Down syndrome. This would help to determine whether better teaching methods would mean learners with Down syndrome would stay in mainstream schools longer.

- The way in which South African schools include learners with Down syndrome is also an area that can receive attention.

- More research can be done by comparing friendships between learners who are partly mainstreamed and those who are completely mainstreamed to investigate the nature of these relationships.

5.8   REFLECTION

On completion of the study I realized the value of taking each individual child on their own merit and basing decisions on what will be best for that child. Sarah is in so many ways just like the rest of us but at the same time her needs should not be ignored. It was a positive experience to hear that there are successful placements and trying to include your child does not have to be a difficult or stressful process. I am still concerned about learners not having their academic needs meet and as a result they leave mainstream placements in which they could have stayed. Therefore I feel continued research in this area is necessary.

5.9   PERSONAL REFLECTION OF PROCESS

My experiences of the research process were positive and I enjoyed networking with parents and teachers. I definitely felt the lack of experience throughout the research process. This research project was completed in a short amount of time due to practical considerations but if it had been possible I would have wanted to get to know my participants and their context better.

REFERENCES

Ashworth, H. (1 June 2002) How much do we know of Down's? *Eastern Daily Press.* p. 16.

Babbie, E. & Mouton, J. (2001) **The Practice of Social Research.** Oxford: Oxford University Press.

Berg, B.L. (1998) **Qualitative Research Methods for the Social Sciences** (3rd Edition). Boston Massachusetts: Allyn and Bacon.

Booth, T.; Ainscow, M. & Dyson, A. (1997) Understanding inclusion and exclusion in the English competitive education system. *International journal of inclusive education,* 1(4):337-355.

Brown, R.I. & Brown, I (2005) The application of quality of life. *Journal of Intellectual Disability Research,* 49(10):718-726.

Buckley, S. & Sacks, B. (2002) An overview of the development of teenagers with Down Syndrome (11-16 years): Issues and Information. www.down-syndrome.org/information/development/adolescent

Buckley, S. & Sacks, B. (2004) From adolescence to adulthood. Portsmouth Down syndrome's trust news. Vol 6. The Down Syndrome Educational Trust. www.down.syndrome.org

Buckley, S. (2006) A comparison of mainstream and special education for teenagers with Down syndrome: Implications for parents and teachers. *Down Syndrome Research and Practice,* 9(3):54-67.

Carrington, S. & Elkins, J. (2002) Comparison of a traditional and an inclusive secondary school culture. *International Journal of Inclusive Education,* 6(1):1-16.

Chadwick, O.; Cuddy, M.; Kusel, Y. & Taylor, E. (2005) Handicaps and the development of skills between childhood and early adolescence in young people with severe intellectual disabilities. *Journal of Intellectual Disability Research,* 49(12):877-888.

Chen, H. (2007) Down syndrome. University of Nebraska: medical center. www.emedicine.com/ped/topic615.htm

Cronk, C.; Crocker, A.C.; Pueschel, S.M.; Shea, A.M.; Zakai, E.; Pickens, G. & Reed, R.B. (1988) Growth charts for children with Down syndrome: 1 month to 18 years of age. *Pediatrics,* 81(1):102-110.

Cuckle, P. & Wilson, J. (2002) Social relationships and friendships among young people with Down's syndrome in secondary schools. *British Journal of Special Education,* 29(2):66-71.

Cummins, R.A. & Lau, A.L.D (2004) **Personal Wellbeing Index** (2nd Edition). Intellectual Disability Manual (English). Melbourne: School of Psychology, Deakin University.

Cummins, R.A. (1997) **Comprehensive Quality of life scale - Intellectual/cognitive disability (ComQol-I5): Manual.** Melbourne: School of Psychology, Deakin University.

Department of Education. (2001) Education White Paper 6: Special needs education. Pretoria: Government Printers.

Department of Education. (2002) Draft conceptualization and operational guidelines for the implementation of inclusive education (2nd draft). Directorate: Inclusive education. Pretoria: Government Printers.

Donald, D.; Lazarus, S. & Lolwana, P. (2002) **Educational Psychology in Social Context** (2nd Edition). Cape Town: Oxford Press.

Dykens, E.M.; Shah, B.; Sagun, J.; Beck, T. & King, B.H. (2002) Maladaptive behaviour in children and adolescents with Down' syndrome. *Journal of Intellectual Disability Research,* 46(20):484-492.

Fackler, A. (2005) Social problems and vulnerabilities related to Down syndrome. Healthwise inc. www.yahoo.com/ency/healthwises/ue5372

Fraser, S.; Lewis, V.; Ding, S.; Kellet, M. & Robinson, C. (2004) **Doing Research with Children and Young People.** London: SAGE Publications.

Freebody, P. (2003) **Qualitative Research in Education.** London: SAGE Publications.

Gilmore, L.; Campbell, J. & Cuskelly, M. (2003) Developmental expectations, personality stereotypes and attitudes towards inclusive education: Community and teacher views of Down syndrome. *International Journal of Disability, Development and Education,* 50(1):65-76.

Glenn, S. & Cunningham, C. (2001) Evaluation of self by young people with Down syndrome. *International Journal of Disability, Development and Education,* 48(2):163-177.

Kane, E. (1985) **Doing Your Own Research: How To Do Basic Research in the Social Sciences and Humanities.** London & New York: Marion Boyars Publishers Ltd.

Landsberg, E.; Kruger, D. & Nel, N. (2005) **Addressing Barriers to Learning: A South African Perspective**. Pretoria: Van Schaik Publishers.

Le Grange, L. & Newmark, R. (2002) A civil society partnership in special education in a changing South Africa. *International Journal of Special Education,* 17(1):85-90.

Lomofsky, L. & Lazarus, S. (2001) South Africa: First steps in the development of an inclusive education system. *Cambridge Journal of Education,* 31(3):303-317.

Lorenz, S. (1998) **Children with Down's Syndrome: A Guide for Teachers and Learning Support Assistants in Mainstream Primary and Secondary Schools.** London: David Fulton Publishers.

Lorenz, S. (1998) Experiences of inclusion for children with Down's syndrome. The Down's syndrome association, London
www.he.net/~altonweb/cs/downsyndrome/inclusion.html

MacDonald, J.D. (2006) Observations on conversations with young adults with Down syndrome. *The National Organization of Parents and Professionals,* 25(6). www.downsyndromeconnection.org/index.

Massachusetts General Hospital Boston: MassGeneral hospital for children (2007) http://www.massgeneral.org/children/adolescenthealth/articles/aa_down_syndrome.aspx

Merrian, S.M. 1988. **Case Study Research in Education: A Qualitative Approach**. San Francisco: Jossey-Bass Publishers

National Down Syndrome Society. (2004) Transitions. www.rnceus.com

Neuman, W.L. (2000) **Social Research Methods** (4th Edition). Boston Massachusetts: Allyn & Bacon.

Patton, M.Q. (1987) **How to Use Qualitative Methods in Evaluation.** Newbury Park California: SAGE Publications.

Pepi, A. & Alesi, M. (2005) Attribution style in adolescents with Down's syndrome. *European Journal of Special Needs Education,* 20(4):419-432.

Pueschel, S.M. (1990) Clinical aspects of Down syndrome from infancy to adulthood. *American Journal Medical Genetics,* 37(S2):52-56.

Pueschel, S.M. (1996) Young people with Down's syndrome: Transition from childhood to adulthood. *Mental Retardation and Developmental Disabilities Research Reviews,* 2(2):90-95.

Rondal, J.R.; Perera, J.; Nadel, L. & Comblain, A. (1996) **Down's Syndrome: Psychological, Psychobiological and Socio-educational Perspectives**. London: Whurr Publishers Ltd.

Rynders, J.E.; Johnson, R.T.; Johnson, D.W. & Schmidt, B. (1980) Producing positive interaction among Down syndrome and nonhandicapped teenagers through cooperative goal structuring. *American Journal of Mental Deficiencies,* 85(3):6-15.

Shalock, R.L. (2000) Three decades of quality-of-life. *Focus on Autism and Other Developmental Disabilities,* 15(2):116-125.

Shalock, R.L. (2004) The concept of quality-of-life: what we know and do not know. *Journal of Intellectual Disability Research,* 48(3):203-214.

Sigman, M. & Ruskin, E. (1999) Continuity and change in the social competence of children with autism, Down syndrome and developmental delays. *Monographs of the Society for Research in Child Development,* 64(1):1-143.

Simmons, E.L. (2007) A comparative study of a holistic approach to wellness: Implications on quality of life. Dissertation for PhD. Touro University International. ProQuest.

Smith, P.K.; Cowie, H. & Blades, M. (2003) **Understanding Children's Development** (4th Edition). Oxford: Blackwell Publishing.

Swanepoel, H. Chairperson: Down syndrome Association Pretoria/Tshwane and member of the department of education (GDE: District: Tshwane South) in Inclusive education and special schools. She provided personal and professional insight as she not only works in the field of inclusion but she has a son with Down syndrome who is in grade 10 and has completed all his schooling in a mainstream school. Personal Correspondence.

Swart, E. (2004). In: Eloff, I. & Ebersöhn, L. **Keys to Educational Psychology.** Cape Town: UCT Press.

Terre Blanche, M. & Durrheim, K. (1999) **Research in Practice: Applied Methods for the Social Sciences**. Cape Town: UCT Press.

Testa, M.A. & Simonson, D.C. (1996) Assessment of Quality-of-life outcomes. *The New England Journal of Medicine,* 334(13):835-840.

Villa, R. & Thousand, J. (2004) Inclusion: Educating students with Down syndrome with their non-disabled peers. National Down syndrome society. www.altonweb.com/cs/downsyndrome/index.htm

Wilks, J. & Wilks E. (1974) **Bernard: Bringing Up Our Mongol Son**. London: Routledge & Kegan Paul.

Wishart, J.G. (1998) Development in Children with Down Syndrome: Facts, findings, the future. *International Journal of Disability, Development and Education,* 45(3):343-363.

Wolpert, G. (1996) Educational challenges inclusion study. National Down Syndrome Society. http://www.ndss.org/index.

Yin, R.K. (1993) **Applications of Case Study Research.** Thousand Oaks. California: SAGE Publications.

Zollers, N.J.; Ramanathan, A.K. & Yu, M. (1999) The relationship between school culture and inclusion: How an inclusive culture supports inclusive education. *Qualitative Studies in Education,* 12(2):157-174. www.downsyndrome.org.sa.

ANNEXURE 1

Information for parents

The Department for Educational Psychology, University of Stellenbosch initiated the "Intellectual Disability: Quality Lifespan Development" project in 2001. The initial broad aims of the project were to establish the needs of selected samples of individuals in the Western Cape with intellectual disability, to explore a sample of existing support programs and to establish national and international relationships for the project. It is under this project that my study falls.

Current movements in education facilitate many actions for individuals with Down syndrome. New ideas, programs and support are developed, but do these new ideas listen to the voices of the very people we're trying to assist? Studies have highlighted the fact that it is very often the researcher's voice that is represented.

From previous research findings it became evident that the individual voices of learners with Down syndrome and their families need to be heard. If their needs are heard, support programs can be developed and implemented to support them more effectively. This is especially true within our country as we are undergoing a transformation process and it is essential to establish if the needs of individuals with special needs are being met. Consequently the following research question emerged:

The high school experience of a learner with Down syndrome: a case study.

The study examines an adolescent with Down syndrome's experiences within a mainstream school in the context of:
- Peer relationships
- Experience of academic activities
- Experience of general school activities
- Experience of extra-mural activities

In order to get a more complete picture of their experiences the opinions and experiences of the parents will be included.

Should you have any questions please feel free to contact my supervisor Prof Rona Newmark at rnew@sun.ac.za or myself at lianna@sun.ac.za.

Thank you

_____   _____

Ms L Morrison   Prof R Newmark

STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

The high school experience of a learner with Down syndrome: a case study.

I am asking you to take part in my research project that I am doing for the Department of Educational Psychology at Stellenbosch University. The information you give me I am going to put in my thesis. I chose you because you are a teenager (adolescent) who is in high school and I want to find out what school is like for you.

1.   WHY I AM DOING THIS PROJECT

The reason why I am doing this project is to find out what school is like for you so that we can understand and try to make the things that you don't like better for other teenagers with Down syndrome and make sure that they keep the things you do like.

2.   HOW IT WILL WORK

If you decided to take part in this project I am going to ask you to let me interview you. This means I am going to ask you someone questions about you and your school.

3.   WHAT HAPPENS IF YOU DON'T LIKE THE QUESTIONS I ASK?

I might ask a question that you are not sure of how to answer or that you don't want to answer, that is fine, you need to tell me and we can leave that question out or I can ask it in a different way.

4.   HOW THIS PROJECT CAN HELP OTHERS
The answers you give may help other teenagers with Down syndrome.

5.   CONFIDENTIALITY
All the information that you tell me I will not tell anybody else without making sure from you that I am allowed to. I will also change your name – you can choose a different name if you want to – so that nobody will know it was you who gave me the information.

6.   TAKING PART
It is up to you to decide whether you want to take part in this project or not. If you don't want to take part anymore then that is your decision. Nothing will happen to you if you decide not to take part anymore or not to answer some of my questions.

7.   WHO I AM
If you have any questions I can be contacted at lianna@sun.ac.za.

PAMPHLET SEND TO PARTICIPANT

Hello XXXXX

I'm sure you are wondering about why you are coming to speak to me on Tuesday. I know it's sometimes difficult to talk to people when you don't know them. So here's a little bit of information about me and what I do.

My name is Lianna Morrison. I am studying to be a psychologist. The work that I do is to help children and teenagers. I want to know how to help teenagers with Down syndrome and that is why I want to speak to you! My questions are about what school is like for you. I want to know about the things about school that you like and the things that you don't like.

Here is a picture of me up the mountain so you will know what I look like.

This is the door you'll come in.

Here's a picture of the room we'll be sitting in on Tuesday:

If you have any thing you want to know or ask me, here is my e-mail address: lianna@sun.ac.za

I am really looking forward to meeting you!

See you soon.

Lianna

ANNEXURE 2

EXTRACT FROM INTERVIEW TRANSCRIPT AND CODES

Interview questions	
Mother:	
BIRTH AND DEVELOPMENT	
When did you first find out that Sarah had Down syndrome? (*While pregnant, immediately after birth, or much later?*) At birth.	
Did you know at the time what Down syndrome was? I didn't have a clue. Although I had been friends with a Down syndrome girl…um but regarding everything else about them I didn't have a clue. So it was a huge adjustment, um my brother's wife brought me a whole lot of literature, while I was still in the nursing home. <u>The literature was so out-of-date that I took one glance at it and said to her I'm not even going to look any further.</u> <u>Cause I'm a very positive person and I just got the feeling from the pages that she'd given me that it was very negative and I just thought I'm not going to do this, so I didn't even read it. That was the first lot of literature I got about DS.</u>	**(SUP)**
	(PA)
……	
It is interesting for me to hear that you had to go out for support. Look we, we, Sarah was born at a Catholic nursing home in Pretoria and the nuns there were very old-fashioned. One <u>nun came to see me one morning and out of the goodness of her heart told me that Down syndrome only learn how to go around the table one and you've got to teach them how to walk around the other way, it was just so archaic.</u> And I just thought I'm just not going to listen to this <u>I treated Sharni as a normal child I haven't treated her any differently from how I've treated her older sister, when she's been naughty she's gotten a wallop but that has been very seldom.</u>	
	(SOCVIEW)
	PA
………………	

But other than that you haven't really experienced problems?
Because her sister was head girl she still tends to continue to be head girl. So she can or when she speaks to Sharni, but I put it down to sibling rivalry I don't think its anything to stress about. They love each other dearly, I mean now her sister's so sick she couldn't do enough for her. But you know this one's also "hardegat" –laughs-. So the problem that I am experiencing now is her need to stamp her authority so she tries her luck with me and I quell it immediately. But the little chap that gets a lift with us, she resorted him into tears the other day. But anyway I spoke with her and told her this is the way we deal with it. You know you must remember you wouldn't like to be spoken to like that and hopefully…She's got an imaginary friend and she goes into her room and closes the door and talks to this imaginary friend and I just hear this authoritative voice, telling this friends not 'this and this and that'. More often than not it sounds like me, which is scary –laughs -.

 But anyway I allow her to do that because where else is she going to vent her anger? And she's finding her place.

BEH

Participant:
Do you have friends at school? Can you tell me what you do together?
Ja…what was the question again? **What type of things do you do with your friends at break time?** *Um we have break, we play cricket…***Do you like batting or bowling more?** *Batting.* **I must attempt I can never hit that ball. Do they have a special place for you to play?** Ja.

                    …………….

So are your friends a little bit important to you or lots important to you?
Lots

                    …………….

INT

What schoolwork do you like doing the most? Can you tell me why?	**FRISHIP**
Maths…um it's my favourite.	
What schoolwork don't you like? Can you tell me why?	
Spelling…it's difficult	
What schoolwork do you find the easiest to do?	**SCH**
Languages	
What schoolwork do you find the most difficult to do?	
Reading	
………….	
What do else you enjoy doing?	
Shopping	
What would you like to do when you have finished school?	
I don't know…hairdressing.	
	INT
	FUT

FEEDBACK FROM PARTICIPANT

Hi Lianna

It all appears to be exactly as we spoke however I noticed the name xxxx in place of
Sarah.

Thanks for your concern, Jane is much better and gearing up for her finals.

Kind regards

xxxxxx

-----Original Message-----
From: Morrison, LM, Mej <lianna@sun.ac.za> [mailto:lianna@sun.ac.za]
Sent: 06 October 2007 06:22 PM
To:xxxx

Subject: Themes

Hello

I hope Jane is better. Here are the themes I identified from the interviews
with you, this is the tabulated format I can send the discussed version if
you have any questions about what I said.

Enjoy your day!

Lianna

Lianna Morrison
Unit for Educational Psychology
Stellenbosch University
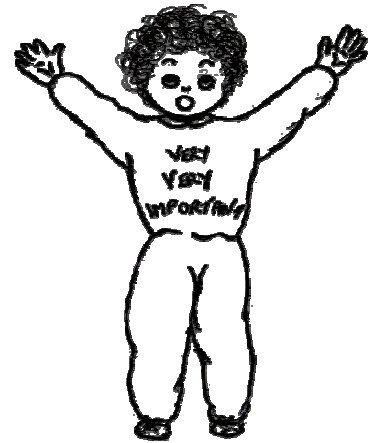lianna@sun.ac.za

ANNEXURE 3

ADDITIONAL MATERIALS

YES	NO

Not important at all

Quite Important

Very, very Important

ANNEXURE 4

INTERVIEW GUIDE

Parents:

BIRTH AND DEVELOPMENT

1. When did you first find out that Sarah had Down syndrome? (*While pregnant, immediately after birth, or much later?*)
2. Did you know at the time what Down syndrome was?
3. How did the news that your daughter has Down syndrome affect your family? (*nuclear and extended*)
4. What type (if any) support structures were there in place? Did you find the support they offer meet your needs? Are there current support structures in your life that offer you support?
5. Can you tell me what type of challenges you have faced? (*frustration with professionals, anxiety about the future, motional wellbeing of parents and marriage, social relations in family, lack of moral and social support*)

ADOLESCENCE

1. What has you experience been regarding Sarah's schooling?
2. Can you tell me more about your involvement with the school?
3. Tell me more about Sarah's adjustment to the school.
4. What (if any) behavioural changes have you noticed.
5. How successful do you think inclusion has been for your child, regarding:
   - academic gains
   - socialization
   - independence
   - language
   - self-esteem
   - development of friendships
6. Five word description of your child.
7. Can you tell me about some of your child's abilities and interests?
8. What are your hopes and dreams for your child?
9. What about your child makes you proud?
10. What do you see as indicators of quality-of-life? (*emotional, social, spiritual and physical aspects*)
11. How do you see Sarah's quality-of-life? What do you think could promote her quality of life?
12. What advice would you give to parents who are considering putting their child in mainstream education?

<u>Participant</u>

1. Do you have friends at school? Can you tell me what you do together?
2. Do you have friends at home? Can you tell me what you do together?
3. Are your friends at home the same as at school or are they different?
4. Have you ever slept over at a friend's house? Has one of your friends ever slept over at your house? Is sleeping over something you'd like to do?
5. What schoolwork do you like doing the most? Can you tell me why?
6. What schoolwork don't you like? Can you tell me why?
7. What schoolwork do you find the easiest to do?
8. What schoolwork do you find the most difficult to do?
9. Where do you spend break times? What do you do at break?
10. Do you have assemblies? What happens there?
11. Does your school ever have school plays? Have you ever taken part?
12. Do you ever use the school library?
13. Do you play sport? What sport do you play? Where do you play?
14. What do you enjoy doing?
15. What would you like to do when you have finished school?
16. What was makes you sad / happy / angry at school/home?
17. Is there anything else about you, you would like me to know?