

**BARRIERS TO ADMISSION TO MAINSTREAM PRIMARY SCHOOLS
FOR CHILDREN WITH HIGH FUNCTIONING AUTISM /
ASPERGER'S SYNDROME (UMLAZI DISTRICT)**

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in fulfilment of the requirements for
the degree

Master of Medical Science- Autism Spectrum Disorders

(Research)

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April 2014

DECLARATION

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And to God who is my foundation, thank you for the skills you have given me to work with children on the Autism spectrum and to impact their lives.

DEDICATION

My son Malachi, you have been the inspiration for this study. Your outlook on life gives me a fresh perspective on the world and your quick sense of humour keeps me young. May you continue to inspire those around you.

ABSTRACT

In South Africa basic education is a right for all children (Constitution of the Republic of South Africa, 1996) and mainstream education for learners with so called mild disabilities such as High Functioning Autism or Asperger's Syndrome (HFA / AS) is available according to government policy (White Paper 6, South African Department of Education, 2001b). The aim was to explore barriers to admission to mainstream primary school education for learners with HFA / AS. A mixed methods research design with two phases was used. Twenty-eight government primary schools in two circuits of a KZN school district completed a questionnaire; five parents of children with HFA / AS took part in a focus group discussion and an autoethnographic essay was written by the researcher. The data were analysed with descriptive statistics and thematic analysis. Some schools and the majority of parents were unaware of the learners' educational rights. Gaps in the implementation of policy exist, which contributed significantly to the barriers to admission for learners with HFA / AS. Main barriers were lack of knowledge and misconceptions about HFA / AS amongst school staff, lack of training for school staff, lack of government funding, lack of unity between parents and teachers/schools and negative attitudes towards inclusion of learners with HFA / AS. Suggested ways of overcoming the barriers to admission included small classes, class assistants or facilitators, improved unity and communication between parents and teachers and greater government support. With solutions addressed in the future, learners with HFA / AS can access suitable education in order to become contributing adults to society (Attwood, 2007).

Key words: HFA / AS; mainstream education; barriers; education policy

Glossary of terms and abbreviations

ASD- Autism Spectrum Disorder

Asperger's Syndrome- One of the five conditions on the Autism spectrum listed in the Diagnostic and Statistical Manual Fourth edition-text revision (DSM-IV-TR, American Psychiatric Association, APA, 2000). One of the eight conditions listed in the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10, World Health Organisation, WHO, 2012). Children with the diagnosis of Asperger's Syndrome are considered high functioning. The diagnosis is defined without language delay, average or above cognitive and age appropriate self help skills.

Autism spectrum-The informal term given to include five pervasive developmental disorders, namely; Autism, Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder- Not otherwise specified [PDD-NOS] (Wetherby & Prizant, 2000; Exkorn, 2005; Volkmar & Klin 2005).

Autism Spectrum Disorder- The term given for general referral to the five pervasive developmental disorders, namely; Autism, Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder- Not otherwise specified [PDD-NOS] without specifying any one in particular, with reference to The DSM-IV (APA, 2000 and ICD-10, 2012). It refers to individuals who have impairment in social interaction, communication skills and who display stereotyped behaviour (Wetherby & Prizant, 2000; Wing, 2006). Autism Spectrum Disorder as defined by the DSM-5 (APA 2013) is a standalone diagnosis.

Classic Autism- The term given to persons on the Autism spectrum who are severely affected by the condition, as defined by Kanner (1943). Persons who have poor language skills, poor independence skills, poor social abilities and strong behavioural difficulties.

Facilitator- A person who works in a mainstream classroom to assist an individual learner with special needs.

HFA / AS- High functioning Autism / Asperger's Syndrome- the general term given to children on the Autism spectrum with strong language, average cognitive and self help skills. This can include: PDD-NOS, Autism and Asperger's Syndrome (McAfee, 2002; Whitby, Travers & Harnik, 2009).

Inclusion- a child with a disability being educated alongside his / her neurotypical peers in a school historically reserved for neurotypical children. The responsibility to learn rests on the teacher and the school system to adjust the curriculum to ensure learning takes place for the learner with a disability

KZN- KwaZulu-Natal. One of the nine provinces in South Africa and the province in which this study takes place

LSEN- learners with special education needs

Mainstreaming- a child with a disability being educated alongside his / her neurotypical peers in a school historically reserved for neurotypical children but having to fit in with the curriculum. The responsibility to learn is upon the child with the disability and his / her ability to keep up academically in the school system

Mainstream school- A school intended for children without any significant disability (South African Department of Education, 2001b; Landsberg, Kruger & Nel, 2005).

NT- Neurotypical- A child with age appropriate functioning levels, cognitively, emotionally, socially etc. i.e. a typically developing child

PDD-NOS- Pervasive Developmental Disorder-Not otherwise Specified. This is one of the five conditions on the Autism spectrum. Persons with this diagnosis have impairments in social interaction, communication skills and stereotyped behaviour is displayed. However, criteria for a specific pervasive developmental disorder are not met. Depending on how the person presents, he / she could be regarded as high functioning

Special needs schools- a school which accommodates learners with disabilities.

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“Teachers need to help autistic children develop their talents. I think there is too much emphasis on deficits and not enough emphasis on developing abilities.”

*Temple Grandin (1995, p. 105). Adult with Autism
taken from “Thinking in pictures- my life with Autism”*

CHAPTER ONE: INTRODUCTION TO HIGH FUNCTIONING AUTISM AND ASPERGER’S SYNDROME

1.1 Introduction

This chapter discusses the motivation for the study and the educational problem of barriers to access to mainstream primary schooling to children who have High Functioning Autism and Asperger’s Syndrome (HFA / AS). It refers to the lack of educational services for children with HFA / AS in South Africa in general as well as makes mention of the limited educational services for children with HFA / AS in KwaZulu-Natal (KZN), the province in which the study took place. The history and background to the condition are outlined, including the characteristics of Autism Spectrum Disorders (ASD) in general and a discussion of the terms HFA and AS is given. The characteristics of HFA / AS are presented, as well as the age of diagnosis for children with ASD and HFA / AS. Lastly, a brief outline of the chapters in this study is provided.

1.2 Motivation

HFA / AS is part of the upper end of the Autism spectrum with those affected by it having average or above average cognitive skills (Schopler & Mesibov, 1992; Whitby & Mancil, 2009) and therefore are potentially able to learn in a mainstream classroom (Exkorn, 2005).

Unfortunately accessing mainstream education for learners with HFA / AS is limited, which is the focus of this study.

Autism Spectrum Disorders (ASD), which includes HFA / AS are currently known as the fastest growing disability (Whitby, Travers & Harnik, 2009; Autism Society, 2011). It is estimated that one in 88 children worldwide have ASD and that almost one in 54 boys are affected by the condition (Centre for Disease Control, 2012a). The prevalence of Autism is increasing with one in 150 children with Autism being reported by the Centre for Disease Control in 2002, one in 125 children in 2004, and one in 110 children with Autism reported in 2006 (Centre for Disease Control, 2012b). In South Africa these figures are adopted in the light of Autism being no respecter of cultures, social groups or financial standing (J. Stacey, personal communication, 1 April 2012¹). Autism Spectrum Disorders currently have a 1148% growth rate (Autism Society, 2011), and calculated on a conservative rate of one in 100 people being affected worldwide by the condition, 1% of the population, that is 70 million people are directly impacted and hundreds of millions of family members and friends are indirectly impacted. This necessitates the provision of increased educational facilities for children who have the condition, who make up part of the 70 million.

According to Autism South Africa (2011) every hour a child is born in South Africa who will develop Autism, yet only 0.1% of these children are able to access appropriate education. Action in Autism (n.d.) in their brochure “Action in Autism, accessing education for all”, suggest there are as many as 70 000 people living with Autism in KwaZulu-Natal, while news reports state there are as many as 90 000 people with Autism in KZN (South African Broadcasting Corporation, 2012). Among these 90 000 will be people regarded as “High Functioning”. In particular there will be children who are High Functioning, who neither fit

¹ Jill Stacey was the national director of Autism South Africa in 2012

into a school for Learners with Special Education Needs (LSEN) such as for cognitive impairment nor who are readily accepted into mainstream classrooms. The access to education for these children forms the basis for this study. Education is a basic right for all South Africans (Constitution of the Republic of South Africa, 1996). Education is not an end in itself but a means to equip persons to become contributing members of society.

As a behavioural therapist, the researcher works with children on the Autism spectrum in the selected circuits of the Umlazi school district. She regularly encounters the stress that parents of these children face in trying to find a school which will accept and educate their children. In addition she is a parent of a child with HFA / AS and faces this challenge herself. In the light of these personal experiences and serious educational concerns this study arose.

1.3 History of Autism Spectrum Disorders

Leo Kanner, a psychiatrist and physician as well as Hans Asperger, a paediatrician used the term “Autism” during the 1940’s to describe patients they treated who presented with the symptoms known as Autism today (Schopler & Mesibov, 1988; Volkmar & Klin, 2005; Wing, 2006). The name derives from the Greek “Auto” meaning “self” as the children affected, presented as self absorbed and detached from those around them (Dodd, 2005; Exkorn, 2005; Volkmar & Klin, 2005). Kanner and Asperger used the term “Autism” independently from one another and unaware of each other’s work (Schopler, Mesibov & Kuncze, 1998; Volkmar & Klin, 2005). Kanner concentrated on children who were severely affected by the condition, known as Classic Autism, while Asperger focused on children with greater capabilities, such as strong language abilities and average or above average cognitive skills (Exkorn, 2005). The term “Asperger’s Syndrome” was later used in reference to Hans Asperger and his work (Schopler et al., 1998) and was adopted for clinical use in 1981 (Attwood, 2007). Kanner classified Autism as a neurological condition but the cause of the

condition was not established (Kanner, 1943). The search for the cause continues today with research unable to give a single definite source for Autism Spectrum Disorders (Schopler et al., 1998; Autism Society, 2013a). Suggestions for causation include hereditary factors and neurobiological aspects (Schopler et al., 1998; Dodd, 2005).

1.4 Background to Autism Spectrum Disorders

As the name indicates Autism Spectrum Disorders (ASD) are complex and present in many forms. A common phrase in the Autism community is that if you have met one child with Autism, you have met ONLY one child with Autism. This statement reflects the uniqueness of the condition as no two children diagnosed with an Autism Spectrum Disorder present in exactly the same way. The child's personality, social abilities, language skills, cognitive ability and intervention given will determine how each child functions (Jordan, 2001; McAfee, 2002). There is a range between people with ASD in mental capacity from severe cognitive impairment to savant (Exkorn, 2005). Jordan (2001 & 2008) notes that although cognitive impairment can be present for persons with ASD, there are also those with ASD who have superior intelligence. Wing (2006) adds that some individuals on the Autism spectrum can go on to living independently and contributing to society in terms of employment. The talents and abilities of those with HFA / AS need to be embraced as society is well able to benefit from what these individuals are able to offer (Attwood, 2007), especially if their talents are developed by means of appropriate schooling. Famous examples of individuals with Autism in modern Society are Daniel Tammet (2006), who is an author and linguist and Temple Grandin (1995) who is a university professor and designer of facilities for the humane slaughter of livestock.

The range of abilities in language, cognitive skills and social skills persons with ASD can lead to confusion about the disorder and consequent actions in dealing with those on the

spectrum being inappropriate, especially when it comes to accessing suitable education. The wide range in abilities across the disorder can lead to uncertainty as to the best school placement and subsequent treatment for the child with ASD, including HFA / AS (Jordan & Jones, 1999). The incorrect school placement can be seen as a pitfall, when attempting to allocate appropriate support strategies and interventions for learners with ASD (Landsberg, Kruger & Nel, 2005). Contributing to the confusion is that presentation of an individual with ASD can change over time, especially in the presence of early intervention and suitable education (Schopler et al., 1998; Jordan, 2001; Volkmar & Klin, 2005). The measure of intelligence is generally accepted as a score achieved in intelligence quotient tests such as the Stanford-Binet and Wechsler tests. These tests however, are designed to determine intelligence for persons with standard language abilities and experiences, which children with ASD typically do not have. These tests can therefore be unreliable for persons on the Autism spectrum (Turkington & Anan, 2007). There is debate around this topic, however, and Jordan (2001) mentions that if a professional is skilled in working with children with ASD the administering of intelligence tests are reliable indicators.

1.5 Diagnosis of Autism Spectrum Disorders

Before considering the options for education for individuals with ASD, a basic outline of the condition is necessary. Autism Spectrum Disorders cannot be identified through medical procedures or tests (e.g. blood tests), rather they are identified by the presence or absence of specific developmental milestones, skills and behaviours (Dodd, 2005; Exkorn, 2005; Landsberg et al., 2005). Diagnosis is made based on criteria outlined from one of two sources. Firstly, the Diagnostic and Statistical Manual Fourth edition-text revision (DSM-IV-

TR) (American Psychiatric Association, APA, 2000),² which identifies five conditions under the category Pervasive Developmental Disorders,

- 299.00 Autistic Disorder [Autism]
- 299.80 Asperger's Disorder [Asperger's Syndrome]
- 299.80 Rett's Disorder
- 299.10 Childhood Disintegrative Disorder
- 299.80 Pervasive Developmental Disorder- Not otherwise specified [PDD-NOS]

Secondly, the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) published by the World Health Organisation (WHO) (2012) lists eight conditions under the category Pervasive Developmental Disorders,

- F84.0 Childhood Autism
- F84.1 Atypical Autism
- F84.2 Rett's Syndrome
- F84.3 Other Childhood Disintegrative Disorder
- F84.4 Overactive disorder associated with mental retardation and stereotyped movements
- F84.5 Asperger's Syndrome
- F84.8 Other Pervasive Developmental Disorders
- F84.9 Pervasive Developmental Disorder, Unspecified

² This project was conceptualised and conducted with focus on children with HFA / AS while the DSM IV was still operational. Thus the DSM IV is applied throughout the study.

Although there is variance between what each source classifies as Pervasive Developmental Disorders, there are more similarities than differences within the listed conditions between the two sources. Both structures are recognised for providing understanding of the goals for diagnostic categorisation (Volkmar & Klin 2005; Jordan, 2008). Each of these sources details specific criteria for the conditions.

The term Autism Spectrum Disorder and the term Pervasive Developmental Disorder (PDD) are used interchangeably to describe a broad continuum of neurodevelopmental conditions (Wetherby & Prizant, 2000; Exkorn, 2005). Volkmar and Klin (2005) say that while Autism Spectrum Disorder is a commonly used term, it is not an official diagnostic term and is generally recognised as an interchangeable term with the term Pervasive Developmental Disorder. This would apply to both to the DSM-IV (APA, 2000) and The ICD-10 (WHO, 2012).

The DSM-5 was released in 2013 (APA, 2013) and the terms Autistic Disorder [Autism], Asperger's Disorder [Asperger's Syndrome], Pervasive Developmental Disorder- Not otherwise specified [PDD-NOS] were replaced with the term Autism Spectrum Disorder (299.00). Persons previously diagnosed with Asperger's Syndrome may now fit the diagnosis Autism Spectrum Disorder. This study focuses on children of school going age between 4.5 years and 12 years (South African Department of Education, 2011a) and all participants were diagnosed under the DSM-IV (APA, 2000) or the ICD-10 (WHO, 2012), hence the use of these two manuals in this research study. The eight conditions listed above under Pervasive Developmental Disorders in the ICD-10 (WHO, 2012), including Asperger's Syndrome remain unchanged despite the changes in terms used in the DSM-5 (APA, 2013). Asperger's Syndrome and Autism are therefore still active diagnoses according to the ICD-10 (WHO, 2012).

1.6 Characteristics of Autism Spectrum Disorders

In the DSM-IV (APA, 2000) for Autistic Disorder, and PDD-NOS, criteria needed for diagnosis include social impairments, communication impairments and repetitive and stereotyped patterns of behaviour (other criteria distinguish the conditions from each other). Criteria for Asperger's Syndrome include social impairments, and behavioural irregularities, communication difficulties but not delayed language milestones but cognitive impairments are not present (APA, 2000).

Characteristics of ASD have a broader range of markers than the diagnostic criteria, some of these are mentioned in this section. A person with ASD does not present with any external physical markers but is rather identified by observed behaviours and the presence or absence of certain developmental milestones and skills, especially in early childhood. (Dodd, 2005; Exkorn, 2005; Landsberg et al., 2005). Dodd (2005) reports how Lorna Wing coined the term "Triad of Impairments" a phrase used to describe the three areas of deficit persons on the Autism spectrum present with at any age, including primary school years. Wing lists the triad of impairments as being: impairments in social interaction, social communication impairments and impairments in social imagination (Wing, 2006). The communication impairments within the triad of impairments are not only limitations in verbal communication but also limitations in interaction, understanding of language and non-verbal language. The social impairments include difficulties in relating to other people and the imaginative impairments include restricted and repetitive behaviours, limited interests, difficulty with abstract thinking as well as atypical play skills (such as spinning wheels of a toy car rather than pushing the car or playing an imaginary game with the car) and the need for sameness (Wing, 2006). The description of the triad of impairments is the core of the clinical features of the conditions forming the Autism spectrum (Roy, Roy & Clarke, 2006).

Communication impairments are still present in persons with Asperger's Syndrome (Attwood, 2007) but the communication difficulties can be masked by strong language skills, for example, correct grammar (Wing, 2006) and above average vocabulary (Attwood, 2007). Thus the triad of impairments also applies to Asperger's Syndrome. The connection between Asperger's Syndrome and High Functioning Autism will be discussed in section 1.7.

Weak auditory processing abilities for persons with ASD may also be present. This can affect memory as the person will still be processing auditory information while new information is being given, causing confusion and difficulty remembering information (Fein & Dunn, 2007).

Persons with Autism may also present with sensory difficulties, such as becoming over stimulated with sensory input or sensory seeking with low response to sensory input (Dunn, Smith-Myles & Orr, 2002; Autism Speaks, 2012). These sensory irregularities although common in many people on the Autism spectrum, do not form part of the diagnosis of an Autism Spectrum Disorder according to the DSM IV (APA, 2000; Dunn et al., 2002).

Sensory issues are however included in the diagnosis for Autism Spectrum Disorder according to the DSM-5 (APA, 2013).

Symptoms of ASD present in the first few years of life (Exkorn, 2005) but may not always be obvious in infancy (Autism Society, 2013b). Several indicators can be noted from as early as 12 months, should certain milestones not be reached by the child, for example not babbling or cooing or gesturing (such as waving) by a year old. Usually, distinguishing features are recognisable from 24 months to six years of age (Autism Society, 2013b). Social deficits and communication deficits become more obvious as a child matures into the school aged years.

Signs of ASD can include but are not limited to:

Social impairments:

- Not responding to their name+ by 12 months*

- Not pointing at objects to show interest or to share interest, known as joint attention (for example pointing at an airplane flying over) by 14 months*
- Avoiding eye contact*+
- Wanting to be alone*
- Trouble understanding other people's feelings*
- Little interest in peer socialisation+
- Indifference to people+

Communication impairments:

- Having trouble talking about their own feelings*
- Having delayed language skills*
- Repeating words or phrases over and over (echolalia)*
- Giving unrelated answers to questions*
- No babbling by age one+
- No single words by 16 months+
- No two word sentences by 24 months+
- Language loss experienced at any time+

Repetitive and stereotypical behaviours:

- Not playing "pretend" games (pretending to feed a doll) by 18 months*+
- Getting upset by minor changes*
- Having obsessive interests*
- Having unusual reactions to the way things sound, smell, taste, look, or feel
- Typically a short span of attention, unless for special interests+ (This characteristic not exclusive to ASD).

- Repetitive body movements (such as hand flapping , spinning or rocking)*+
 - Intense tantrums+
 - Fixations on or obsessions with a single object or parts of an object, such as observing wheels spin*+
 - Difficulty with changes in routines or schedules displayed in unusually strong resistance+
 - Sensory issues such as over or under sensitivity to sensory input for example, certain smells, sounds, sights, tastes* +
- (+Dodd, 2005; *Center for Disease) Control, 2010).

Persons with High Functioning Autism can present with the above features, however, those with Asperger’s Syndrome may not experience all the language deficits as listed above, however communication deficits are still present (APA, 2000). HFA / AS will be discussed in the next section, 1.7 followed an outline of the characteristics of HFA / AS in 1.8.

1.7 High Functioning Autism / Asperger’s Syndrome discussed

The terms Asperger’s Syndrome and High Functioning Autism can be used interchangeably (Attwood, 2007; Schmidt, Stichter, Lierheimer, McGhee, & O’Connor, 2011) and intervention for persons with High Functioning Autism and Asperger’s Syndrome follows the same treatment (Attwood, 2007; The Autism Society, 2013c). Asperger’s Syndrome has been used in research to refer to individuals with varying presentations of ASD namely what is referred to as “Higher Functioning Autism” (Volkmar & Klin 2005). “High Functioning” (HF) however, is not an official diagnosis according to the DSM-IV (APA, 2000) or the ICD-10 (WHO, 2012) but is used extensively by teachers, doctors and therapists to describe the level of performance a child with an Autism Spectrum Disorder displays (Autism Society of

America, 1998). This is evidenced by the numerous references to HFA for example, Schopler and Mesibov (1992); Volkmar and Klin (2005); Attwood (2007); and Fein and Dunn (2007).

Within Autism and PDD-NOS, a child may be described as High Functioning depending on how the child presents (McAfee, 2002). For a child to be considered High Functioning he or she must have an IQ of 80 or above (i.e. within the average range) in addition to a diagnosis of Autism, Asperger's Syndrome or PDD-NOS (Whitby et al., 2009). An IQ of 70 and above can also be considered High Functioning in some settings (Whitby & Mancil, 2009; Schmidt et al., 2011), which would mean up to 52% of the population of those on the Autism spectrum could be considered High Functioning (Whitby & Mancil, 2009).

Additionally, the person should have peer level independence skills (self help skills), which in a young child could include independent dressing and for an older child independent completion of chores around the house such as caring for pets (Leaf & McEachin, 1999).

Typically developed language skills (such as age appropriate grammar and peer level vocabulary) are also needed for a person to be considered High Functioning (Autism Society of America, 1998). Typically developed language skills however, can still mean the person with HFA / AS has communication difficulties in interaction such as conversation skills.

Persons who are High Functioning can also display deficits in social skills, social language such as humour or irony and inappropriate behaviour, such as isolation, repetitive body motions or emotional outbursts (Autism Society of America, 1998).

Asperger's Syndrome in itself is considered High Functioning and is described in the ICD-10 (WHO, 2012) as a person with impairments in social functioning and having restricted, repetitive, and stereotyped patterns of behaviour. Persons with the condition present with a lack of significant delay in language, cognitive development or self help skills. In addition the criteria for other pervasive developmental disorders are not met. Criteria for Asperger's

Syndrome according to the DSM-IV (APA, 200) follow similar criteria. These criteria are in agreement with the criteria above used to determine a child to be High Functioning. For the purpose of this study High Functioning Autism / Asperger's Syndrome (HFA / AS) will refer to Asperger's Syndrome, High Functioning Autism, and High Functioning PDD-NOS.

There is much controversy around the separation of the conditions, High Functioning Autism and Asperger's Syndrome, with some professionals supporting the idea that the two conditions are the same while others draw very distinct differences between them (Volkmar & Klin, 2005; Fein & Dunn, 2007). Some professionals distinguish between the two conditions by saying persons with Asperger's Syndrome have no history of language delay, while those with High Functioning Autism had a delay in language development in early years. These language delays resolve as the child matures or as a result of intervention. (Noterdaeme, Wriedt & Höhne, 2010). In the study done by Noterdaeme et al. (2010) individuals with Asperger's Syndrome scored higher on IQ tests than the participants with High Functioning Autism. In addition those with Asperger's Syndrome also scored higher on language tests than those with High Functioning Autism. It was suggested, that the higher scores in IQ were due to the language capacity of those with Asperger's Syndrome. Due to these unresolved deliberations, some clinicians have resorted to developing their own definitions of Asperger's Syndrome, which does not assist in clarity of the condition (Whitby & Mancil, 2009). The debate remains inconclusive (Schopler et al., 1998; Noterdaeme et al., 2010). The release of the DSM-5 (APA, 2103) addresses some of these concerns by replacing the term Asperger's Syndrome with Autism Spectrum Disorder.

1.8 Characteristics of High Functioning Autism / Asperger's Syndrome

As mentioned in section 1.6, the triad of impairments applies to all persons on the Autism spectrum, which includes persons with HFA / AS. Many of the characteristics of HFA / AS

are therefore recognised within the triad. To review, the triad of impairments are communication difficulties, difficulties with social interaction and behavioural challenges (Roy et al., 2006; Wing, 2006).

1.8.1 Communication impairments

Persons with High Functioning Autism, have higher language skills compared to those with Classic Autism (Autism Society, 2013c) but it should be noted though that persons with Asperger's Syndrome can have even stronger verbal and communication skills than those with High Functioning Autism (Volkmar & Klin, 2005; Noterdaeme et al., 2010). Language skills, such as vocabulary, grammar and pronunciation are usually intact for those with Asperger's Syndrome but the social use of language can still be impacted, for example tone of voice, back and forth conversation and non verbal language (Wing, 2006; Shane, 2012). There may also be misunderstanding or difficulty interpreting and recognising figures of speech as those with HFA / AS have a literal understanding of language. For example, understanding that "fit as a fiddle" means a person is well may be lost on someone with HFA / AS (Shane, 2012). The impairment therefore is in communication and not necessarily in speech.

1.8.2 Social impairments

The impact of impaired social skills for a child with HFA / AS (McAfee, 2002; Volkmar & Klin 2005; Attwood, 2007), means peer level interaction is limited. The person with HFA / AS may present as immature or be restricted in his / her ability to initiate socially or to be successful in group participation. He / she may struggle with reciprocal verbal exchanges and may be unaware of the conversational rules for starting and ending conversations. He / she may struggle to maintain a conversation or stay on topic if the conversation is not of interest to him / her (Attwood, 2007). Turn taking may also be problematic (Koegel, Matos-Fredeen, Lang & Koegel, 2011). He / she usually experiences difficulty making and keeping friends

(Attwood, 2007; Koegel et al, 2011) and has difficulty reading the emotions and social cues of others (Schopler & Mesibov, 1992; Koegel et al., 2011). Interaction with peers is often desired but understanding as to why their own behaviour and responses are off putting to neurotypical peers is not present (Shane, 2012). Abstract thinking can be problematic (Schopler & Mesibov, 1992; McAfee, 2002) as well as understanding someone else's point of view as separate from his / her own point of view. This is known as an impairment in Theory of Mind (McAfee, 2002; Schmidt et al., 2011).

1.8.3 Stereotyped and repetitive patterns of behaviour

People with HFA / AS often experience inflexible behaviour and like to adhere to routines (Wing 2006; Schetter & Lighthall, 2009). McAfee (2002) mentions that a typical indicator of a child in this category is behavioural difficulties in dealing with change. Restricted, repetitive, and stereotyped patterns of behaviour, such as repeating a motion over and over are also present (APA, 2000; WHO, 2012). Managing his / her own emotions is equally challenging and he /she may have difficulty recognising and appropriately reacting to his / her own emotions (McAfee, 2002). Immature outbursts in reaction to small issues can be displayed and the emotional management of neurotypical peers is typically more advanced than that of a person with HFA / AS (Schopler & Mesibov, 1992). Other indicators which may be present but are not part of the diagnostic criteria can include limited organisational abilities and a child with HFA / AS can find managing and planning his / her tasks challenging. Dealing with distractions, keeping on task and self monitoring progress may also be difficult (McAfee, 2002). Attention skills may be diminished and this combined with organisational difficulties means the child may struggle with complex mathematics problems (Whitby & Mancil, 2009). These limitations are collectively known as deficits in executive functioning (McAfee, 2002).

1.8.4 Other indicators

1.8.4.1 Sensory issues

As mentioned in section 1.6 persons on the Autism spectrum can experience sensory challenges (APA, 2000; Dunn et al., 2002; Autism Speaks, 2012). There may be difficulty in dealing with sensory input such as bright lights or high pitched noises (Dunn et al., 2002; Schetter & Lighthall, 2009). Due to the diversity of how each person with HFA / AS presents, sensory difficulties range from hypersensitive (over sensitive to sensory input) to hyposensitive (sensory seeking and desiring increased amounts of sensory input) (Dunn et al., 2002; Autism Speaks, 2012). As a result of the challenges in the above mentioned areas, stress can be high for children with HFA / AS (McAfee, 2002; Schmidt et al., 2011).

1.8.4.2 Cognitive functioning

Fein and Dunn (2007) describe Asperger's Syndrome and High Functioning Autism as a child being diagnosed with Autism yet having an average IQ; that is no cognitive impairment is present. Persons with ASD who are considered High Functioning are therefore without cognitive impairment (McAfee, 2002; Autism Society, 2013c). Attwood (2007) describes the presentation of Asperger's Syndrome and High Functioning Autism as average cognitive skills but better intellectual skills compared to persons with Classic Autism. Foley-Nicpon, Assouline & Stinson (2012) note that persons with HFA / AS can have superior intelligence and be classified as "gifted", which supports Shane's report (2012) that many people with Asperger's Syndrome work in "techheavy" industries being skilled in information technology and computer related development. These types of employment suit individuals who excel academically in mathematics. There are an abundance of High Functioning individuals with ASD in areas such as Silicon Valley in California (Shane, 2012).

1.8.4.3 Self help skills

Self help skills are not as negatively affected for those with HFA / AS as they are for persons with Classic Autism (Attwood, 2007). Independence abilities may be present in persons with HFA / AS (Autism Society of America, 1998). Persons with HFA / AS may not be as reliant on support for general functioning and daily living as are others on the Autism spectrum. The Autism Society (2013c) mentions that individuals with Asperger's syndrome would be considered the same as a neurotypical child but his or her behaviour would be different from a neurotypical child.

1.8.5 Age of diagnosis

Many parents of children with Asperger's Syndrome report that there were no noticeable developmental abnormalities until approximately age three. Thereafter irregularities in interaction, behaviour and communication style began to emerge (Schopler et al., 1998). Children with Asperger's Syndrome are typically diagnosed between the ages of eight and 12 years (Attwood, 2007; Schetter & Lighthall, 2009) but some have been noted to receive their diagnosis as early as five years old (Exkorn, 2005). Children with ASD, including High Functioning Autism, usually receive their diagnosis at a younger age of approximately three years (Exkorn, 2005; Schetter & Lighthall, 2009). The difference in the age of diagnosis between the two conditions is due to the strong language skills which those with Asperger's Syndrome present with, which can mask a communication difficulty. Children with High Functioning Autism have speech and language delays, which can be identified in early childhood when language milestones are not reached (Exkorn, 2005; Noterdaeme et al., 2010).

1.9 Brief outline of Chapters

An outline of the chapters presented in this research study is presented in Table 1.1 below.

Table 1.1: Outline of Chapters and content

Chapter	Title	Content
2	Literature review, mainstream education for children with High Functioning Autism and Asperger’s Syndrome	The challenges associated with mainstream education for children with HFA / AS are discussed in this chapter. These include schooling options, educator support, financial difficulties, educator training, sensory difficulties curriculum adjustment and class sizes. The Education White Paper 6 (South African Department of Education, 2001b) is considered along with barriers and solutions for mainstream education for children with HFA / AS.
3	Methodology	In Chapter Three the aim and objectives of this study are presented. Procedures used to obtain and analyse data for the study are discussed. The motivation for the research design chosen will be explained along with participant selection criteria and validity and reliability. Lastly, ethical considerations are discussed.
4	Results and discussion	The results of the study are presented and discussed in this chapter; they are presented quantitatively and qualitatively in line with the research design of the study. Results are presented with reference to current literature on the topic and with other research.
5	Conclusion, limitations and recommendations	The final chapter of this dissertation discusses the conclusions deduced from the study. Recommendations as a result of the study for schools, parents, and further research on the topic are presented here.

1.10 Summary of Chapter One

This chapter presented the motivation for wanting to explore barriers to mainstream education for children with HFA / AS. The educational challenge of the growing number of children on the Autism spectrum in South Africa was discussed and a brief history and background on ASD with characteristics of the condition was given. Specific reference was made to HFA / AS and the characteristics of HFA / AS were highlighted. The different conditions were discussed and a brief outline of chapters was made.

“Sometimes what we dislike we have to do. School is one of those things”

Malachi Collins, 13 year old son of the researcher, who has HFA / AS (2013).

CHAPTER TWO: LITERATURE REVIEW, MAINSTREAM EDUCATION FOR CHILDREN WITH HIGH FUNCTIONING AUTISM AND ASPERGER’S SYNDROME

2.1 Introduction

In Chapter Two the options for educational placement for children with HFA / AS are raised. The need for increased services for children with HFA / AS in KwaZulu-Natal and in South Africa in general are referred to, with reference to studies done in South Africa as well as to international research. Experiences of schools which do accept children with ASD and in particular HFA / AS are explored. The challenges associated with mainstream education for children with HFA / AS are reviewed giving specific examples. In the South African context, inclusion of learners with HFA / AS is addressed in the light of the Education White Paper 6, Special Needs Education-Building an inclusive education and training system (South African Department of Education, 2001b), which outlines the provision for mainstream education for learners with mild disabilities, including HFA / AS. Lastly barriers and solutions to inclusion of learners with HFA / AS are discussed.

2.2 Schooling options for children with HFA / AS

Not all persons with an Autism Spectrum Disorder would benefit from mainstream education. Those considered to be more severely affected by the condition typically have poor educational success, exhibit inappropriate and challenging social behaviour and have significant communication problems (Schopler & Mesibov, 1992). Those with ASD who are

have the opportunity for treatment following for instance Early Intensive Behavioural Intervention hold a 50% chance of being able to be educated alongside their peers (Thomson, 2013), promoting their presentation to the High Functioning category. These children would however, still need the opportunity to enrol in schools alongside their peers. This study focuses on those said to be “High Functioning”, that is, those without cognitive impairment whose intellectual abilities are within the average or above average range (Schopler & Mesibov, 1992; Whitby & Mancil, 2009) (see section 1.7, High Functioning Autism / Asperger’s Syndrome discussed). Persons with HFA / AS possess the ability to function in a typical classroom (Exkorn, 2005) and hold a high capacity for learning (Schopler & Mesibov, 1992; Whitby & Mancil, 2009). This can include persons with PDD-NOS who do not meet the criteria for other developmental disabilities (APA, 2000; WHO, 2012). The importance of an individual with HFA / AS attending mainstream schooling and achieving well academically, is that this would open opportunities for university attendance which in turn would provide options for meaningful employment (Whitby & Mancil, 2009).

The South African Department of Education (1996b) in the South African Schools Act, outlines that learners aged 7-15 (or grades 1-9, whichever is reached first) are required to attend school; that is, for this age range of children, schooling in South Africa is mandatory. In point (3)(2) it goes on to say that schooling is also compulsory for children with special needs but ages are not specified. Currently, many mainstream schools in KwaZulu-Natal restrict their acceptance of children with ASD (Triad Behaviour Consultants, personal communication, June 2008³) and some LSEN schools do not accept children with Autism.

The question then arises: Where are these children if they are not in school? What options are

³ Triad Behaviour consults operate an Autism therapy centre in Pinetown, KwaZulu-Natal. One of the goals of the directors of the centre is to mainstream as many children they work with as possible. As such they are well aware of the current situation regarding schooling options of children on the Autism spectrum.

available to parents for the education of their children with HFA / AS who function at a peer level, cognitively? Internationally the placement of children with ASD into appropriate schools is also problematic even though the rights of those with ASD are recognised (Jordan, 2012). Issues such as staff training, adjusted curriculum, therapy and individual support for the child with HFA / AS at school make the reality of implementing the rights of learners on the Autism spectrum limited.

Action in Autism, a lobbyist organisation, supporting individuals with Autism, hosted a meeting with the KZN Department of Education in 2010 called the Autism Indaba. The result was a project aimed at altering all 72 special needs schools in KZN to enable them to accommodate learners with Autism by 2014 (KwaZulu-Natal Department of Education, 2011b). This will be a 453% increase from the 13 LSEN schools in KZN which currently accept learners with ASD. Even so, following the expansion of LSEN schools, which is still in the process of being realised, the option for children with HFA / AS to mainstream remains limited. The result of the Autism Indaba was to improve services at LSEN schools and full services schools. Unfortunately the Indaba did not address mainstream schooling for children with HFA / AS (Kwazulu-Natal Department of Education 2011b).

Some parents of children with HFA / AS, following refusal to admission into mainstream schools, choose to home school their children. This refers to a parent taking on the role of the teacher to his / her child and educating the child at home instead of the child attending school with children from the greater community. Homeschooling can mean loss of income for the family as one of the parents would be unable to work in formal employment due to the time demands of taking on the role of teacher to the child (Schetter & Lighthall, 2009). Another option for families who have sufficient financial means as suggested by Roberts (2007) is to employ a paraprofessional (facilitator) trained in Applied Behaviour Analysis (ABA) to work with their child at home to promote learning.

Other parents utilise the government or non- government special needs schools available, knowing their children will not have the opportunity to complete their schooling to grade 12 or matriculate at those schools. These schools provide basic education but not all provide education up to grade 12 level for all learners with ASD, including HFA / AS. This is unfortunate for learners with HFA / AS as they have peer level cognitive skills (Exkorn, 2005; Whitby et al., 2009). In addition, many of the government special needs schools typically have long waiting lists, which take several years to reach the top. Still other parents who are desperate to get an educational placement for their children with HFA / AS, may resort to concealing the child's condition on application to a school in the hopes that the child will be accepted. Barratt (2005, p. 25) states; "Evidently, some principals have occasionally refused entry to children because of their special needs. According to the interviewee, this has resulted in some parents withholding from informing schools of their child's diagnosis in order to guarantee a placement." One would anticipate that this scheme would be neither beneficial for the child who may need some additional understanding from the educators, or for the teachers who may be unprepared in the classroom or unaware of the child's learning style. In the South African context, parents who were aware of their children's educational rights have insisted that the mainstream government neighbourhood schools enrol their children, whereas parents who were not aware of their children's rights have accepted whatever outcome the school decided about the child's placement (Swart, Engelbrecht, Eloff, Pettipher & Oswald, 2004; Yssel, Engelbrecht, Oswald, Eloff, & Swart, 2007).

Lawrence (2012) suggests an approach called "flexischooling" which is targeted at children on the Autism spectrum, including those with HFA / AS. With this approach, children with ASD spend part of their day in a mainstream school setting and part of the day at home learning in a home school environment. Education remains full time but the child's presence in a mainstream school setting is part time. This option Lawrence suggests, gives the child

time to process difficulties experienced at school in the home setting, as well as giving exposure to neurotypical children for the important development of social skills. This concept she admits is still at the developmental stage in many schools in the UK. No research was found indicating that this method has been applied in South Africa yet or whether it would be suited to the South African setting.

Lastly, mainstream private schools may be considered by parents of children with HFA / AS who do not gain entry into mainstream government primary schools, as certain private schools do enrol learners with HFA / AS (Walton, 2002; Roberts, 2007; Walton, Nel, Hugo, and Muller, 2009). This would mean an added financial burden to the parents of the child with HFA / AS compared to the finances needed for attendance at a government school (Yssel et al., 2007).

In the United States of America, the educational options for children with ASD in general, and including those with HFA / AS, are dependent on the individual needs of each child. They are specified in the IDEA Act of 2004 (Individuals with Disabilities Education Act) (United States Department of Education, 2004). They include:

- Mainstreaming (may include a personal aide/ facilitator)
- Resource rooms (for one on one work with an instructor)
- Special education classrooms at mainstream schools
- Special schools
- Home programmes (Applied Behaviour Analysis)
- Teaching at hospitals or residential schools (such as psychiatric facilities, however, this is uncommon)

A team decision is made by the child's teachers, parents and therapists as to the best placement for the child, starting with the least restrictive option (i.e. inclusion) with the most

access to neurotypical peers, which would be mainstream schooling (United States Department of Education, 2004; Fein & Dunn, 2007; Koegel et al.2011).

South Australia practices inclusion of children with Asperger's Syndrome in mainstream classrooms. Although specialised settings of eight children per class in a special school and homeschooling are also available, they are not widely used. Teachers are given training support from the government on effective teaching strategies for children with Asperger's Syndrome (and High Functioning Autism) in order to equip the educators in their role and to optimise education for the learners with HFA / AS (Government of South Australia, 2006).

Likewise, in the United Kingdom inclusion is practiced depending on the needs of the individual child. Teachers are provided with training and support in working with children with special needs, including HFA / AS. Particular mention is made of assistance in dealing with behaviour which can be an area of challenge for children with HFA / AS (Department for Education, UK, 2011).

Although South Africa's introduction to inclusion policy was in 2001 (South African Department of Education, 2001b) the fulfilment of the policy has not yet been realised. Nonetheless we are moving forward in the pursuit of inclusive education like developing countries such as Uganda, Lesotho, Vietnam, Lao People's Democratic Republic, Jordan, Palestine, Morocco, Egypt, Yemen, Brazil and India (Mittler, 2003). Mittler's paper, which was originally prepared for UNESCO in 2003, outlines how the above mentioned countries have limited resources compared to many western countries, yet they are recognising the role of inclusion for children with disabilities. These include learners with HFA / AS in mainstream schools (Mittler, 2003). In Uganda special mention is made that the learning needs of children with ASD are beginning to be recognised as a new area in the country.

In Robert's study (2007) schooling options for children with HFA / AS in Gauteng are discussed. She found that a limited number of mainstream schools do accept learners with HFA / AS and place is made for some children with HFA / AS in selected LSEN schools. Unfortunately in South Africa in general there are very few schools which accommodate children with Autism, including HFA / AS (Roberts, 2007).

2.3 Challenges associated with inclusion and children with HFA / AS

2.3.1 Educator support

Roberts (2007) in her study in selected government primary schools in Gauteng found that educators were supportive of including learners with HFA / AS in mainstream schools. They noted that the presence of a personal paraprofessional (facilitator) for the child in the mainstream classroom would help overcome some of the challenges of teaching a child with HFA / AS alongside his or her peers. The teacher would benefit from the assistance of another adult in the classroom to manage the challenges, such as behavioural difficulties, which the learners with HFA / AS may have, which can reduce learning (Koegel et al., 2011) or assist with curriculum adjustment which may be needed. It would be assumed that those filling the role of class assistant or facilitator would be persons who are properly trained, Koegel et al. (2011) however, found this not always to be true making the teacher assistants feel inadequate for their jobs.

Additional support in the form of specialist staff (such as remedial teachers or psychologists) was also noted to be necessary for the educational success of learners with HFA / AS (Walton et al., 2009). This was expressed in the study on inclusion done in private schools in South Africa (Walton et al., 2009). It echoes the policies outlined in the Education White Paper 6 (South African Department of Education, 2001b), where specialist support staff making up district support teams would be assigned to mainstream schools to assist teachers with

learners who have mild to moderate special needs. Walton et al. (2009) revealed that schools in affluent areas were more likely to have access to support staff than schools in lower income areas, which introduces a further challenge to inclusion of learners with HFA / AS in mainstream schools: financial limitations.

2.3.2 Financial challenges

Anthony (2009) who refers to finances as a barrier to acceptance of children with special needs into mainstream schooling is in agreement with Walton et al. (2009). In the South African setting, currently, parents are responsible for the financial burden of having a facilitator for a child with HFA / AS in the mainstream classroom should one be needed. They are also responsible for costs of support specialists such as psychologists or occupational therapists who typically assist the child after school (Yssel et al., 2007).

2.3.3 Educator training

A difficulty experienced by teachers of learners with HFA / AS in mainstream schools was the lack of training around the topic of ASD (Roberts, 2007; Walton et al., 2009). In the selected government primary schools in Gauteng (Roberts, 2007), the teachers expressed that they had received little or no training as educators to teach children with HFA / AS. There was a great need felt for practical contact with children with HFA / AS in order to gain experience and exercise the skills needed to work with them. The development of social skills for learners with HFA / AS is an area educators need to be familiar with, however, little training is provided for the educators (Attwood, 2007). The addition of social skills to the school programme is an example of an adjustment to the mainstream curriculum.

2.3.4 Sensory difficulties

The sensory difficulties experienced by some learners with HFA / AS (Dunn et al., 2002; Autism Speaks, 2012) may also present challenges in the mainstream classroom (Fein &

Dunn, 2007). The hyposensitive may need to be monitored for injury due to very low pain registry resulting in the lack of complaint or expression from the child if the child is injured. The hypersensitive child may need assistance with redirection in the presence of noises outside the classroom such as drilling or aeroplanes which can be experienced not only as distracting but also as painful (Dunn et al., 2002; Fein & Dunn, 2007) and can lead to distress and anxiety (Dunn et al., 2002; McAfee, 2002; Schmidt *et al*, 2011). Processing sensory information and acting upon it may be difficult for children with HFA / AS, especially regarding auditory processing (Dunn et al., 2002) which can mean slower response or interpretation of auditory information as compared to neurotypical peers.

2.3.5 Curriculum and teaching technique adjustments

Changes in learner assessment and changes in teaching methods are areas which need to be addressed when considering inclusion of learners with HFA / AS in mainstream classes (Walton et al., 2009). For example, taking into consideration the weak auditory processing skills mentioned above, the presentation of the learning material may need to be done in a visual form. Since children with HFA / AS have been noted to be visual learners (Dunn et al., 2002), work schedules which follow a sequential and predictable pattern may need to be implemented and instructions may need to be simplified (Dunn et al., 2002; Fein & Dunn, 2007). Technology such as mobile tablet devices and smart phones have applications to aid those with HFA / AS in education and independence (Shane, 2012). These devices have learning materials which are presented in a visual format and direct response from the child is prompted following the presentation of information, which assists with concentration. However, the use of these devices in mainstream classroom has financial implications (Shane, 2012).

Changes in learner assessment and changes in teaching methods are areas which need to be addressed when considering inclusion of learners with HFA / AS in mainstream classes

(Walton et al., 2009). Concerning assessments Whitby and Mancil (2009) conclude that ascertaining the academic learning profiles of learners with HFA / AS would be of great value to teachers. This would be in a general sense for those with HFA / AS as well as for each individual with HFA / AS in the class. Knowing each child's strengths and weaknesses and devising a teaching plan accordingly, would facilitate enhanced learning for the children in question (Koegel et al., 2011). This is widely practiced in the USA (United States Department of Education, 2004). Varying how assessments take place is recommended by Koegel et al. (2011). They suggest that assessments could take the form of observations and the environment in which the assessment takes place should be considered for the child with HFA / AS (that is, assessments done in a natural setting). Additionally the person giving the assessment, should be considered as children with ASD, including HFA / AS have varied responses depending on who is attending to them (Koegel et al., 2011).

An additional adjustment to the curriculum would be to include strategies to help develop social skills for learners with HFA / AS (Attwood, 2007). Social deficits are part of the triad of impairments (Dodd, 2005). This means children with HFA / AS need assistance to develop social skills. The importance of a mainstream placement is that neurotypical social modelling is present (Autism Independent, UK, 2010; Fein & Dunn, 2007). Additionally there are many more opportunities in a mainstream school for a child with Autism to interact socially, develop friendships with neurotypical peers and learn in a group. These advantages are not available to a child with HFA / AS if they are in a special needs school (Autism Independent, UK 2010; Fein & Dunn, 2007). To achieve this goal, teachers need to be aware of the social challenges children with HFA / AS face and be equipped to assist them (Attwood, 2007; Koegel et al., 2011). Doing so would uphold the goals of the Education White Paper 6 (South African Department of Education, 2001b), where the individual needs of the special needs learner are recognised and attended to.

Simpson, de Boer-Ott & Smith-Myles (2003), outline the importance of social skills development of students with ASD as one of the benefits of inclusion saying there are four methods to assist in this area:

- Direct skill instruction, that is, teaching by an adult on how to respond or behave in various social settings.
- Antecedent prompting methods, this is where an adult directs the child with ASD to actively engage or respond to a peer.
- Peer initiated training strategies. This is where neurotypical peers are utilised to initiate and promote social interaction with their classmates with ASD.
- Peer tutoring. That is where competent neurotypical peers are utilised to give the child with ASD instruction on how to respond or interact in a given social situation.

Simpson et al. (2003) go on to say these types of methods help protect the child with ASD from loneliness and rejection, which can negatively affect academic performance and can help to build positive relationships between the children on the Autism spectrum and their neurotypical peers.

Schmidt et al. (2011) in their study on intervention to improve social functioning in youth with HFA, proposed that the curriculum used could assist within a school setting. The study gave evidence that their social skills curriculum can successfully be implemented in schools. While the study was aimed at youth, we assume that it would apply at least in part to learners with HFA / AS in senior primary school who may be up to age 14 should grades have been repeated (South African Department of Education, 1996b). The positive results from the study may also be carried over beyond the school environment (Schmidt et al., 2011).

The element of social development can easily be overlooked when addressing learning as gaining information only and not looking at the holistic development of the child. Allowing a child with HFA / AS to attend a mainstream school supports the personal growth of the individual in this area. In this regard programs for enhancing social development and relationship skills would well assist the child with HFA / AS at school (Attwood, 2007). Additionally, the anxiety experienced by many people with HFA / AS (McAfee, 2002) can be reduced by giving support in developing social skills (Schmidt et al., 2011).

Some learners with HFA / AS perform well and even above peer level in the early school years but experience some learning difficulties as the primary school years advance (Whitby et al.2009). Learning to read, both for neurotypical children and children with HFA / AS, involves moving from initial concrete word decoding in the initial stages to deeper comprehension in later years. This next step of comprehension and analysis of a passage, becomes increasingly difficult for some children with HFA / AS, while their neurotypical counterparts do not experience the same difficulty (Whitby & Mancil, 2009). Likewise with mathematics, the work moves from basic computational skills to critical analysis during the primary school years and this too can be problematic for some learners with HFA / AS (Whitby et al., 2009; Whitby & Mancil, 2009). These learners may need additional teacher support in these subjects. Whitby et al. (2009) go on to outline strategies to assist these learners, indicating that inclusion is possible, provided the teacher is instructed in the appropriate strategies. It should be recognised that the cognitive abilities of the learners with HFA / AS have not changed but the method of assessing the cognitive skills has changed as the school years advance (Attwood, 2007).

2.3.6 Class sizes

When working with children with HFA / AS in the mainstream setting, it was felt that small classes were necessary to enhance success of these children (Roberts, 2007). A child with

HFA / AS is likely to cope better academically in a class with small numbers as this gives the teacher time to vary teaching methods according to each child's needs and gives the student increased personal time with the teacher. With a small class, discipline and behavioural challenges are also easier to handle (Simpson et al. 2003). In private schools this is easier to achieve than in government schools due to the increased finances available (Walton et al., 2009).

2.4 Inclusion and HFA / AS

Barratt (2005, p. 10) lists three forms of inclusion to describe three different ways a child with special needs may be accommodated within a mainstream setting to be educated alongside his / her neurotypical peers:

- “Integration: children from special schools or units integrate into mainstream schools for certain lessons.
- Supported Inclusion: as above, however, a support teacher is supplied for the child while in the mainstream school.
- Full Inclusion: a full time mainstream placement without a support teacher.”
[teacher's aide]

In contrast, Fein and Dunn (2007) refer to full inclusion as children with special needs, who attend mainstream schools alongside neurotypical peers if they spend all or most of their school day in the general classroom. They may receive additional one on one support at school or make use of a personal aide in the classroom but are still referred to as being in “full inclusion”.

Landsberg et al. (2005) bring a South African perspective and separate the terms mainstreaming and inclusion by saying with mainstreaming, the child with a disability must “earn” the right to attend school alongside his or her neurotypical counterparts by being able to keep up academically. Inclusion they go on to say looks at how to adjust the outlook of the school to accommodate the child’s learning needs. For the purpose of this study “Inclusion” will refer to Full Inclusion as defined by Fein and Dunn (2007), which encompasses what Landsberg et al. (2005) present. Since many of the inclusion models are based on western approaches, these should be considered in the light of the particular needs presented in Africa (Siewe, 2012). The Educational White Paper 6 (South African Department of Education, 2001b) therefore addresses specific special needs educational issues relevant to South Africa.

2.5 HFA / AS and the Education White Paper 6 (South African Department of Education, 2001b)

The reality of a child with ASD, including HFA / AS, attending a mainstream school is dependent on how that child presents and the educational policies of the country concerned (Jordan & Jones, 1999; Siewe, 2012). The Constitution of the Republic of South Africa (1996, p. 1257) declares in point 29 .1 a) that “everyone has the right to a basic education.” In the Admission Policy for Ordinary Public Schools, point 22 (South African Department of Education, 1996a, p. 4) it is stated: “The rights and wishes of learners with special education needs, must be taken into account at the admission of the learners to an ordinary public school. The South African Schools Act (1996b) requires ordinary public schools to admit learners with special education needs, where this is reasonably practical”. It goes on to say that the schools are to promote change and make accommodations to assist special needs learners in their schools.

However, children with HFA / AS appear to fall into a gap educationally, even though provision is made for their education in educational legislature (The South African Department of Education, 2001b; 1996b) due to the nature of the condition (Schopler et al., 1998; Jordan , 2001; Volkmar & Klin, 2005). The South African Department of Education published the Education White Paper 6 -Special Needs Education Building an Inclusive Education and Training System (2001b, p. 24), in which it states that learners with less severe disabilities be included in mainstream schools. “Learners who experience mild to moderate disabilities can be adequately accommodated within mainstream education through appropriate support from district-based support teams including special schools and specialised settings”. Since children with HFA / AS are considered to have IQs of 80 or above they would not be considered severely cognitively disabled (Whitby et al., 2009) and would therefore be encompassed by the Education White Paper 6 (South African Department of Education, 2001b), for inclusion into mainstream schools. Should a child with HFA / AS have a physical disability such as hearing loss, visual impairment or be in a wheel chair, in addition to the diagnosis of HFA / AS, the enrolment at a mainstream school for that child would be dependent on facilities for those particular disabilities. This study seeks to explore the accessibility to mainstream education for children with HFA / AS and as such they would have peer level cognitive skills. Other disabilities in addition to HFA / AS will not be addressed in this study.

The Education White Paper 6, (South African Department of Education, 2001b), goes on to say that the admission policies for children with special needs will be revised to accommodate these learners in school settings outside of special needs schools. The reality of this policy of admissions for children with HFA / AS will be discussed in this study.

Considering the South African Department of Education published the Education White Paper 6 -Special Needs Education Building an Inclusive Education and Training System in

2001 (South African Department of Education, 2001b), it would be assumed that senior school management staff would be familiar with the policies outlined in the document.

The proposed changes referred to in the Education White Paper 6 (South African Department of Education, 2001b) can be better understood by highlighting the differences in special needs education models. Landsberg et al. (2005) and Jordan (2008) outline a Medical model where learning problems are seen to lie within the child and identifying the problem and providing the most effective treatment for the condition within a special needs educational setting is the goal. The Education White Paper 6 (South African Department of Education, 2001b) refers to this as mainstreaming or integration. In contrast the Social Ecological model seeks to change attitudes towards learners with special needs in order to find the most successful way to facilitate learning for that child (Landsberg et al., 2005). The Education White Paper 6 (South African Department of Education, 2001b) refers to this as inclusion. The Education White Paper 6 (South African Department of Education, 2001b, p. 16) puts forward the ideals of the Social Ecological model, "...about changing attitudes, behaviour, teaching methodologies, curriculum and the environment to meet the needs of all learners". That is, the responsibility for learning lies within the education system and not with the learner, thus accommodation should be made for children with HFA / AS in mainstream schools since they have average or above average cognitive skills (Whitby et al., 2009). Fein and Dunn (2007), explain how children with HFA / AS can have atypical learning styles. The importance of teachers realising the principle of the Social Ecological model within the Education White Paper 6 (South African Department of Education, 2001b) is therefore essential. Due to the age appropriate cognitive skills of a child with a HFA / AS, he / she is likely to be able to interpret and interact with educational curriculum designed for his / her peers. However, there may be those learners with HFA / AS who may need the material presented to them in a manner different from the presentation for their peers due to the

difference in learning styles. These could be in the form of visual presentation, predictable work schedules or simplified instruction (Fein & Dunn, 2007).

2.6 Barriers and solutions to inclusive education for children with HFA / AS

Conclusions from Carrington's paper (1999) were that the attitudes of educators directly affect the success of inclusion. How educators perceived their roles and responsibilities towards learners with special needs influenced the acceptance of these learners. One could conclude that these attitudes would be applicable to school Principals who act as gatekeepers to the schools. Her paper reflects the information presented in the Education White Paper 6 (South African Department of Education, 2001b) which states ongoing training as well as pre-service training of educators is needed to make inclusion successful. However, Carrington (1999) goes on to say that attitudes and beliefs of educators need to be addressed as studies have shown that staff enhancement programmes are unsuccessful in changing a person's outlook. The teachers need to be willing to make changes to allow the child with ASD, including HFA / AS, to achieve maximum learning outcomes (Koegel et al., 2011). Educator support and hands on guidance of new programs for educators with favourable outcomes have been able to bring about a new point of view or new mindset towards inclusion (Carrington, 1999).

Attitudes of school staff were reported to affect the acceptance of students with special needs, including Asperger's Syndrome, into mainstream schools in New Zealand (Education Review Office, 2010). Parents lodged complaints about enrolment problems, among other issues. The students were reported to have had less access to time with the teachers and were assumed to hold lower value as students and participants in general school activities than their neurotypical counterparts. Funding for classroom assistants was reported as lacking and the

view the teachers had about their own roles as educators was reported to have influenced the above factors (Education Review Office, 2010).

In Ghana (Anthony, 2009) the pursuit of acceptance of children with ASD into mainstream schools was questioned under the presence of the following challenges: limited teacher training in ASD, teaching curriculum which are rigid, peer learner intolerance and sizeable numbers per class. In contrast to Autism Independent, UK (2010), Anthony (2009) in the Ghana study found that the educators had lowered expectation of the learners with ASD, and this coupled with challenges already listed would not hold a positive outcome for learners with ASD in mainstream schools. Currently there are no such studies for learners with HFA / AS.. In order to change attitudes and work towards positive acceptance of those with HFA / AS in mainstream schools, training is essential. Without a change in attitudes the abilities of those with HFA / AS cannot be recognised and their educational options would therefore remain fixed (Attwood, 2007).

Ainscow and Haile-Giorgis (1998) in a study commissioned by UNICEF, report that children worldwide with various disabilities have historically been barred from education due to their conditions. The researchers concluded that the barriers to mainstream education for children with special needs in Central and Eastern Europe were mainly attitudinal and financial. Attitudinal barriers were that these children were best attended to in special needs schools, that the status quo of the traditional education system should be maintained and that these children must fit into the current educational structure. This means that a child's individual learning style is not considered, and the current system is inflexible to accommodate the child. This typifies the Medical model (Landsberg et al., 2005; Jordan, 2008) where the child must adapt to the system and that the system does not accommodate the child. This has been the approach of the traditional school system in South Africa (The South African Department of Education, 2001b).

Likewise Pivik, McComas and Laflamme (2002) in a study in Canada, entitled *Barriers and Facilitators to Inclusive Education*, mention attitudes amongst barriers to mainstream education for children with special needs. The attitudes which formed barriers to mainstream education for children with special needs were: the lack of familiarity of a condition or the perception of it, as well as the deliberate rejection of the disability in the form of isolation or bullying. Barnard, Prior and Potter (2000) revealed that twenty percent of children with Autism or Asperger's Syndrome in the United Kingdom are excluded from school for some time at some stage during their educational years. The study revealed the barrier to be difficult behaviour and the lack of staff training to deal with that behaviour.

The concept of inclusion is relatively new to South Africa and traditionally only neurotypical children attended mainstream schools (The South African Department of Education, 2001b). There are currently no data on what barriers exist to children with HFA / AS being accepted into mainstream schools. Some such barriers which have been expressed to the researcher informally during Autism support meetings by parents of children with Autism include; teachers being untrained to work with children who learn in different ways from neurotypical children, lack of understanding around ASD, large classes, time restraints, and the absence of teacher assistants.

Other areas forming barriers to mainstream education for children with ASD expressed by Anthony (2009) are economic resources and confusion about placement. Placement issues can be an ongoing source of difficulty as a child with HFA / AS or ASD in general will have fluctuating education needs over his or her school years (Jordan & Jones, 1999). In Ghana, as in KZN, not all children with ASD are in school (Action in Autism, n.d). Budget planning for ASD does therefore not account for these children and future services are therefore restrained. In addition, cultural barriers (such as how an individual with a disability is perceived in Ghana) are mentioned as responsible for limited access to schooling for children

with ASD. Access to education can be based on the predicted success of the child, and children with ASD due to the presentation of the condition can be deemed unsuccessful candidates. The children were seen as “useless and not capable of learning” (Anthony, 2009, p. 14). In conjunction with the cultural views are religious beliefs that the child has a curse or that witchcraft was responsible for the condition which promoted stigmatism for the child (Anthony, 2009).

Managing these obstacles and allowing children on the Autism spectrum access to mainstream schooling can give the children with Autism Spectrum Disorders valuable developmental input as well as be of benefit to the neurotypical children in the classroom (Fein & Dunn, 2007; Yssel et al., 2007). Additionally the teaching skills and experience of the school staff can be expanded following this educational approach. Autism Independent, UK (2010) presents the idea that in a mainstream school, educators hold higher expectations of the learners with ASD than their counterparts in special needs schools. Therefore, children with ASD in mainstream settings would be given greater opportunities to grow educationally than in a special needs school placement (Fein & Dunn, 2007). In the Autism Spectrum Disorder Inclusion Collaboration Model (ASDICM) (Simpson et al., 2003), a method is outlined to help support educators working with children with ASD. The underlying premises are that it is beneficial to both children with ASD and neurotypical children to be educated alongside one another and that given suitable support and resources educators are open to inclusion of certain students with ASD [HFA / AS] in the mainstream setting. This supports the views of Fein and Dunn (2007). The ASDICM states that educators are willing to take on the main responsibility of teaching the children with ASD provided there is involvement from special education staff and other support staff, such as remedial teachers, psychologists or occupational therapists. The ASDICM is contingent on collaboration, as the name suggests: collaboration between teachers, special education teachers, and support staff. This is in

agreement with the Education White Paper 6 (South African Department of Education, 2001b) where support for teachers working with children with special needs in mainstream schools is proposed to come from district based support teams and specialised staff, such as remedial teachers.

The ASDICM is built upon five pillars:

- “Environmental and curriculum modifications, general education classroom support and instructional methods
- Attitudinal and social support
- Coordinated team commitment
- Recurrent evaluation of inclusion procedures
- Home-school collaboration” (Simpson et al., 2003, p.17)

The stress levels of parents of children with ASD have been noted to be lower when the parents are actively involved in the education of their children and the children experience more positive parent interaction as a result (Schetter & Lighthall, 2009). This is an additional benefit of parental involvement at the educational level of children with HFA / AS.

The importance of collaboration between home and school for the success of children with ASD in the mainstream environment is also presented amongst other ideas by Yssel et al., (2007). In their study comparing parents’ experiences of inclusion in South Africa and America, they found that the barriers in South Africa were teacher training and the need for parent involvement in the child’s education. Parents felt that inclusion could not be successful if the parents of the special needs child were not actively involved in the education process of their children. This is a concept also raised by Koegel et al. (2011) and Matthews and

Matthews (2012). An additional barrier in the South African setting, not experienced by the American parents was that of finances. The South African parents are financially responsible for hiring class assistants, facilitators and various therapists for their children to enable them to attend mainstream schools. Another financial issue in some areas in South Africa where families are from low income backgrounds, is that of transport (Kujwana, 2008), which prevents parents having regular contact with their children's teachers.

In their reflection on The charter of rights for people with Autism, Matthews and Matthews(2012) note that in countries where education is free, parents of children with Autism (including HFA / AS) should not have to incur any additional cost to educate their children. Likewise, in countries where education costs are covered by the parents, the educational cost for a child with ASD (including HFA / AS) should not be greater than the costs encountered by that of a neurotypical child within the same educational setting. The education of a child with ASD should not place a severe financial burden on the family of that child. For children with HFA / AS in South Africa, however, this is not the case (Yssel et al., 2007). Some South African school teachers also face a challenge in partnering with parents in the education of their special needs children in that some parents are illiterate or have limited education (Kujwana, 2008). This leads to misunderstanding between the two parties, lack of unity and increased anxiety.

Harrington (2011) agrees with the importance of parent involvement for successful inclusion of children with Asperger's Syndrome in mainstream schools. She says that parents of children with Asperger's Syndrome, who were included in mainstream schools in Australia, reported they needed to take the initiative in dealing with teachers. They also reported the need to follow up on classroom strategies to ensure that inclusion was successful for their children. Parents in essence needed to be active advocates for their children ensuring policies

were adhered to, to meet their children's educational needs. Open communication between school and parents was viewed as essential.

In their study, focused on general inclusion in private schools in South Africa, Walton et al. (2009) found that barriers to acceptance of learners with special needs were overcome depending on the challenge presented by each special needs situation. Solutions included teacher support, physical structural changes (to access wheelchairs), specialist staff, changes in learner assessment and changes in teaching methods. For special needs learners with HFA / AS many of the solutions mentioned by Walton et al. (2009) would apply; those being teacher support, in the form of training on ASD / AS and specialist staff (meaning therapists) (Roberts, 2007); changes in learner assessment, taking into account the communication challenges of children with HFA / AS and changes in teaching methods, by means of visual supports (Fein & Dunn, 2007).

It should be noted, however, that private schools do have access to greater funds to make these changes possible compared to government schools (Walton et al., 2009). The significance of some barriers being overcome in the private school arenas in South Africa (as listed above), gives hope that government schools may be able to follow suit in the future.

2.7 Conclusions from Chapter Two

The South African government seeks to address the need for training of educators to implement inclusion in our country by means of district support teams, pre-service and in-service training as well as providing professional support services (South African Department of Education, 2001b). The teacher's role is undoubtedly essential for the educational success of a child with HFA / AS and without suitable supports in place to educate the teachers on the awareness of the condition and understanding of it, those children diagnosed with HFA / AS could experience difficulties such as loneliness, nervousness, anxiety and depression

(Attwood, 2007). However, it was also acknowledged in the Education White Paper 6 (South African Department of Education, 2001b) that there will be financial implications for such strategies but that in the long run, inclusive education will increase the number of productive citizens and therefore lead to a drop in the country's fiscal burden. Discovering what the barriers to mainstream education are, for children with HFA / AS in two selected circuits of the Umlazi school district, will provide input for change in teacher training in those areas and will therefore support the changes presented in the Education White Paper 6 (South African Department of Education, 2001b). This will potentially also support the educators as individuals in the execution of their jobs, as well as be a support for schools who wish to be true to the Education White Paper 6 (South African Department of Education, 2001b) but who are currently ill-equipped to do so.

The Education White Paper 6 (South African Department of Education, 2001b), Pivik et al. (2002) and Barnard et al. (2000) reveal that there are realistic challenges to inclusive education for children with special needs. In the South African Journal of Education, Engelbrecht, Swart and Eloff (2001), in a study on inclusive education for children with Down syndrome and the stressors caused to educators by inclusion, concluded that educators needed greater support to meet the needs of special needs learners in a mainstream setting as well as further training to be effective in their roles as educators. They suggest that although their study was of limited scope, it is probable that similar results would be found in other inclusive situations in mainstream schools in South Africa. Presumably inclusive education for children with HFA / AS would follow this account.

Therefore, this study aims to explore the barriers to mainstream primary school education for children with High Functioning Autism / Asperger's Syndrome and the ideals presented in the Education White Paper 6 (South African Department of Education, 2001b), to adopt such children into mainstream schools.

2.8 Summary of Chapter Two

The educational placement needs and options for children with HFA / AS were discussed in this chapter. Reference was made to the limited services for children with HFA / AS in South Africa and in particular KwaZulu-Natal. International studies as well as research from South Africa were reflected upon in this chapter to give an overview of the problem as well as highlight the experiences of mainstream schools which accept children with disabilities and in particular Autism Spectrum Disorders. Challenges associated with mainstream schooling for learners with HFA / AS were raised. This information was processed with reference to the Education White Paper 6 (South African Department of Education, 2001b) which regards mainstream education as being available to all children with mild disabilities (such as HFA / AS). Lastly, barriers and solutions to inclusion to mainstream schooling for learners with HFA / AS were discussed in Chapter Two.

“They knew I had my own way of doing things, and they didn’t interfere with my methods so long as the effort was genuine and the result positive”

Liane Holliday Willey- Adult with Asperger’s Syndrome.

Taken from “Pretending to be normal” 1999, p. 22

CHAPTER THREE: METHODOLOGY

3.1 Introduction

In Chapter Three the aims and objectives of the study are presented. The motivation for the research method chosen, that being, mixed methods, using quantitative and qualitative elements is explained. The procedures for each of the phases of the study is outlined including; the target population, participant selection criteria, sampling technique, data collection method, data gathering instrument and data gathering process. The pilot study process along with results from the pilot study will be presented and validity and reliability relevant to the study will be outlined. Procedures used to analyse data for the study will be discussed. The ethical considerations for the study will be discussed in Chapter Three.

3.2 Aim and objectives of the study

The aim of this study was to determine and explore barriers to admission to mainstream primary schools for children with High functioning Autism / Asperger’s Syndrome in two circuits of the Umlazi school district.

This aim was achieved by means of addressing the following objectives:

- To explore reasons for refusal to admission into mainstream schools for children with HFA / AS
- To explore schools' perceived barriers to mainstream education for children with HFA / AS
- To explore the experiences of admission or attempted admission to mainstream education for parents of children with HFA / AS
- To explore the encounters of schools who admit children with HFA / AS
- To determine the current numbers of children with HFA / AS admitted into mainstream primary schools in a specific population
- To explore possible ways barriers to admission to mainstream schools for children with HFA / AS may be overcome

3.3 Research methodology

A mixed methods design was used in this study including Phase 1: A descriptive survey questionnaire, where data were descriptively analysed as well as Phase 2: A focus group, where data were thematically analysed. Additionally an autoethnographical essay contributed data to the study. This element was also thematically analysed. Tashakkori and Teddlie (2010) discuss how using mixed methods research is not to overcome faults of contrasting methods but to adopt different research methods- traditionally thought to be mutually exclusive- to effectively answer interrelated research questions (Creswell & Plano Clark, 2007). Mixed methods research also gives a broader evidence base of data than qualitative or quantitative research could provide alone in a study, giving a more comprehensive and confident conclusion on the research topic (Vaughn, Schumn & Sinagub, 1996; Delport & Fouche', 2011). Although mixed methods research design is a relatively new concept, it is

now recognised as a valid means to conduct a research study (Creswell & Plano Clark, 2007; Delport & Fouche', 2011). The two phases of the study are described below.

Phase I: A descriptive survey questionnaire was used to present a broad brush stroke of the current situation of admission of children with HFA / AS into mainstream primary schools in the specified population. Descriptive analysis took the form of simple frequency distributions.

Phase 2: A focus group was utilised to collect qualitative data from parents of children with HFA / AS by means of open-ended questions for group discussion. Their experiences in enrolling their children in mainstream primary schools and any possible barriers encountered to the process of admission were explored. Tashakkori and Teddlie (2010) note the practice of using the quantitative component of a study to influence the qualitative sample; however, in this study the results of the quantitative section were used to construct the content of the interview schedule for the qualitative section of the study.

Additionally an autoethnographical (Holstein and Gubrium, 2008) element was applied to this study in the form of a personal essay written by the researcher. This method seeks to connect the experiences of a researcher, the experiences of others and current cultural issues (Holstein and Gubrium, 2008). The essay outlined the researcher's own experiences in enrolling her son with HFA/ AS into mainstream schooling. Analysis was done by two parties, firstly by an analyst separate from the researcher to prevent researcher bias due to the researcher's relationship with the topic and secondly by the researcher as is traditional in the autoethnographic method (Ellis, Adams & Bochner, 2011). The essay was thematically analysed. The autoethnographical essay is part of the qualitative element of the study but does not form part of Phase 2, which is a focus group.

These three sources of data ensure triangulation of data and thus contribute to greater validity of the outcome (Babbie & Mouton, 2007; Creswell & Plano Clark, 2007). The data collected from these three sources were compared, contrasted and discussed in response to the research objectives.

The following sections will be discussed separately for Phase 1 and Phase 2 of the study: target population, participant selection criteria, sampling technique, data collection method, data gathering instrument, data collection process, pilot study, validity and reliability and data analysis. Following this, the data from the two phases and data from the autoethnographic essay will be integrated. (Please see section 4.6 of Chapter Four, Results and discussion).

3.4 Phase 1: Descriptive survey questionnaire

3.4.1 Target population

The target population for this phase was senior management staff of government primary schools in selected circuits of the Umlazi school district. These two circuits of the Umlazi school district are of interest to the researcher due to the location of her work. Since the researcher works as a behavioural therapist with children with ASD (including HFA / AS) in the Umlazi area the available schooling for these children is of significance to the researcher.

Two urban circuits of the Umlazi school district are comprised of 216 government schools. Within these two circuits are eight wards. All high schools from the list were eliminated, leaving 154 mainstream government schools which cater for primary school children. These 154 schools make up the population for this study.

3.4.2 Participant selection criteria and description

The population of a study must be relevant to the study (Stewart, 2007). The participant schools in the study were therefore primary schools in two circuits of the Umlazi school

district. A questionnaire was completed by one of the following senior school staff members: the Principal, the Deputy Principal or a Head of Department. Teachers or other staff members are not typically part of the admission approval process of potential learners and were therefore not included as participants. This is presented in Table 3.1 below.

Table 3.1: Selection criteria for school staff

Selection criteria of school staff participating in the study	Motivation for selection
Principal	<p>Principals (in conjunction with the school board) are gate keepers for admissions to schools. They are key people involved in decision making for the school policies and influence the attitudinal tone for the school (Williams, 1983). They are actively involved in the admission procedure for learner applications. Additionally Principals are responsible for staff morale and enthusiasm (Coleman, Thurlow, & Bush 2003). This applies to attitudes towards special needs including attitudes towards children with HFA / AS. These potential attitudes of the Principals could influence staff support of the acceptance of children with HFA / AS into the school concerned.</p> <p>The Principal is also responsible for keeping records of all learner admissions at the school (KwaZulu-Natal Department of Education, 2010 Admission policy for ordinary public schools).</p>
Deputy Principal	<p>The Deputy Principal stands in place of the Principal assuming the duties of the Principal in the absence of the Principal and acts as a support to the Principal. The Deputy Principal is also involved in school administration and systems (Coleman et al.2003).</p>
Head of Department	<p>The Head of Department takes on the role of the Deputy Principal in schools where no position for a Deputy Principal is held. The role of the Head of Department is to be a subject specialist as well as to give administrative support (Coleman, et al.2003).</p>

Twenty-eight senior staff members completed the questionnaires. Twenty-five of the 28 were Principals or Deputy Principals and three were Heads of Department. To ensure all senior

school staff participating in the study met the selection criteria, a letter accompanied the questionnaires, which was addressed specifically to the senior staff members requesting the completion of the questionnaire (See Appendix D for a copy of the letter). Additionally, it was specified on the questionnaire that completion was to be done by a Principal, Deputy Principal or Head of Department only. Participants were asked to mark the box which applied; to give the researcher assurance that completion was made by the appropriate person (See Appendix A for a copy of the questionnaire).

Two circuits of the Umlazi school district were selected for participation in the study. These areas were chosen as they hold significance to the researcher who works as a behavioural therapist in those regions. In addition the schools in the areas presented with a range of resources, class sizes, grades available, number of children per school and genders enrolled giving a cross section of the community. All schools were mainstream primary government schools. Twenty-seven of the 28 schools which returned questionnaires consisted of female and male learners. One school was a female only school. All but one school requested feedback on the study following its conclusion. Of the participant schools, two schools offered grades R to grade 3, three offered grades 4 to 7, five offered grades 1 to 7 and 18 offered grades R to 7. Twenty schools in total offered grade R (along with other grades). Thirteen of the 28 schools had between one and 30 children per class and were able to accommodate between 501 and 750 learners. Further discussion on class size and number of children per schools as well as grades offered at schools is given Chapter Four in section 4.2.3. The selection criteria for schools participating in the study are presented in Table 3.2. below.

Table 3.2: Selection criteria for participant schools in the study and motivation therefore

Selection criteria for schools participating in the study	Motivation for selection
<p>The school must be a primary school</p>	<p>The importance of the schools being primary schools is that inclusion in the South African context is a relatively new concept; it is thus unlikely that older children with HFA / AS would have had the opportunity to benefit from inclusive education in the past and are therefore unlikely to make the change to a mainstream school in high school (South African Department of Education, 2001b).</p> <p>Preschools do not form part of this study, as preschool is not considered formal schooling and falls under Early Childhood Education, for learners aged 3-5 years (South African Department of Education, 2001a).</p>
<p>Children enrolled at the school must be within the primary school age range of 4.5-12 years</p>	<p>Learners can enrol for grade R between the ages of 4.5 years and 5.5 years (KwaZulu-Natal Education Department, 2010). Children should complete grade 7 at age 12, with the exception of children who have repeated a year or years during primary school education (South African Department of Education, 1996b).</p>
<p>Grades offered at the school must be in the range between Grade R and Grade 7, with a minimum of three grades within the specified range</p>	<p>Schools with fewer than three grades would have reduced opportunity for observation of children with ASD. Grade R is currently also not part of formal schooling but the Education Department is moving towards including it in the formal schooling years. A goal was set in the Education White Paper 5 (2001a) to have all children who enter Grade 1 by 2010 attend a grade R year. In the KwaZulu-Natal Department of Education's Annual Report 2010/2011 this was said to be achieved in excess of 85% (2011a).</p>

The school must be a mainstream school	Exkorn (2005) outlines the benefits of inclusive education for children with HFA / AS. This study focuses on barriers to inclusive education for children with HFA / AS, therefore special needs schools will be excluded.
The school must be a government school	The value of selecting government schools is that they are subject to the requirements of the South African Education Department and therefore one would expect them to follow the relevant policies and legislation of the country (South African Education Department, 2002).

To ensure participant schools met the selection criteria, a list of government schools in the target area, including contact details for the schools, was obtained from the KZN Department of Education district office. The researcher personally hand delivered questionnaires to the schools or hand addressed envelopes which were sent to the schools to ensure only schools which met the selection criteria were contacted regarding the study.

3.4.3 Sampling technique

Convenience sampling was used to determine the target areas for schools. Convenience sampling is one of the most commonly used sampling techniques due to the low costs involved and the time efficiency (Stewart, 2007; Gravetter & Forzano 2010). Cost and time, however, should not take from the need for participants to effectively answer the research questions (Stewart, 2007). The two selected circuits of the Umlazi school district hold interest for the researcher as the researcher works as a behavioural therapist with children with ASD who live in the Umlazi area. Therefore available schooling for these children is of significance to the researcher. The receptiveness of the schools in this district to children with HFA / AS is of relevance. The location is therefore practical and convenient. A list of mainstream primary schools in the Umlazi district was obtained from the KZN Department of

Education's District office and two circuits of the Umlazi school district were identified from this list to establish the population of the study.

3.4.4 Data collection method

A descriptive survey questionnaire was utilised to obtain data from the schools. Due to the size of the population being studied and the volume and variety of data collected, this method was chosen, since surveys are an efficient method of gathering large amounts of primary data from relatively large population groups (Babbie & Mouton, 2007). A survey should only be considered as an effective data gathering tool if it is known that the participants are literate (Babbie & Mouton, 2007). In this study the persons completing the questionnaire were senior school staff members, where it was assumed all are literate, having completed secondary and tertiary education. Data were collected concerning the understanding of HFA / AS, the number of children with HFA / AS present in the schools, the barriers to admission to the schools for children with HFA / AS, the structure of the schools and conditions needed to remove barriers to admissions for children with HFA / AS.

In order to obtain particular information from mainstream schools on admission of learners with HFA / AS, a questionnaire was constructed. Questions about the admission of children with HFA / AS to mainstream schools were developed based on the literature survey and the use of policy documents, combined with the researcher's experience as a behavioural therapist working with children on the Autism spectrum. Although qualitative studies on the topic were found (Yssel, et al., 2007; Walton et al. 2009; Kujwana, 2008; Harrington, 2011), no similar existing questionnaire was found in the literature, therefore the researcher designed a questionnaire to fill this aim.

3.4.4.1 Data gathering instrument

The questionnaire was developed using the aim and objectives of this study and was submitted to the departmental statistician where it was scrutinised and approved (Mrs Fikile Nkwanyana Biostatistician / Lecturer College of Health Sciences University of KwaZulu-Natal 16 March 2012). The proposed questionnaire was also presented to a Deputy school Principal and the researcher's supervisor and co-supervisor for review and discussion of the questionnaire content, type of questions developed and to establish a base time a participant would take to complete the questionnaire. This questionnaire was later piloted (See section 3.4.5.).

The questionnaire comprises 28 questions: eight open ended questions, six fixed response questions, five multiple choice questions and nine contingency questions. The questionnaire was designed to take 10-20 minutes to complete. Eiselen and Uys (2005) suggest that a self administered questionnaire should take no longer than 15- 20 minutes to complete and that self administered questionnaires longer than that time, are likely to directly negatively influence response rates. A more precise time estimate was determined after the pilot study had been completed.

Below is Table 3.3 which presents the sections and motivation for sections included in the questionnaire.

Table 3.3: Sections included in the survey questionnaire and motivations therefore

Sections and questions		Motivation for inclusion in the study
A	Biographical information of senior staff member completing the questionnaire	Variables such as age, gender, years of teaching experience and training may contribute towards a senior staff member's attitude about learners with HFA / AS being accepted into the school concerned. Horrocks, White and Roberts (2008) found that demographics such as gender, years of experience as a Principal, formal training in the field of ASD and professional experience positively influenced the Principal's placement recommendations for learners with ASD in mainstream schools. Age of Principals close to retirement age was shown to affect negative attitudes towards inclusion (Geduld, 2009). These variables were looked at in relation to data collected from the senior staff members who completed the questionnaire.
B	Information regarding the structure of the school	Walton et al. (2009) in their study on inclusion found that how the school was structured, for example in terms of support staff, positively affected inclusion. However, the study involved private schools which they note have small classes. Areas such as these were investigated in this study regarding government schools.
C	Enrolment history and experience of children with HFA / AS in the school	The experiences of schools which have had learners with HFA / AS enrolled in the past may influence the attitude towards repeating the process in the future. Should a child with HFA / AS have attended the school in the past and achieved well, it was likely that the school management will look positively on accepting another learner with HFA / AS in the future. Likewise, a negative experience with a learner with HFA / AS is likely to hinder acceptance of another learner with HFA / AS in the future (Barnard et al., 2000). However, each child on the Autism spectrum presents differently within the triad of impairments (Exkorn, 2005), so past experience can easily form a barrier to enrolment in the form of attitudes of stereotyping and biases.

D	Barriers to enrolment for children with HFA / AS and conditions needed to overcome these barriers	Ainscow and Haile-Giorgis (1998) concluded that barriers to inclusive education for special needs learners were attitudes and finances, while Barnard et al. (2000) found lack of staff training and difficult behaviour from learners with HFA / AS to be barriers to acceptance of learners with special needs into mainstream schools. Pivik et al. (2002) found bullying to be among the barriers as well as other attitudes being barriers. Thus a variety of barriers were explored.
E	Understanding of HFA / AS and related attitudinal barriers	A senior school staff member's understanding of what HFA / AS is will influence that person's attitude about suitability of a learner with HFA / AS in the school concerned. Misunderstanding about or lack of familiarity with a condition was seen to be a barrier to inclusive education for children with special needs in the study by Pivik et al. (2002).
F	Understanding of the Education White Paper 6 inclusion policy for children with special needs (including HFA / AS) and government support	<p>The Education White Paper 6 (South African Department of Education, 2001b) is an official government document and understanding of how this special needs document should be implemented in a school will influence a senior staff member's actions in terms of accepting or rejecting a child with special needs (specifically HFA / AS for this study) into the school concerned.</p> <p>Likewise, the Education White Paper 6 (South African Department of Education, 2001b) outlines that one of the conditions needed in overcoming gaps with special needs learners in mainstream schools is teacher support and training.</p>

Sections A-C of the questionnaire regards facts about the person completing the questionnaire as well as facts about the schools participating in the study. Section D concerns barriers to mainstream education for children HFA / AS and possible conditions needed to overcome the

barriers. Sections E and F regard understanding and views about HFA / AS and government policy.

The formulation of these categories was based on the barriers found in the literature (Barnard et al., 2000; The Education White Paper 6, South African Department of Education, 2001b; Pivik et al., 2002; Anthony, 2009; Walton, et al., 2009) as well as the researcher's experience as a behavioural therapist and her clients' experiences of barriers to mainstream schooling. In addition information presented to the researcher in her role as the facilitator of a support group for parents of children with ASD was used to construct the categories. (See Appendix A for a copy of the questionnaire).

3.4.4.2 Data collection process

Following ethical clearance being granted by the Humanities and Social Sciences Research Ethics Committee of University of KwaZulu-Natal (See Appendix B for a copy of the letter) permission was requested from the KZN Department of Education to conduct this study in the Umlazi school district (See Appendix C for letter of permission from the KZN Department of Education, please also see section 3.8 for additional information). The KZN Department of Education is the gatekeeper for entry into schools for this study. Written permission was therefore needed from the KZN Department of Education before the research could commence. Permission was given on 11 June 2013 via electronic mail. A hard copy was later received via the South African postal service. Following the permission from the KZN Department of Education, Principals of mainstream primary schools in the two selected circuits of the Umlazi school district were contacted regarding participation in the research and questionnaires were distributed.

The distribution of questionnaires was done in one of three ways; sent electronically to schools, sent via the South African postal service or in the case of schools which were in

close proximity to the researcher, delivered by hand. Email responses received by the researcher were printed out and posted questionnaires included stamped envelopes addressed to the researcher's residence for return. Responses from hand delivered questionnaires were collected either by the researcher or for schools which were further away from the researcher's residence, stamped envelopes addressed to the researcher's residence were included with the questionnaires when delivered (Babbie & Mouton, 2007). These were returned via the South African postal service. When no further emails were returned, attempts were made to contact the remaining schools via telephone. Telephonic attempts were also made to contact all other schools which had not returned questionnaires which were hand delivered or sent via the South African postal service. Babbie and Mouton (2007) outline the option of mixing methods for collecting questionnaires, adding that hand delivered and collected questionnaires yield a higher response rate.

Attached to each questionnaire was a covering letter explaining the purpose of the study and information about the researcher and the university represented (UKZN) (Babbie & Mouton, 2007). The letter discussed the importance of participating in the study to assist with offering information about children with HFA / AS in mainstream schools and how to overcome barriers to enrolment for these children. It also outlined how long the questionnaire would take to complete and when it should be completed by as well as how to return the questionnaire once completed. The letter also included information about confidentiality regarding the participating schools' identities (Eiselen & Uys, 2005). An informed consent form accompanied the letters. Each person wishing to participate in the study was asked to give their consent to participate in the study by completing an informed consent form. A copy of the consent form was given to each participant (See Appendix D for copies of the letter to schools and informed consent forms).

The questionnaire was administered to the Principal, Deputy Principal or a Head of Department only. This was to eliminate responses from staff members who may have minimal or limited experience or limited involvement in the enrolment process of learners. Principals (in conjunction with the school board), being gate keepers for the school, are key people in deciding policy for the school and are therefore actively involved in admission procedure for learner applications. Teachers will not have the same authority as to who is accepted or refused from the school (Williams, 1983).

The Principal, Deputy Principal or a Head of Department of the schools were requested to complete the questionnaire in writing or via email depending on the presence of internet access at the school.

3.4.5 Pilot study

3.4.5.1 Validity and reliability testing:

Validity in a research study can be understood as “the concern for the truth of the research or the accuracy of the results” or “the degree to which the study accurately answers the question it was intended to answer” (Gravetter & Forzano, 2010, p. 167). This can be achieved in a study by addressing the quality of the process of gaining data. This means the measure used to gather data must be an appropriate means to do so (Babbie & Mouton, 2007; Creswell & Plano Clark, 2007). Due to the time and budget restraints of this study, it was not possible to use the test-retest method of establishing reliability. Other tests of reliability were not relevant with the different measuring instruments involving different populations that were used in the research. Validity was developed by means of face and content validity. To this end, the questionnaire for the focus group contained concepts derived from the literature, and was guided by specialist evaluation. A pilot study of the questionnaire was conducted (Creswell & Plano Clark, 2007). The outcome from the pilot study was that the content

pertaining to schools and ASD was accurate (See Table 3.4). This was established by the professionals and specialists who participated in the pilot study. Content validity was therefore the focus. To develop the proposed questionnaire, before piloting it, it was presented to a biostatistician, a Deputy school Principal, the supervisor and the co-supervisor of the researcher for discussion, to assess content and appropriateness of questions asked. Content validity was further addressed during the pilot study.

Tashakkori and Teddlie (2010) comment on the importance of pilot studies to evaluate the appropriateness of a tool for a given study. Adjustments made to the instrument resulting from the pilot study should be used to refine the instrument. The pilot study is part of the development of the research. The questionnaire was therefore piloted in a study conducted before the research was initiated, to determine the validity of the questionnaire. The questionnaire was given to an individual who held the position Deputy Principal in a mainstream primary school in the target area in the past as well as to the head of an Autism facility (therapy centre) in KwaZulu-Natal to complete. The need for a Deputy Principal of a mainstream primary school to pilot the questionnaire was to determine if the questions are applicable to the mainstream setting and the importance of the Autism specialist was to determine the validity of the content, specific to ASD, in particular, HFA / AS.

3.4.5.2 Deputy Principal

The profile of a person who had held the position of Deputy Principal at a school in the Umlazi district in the past and who is currently working at a private school in the role of the Head of Department was identified. The researcher contacted this person via email. The person agreed to complete the questionnaire for the pilot study. The person was approved by the researcher's supervisor considering she had worked in the target area in the past and that she had held the position of Deputy Principal, which is one of the criteria for participants for the main study.

The researcher emailed the questionnaire, the covering letter and letter of consent to the pilot study participant. The email also included instructions about recording the length of time taken to complete the questionnaire and requested comments regarding clarity of the questions asked. The participant completed the questionnaire and emailed it back to the researcher. There were no comments about the lack of clarity and length of time to complete the questionnaire. The researcher then met with the participant, who said the questionnaire had taken 30 minutes to complete and that no questions were ambiguous or confusing. She did mention, however, that she did not know what PDD-NOS was and that she took time while filling out the questionnaire to research it online. PDD-NOS is mentioned in the covering letter which accompanied the questionnaire, so it would appear that the participant did not read that section of the covering letter clearly. The time needed to complete the questionnaire was therefore estimated to be approximately 20 minutes.

3.4.5.3 Autism facility

The researcher contacted a well known Autism facility (therapy centre) in the greater Durban area, via email and telephone regarding participation in the pilot study, as no facility was found in the target area (Umlazi district). One of the managers of the centre agreed to participate in the pilot study and the researcher delivered the questionnaire. The researcher explained that the purpose of the manager's participation in the pilot study was to review the HFA / AS content of the questions and to give feedback regarding terms used, clarity of questions and length of time taken to complete the questionnaire. Following the completion of the questionnaire, the researcher asked the manager if any changes were need to the questionnaire. The manager replied that she did not understand question 21.a). Question 21.a) states "For each method marked above, indicate what criteria you apply to the screening methods." However, she was able to complete the section and on review by the researcher, the question had been answered correctly. It took the manager less than half an hour to

complete. The manager evaluated the questionnaire to be suitable for use in the study and confirmed that the content pertaining to HFA / AS was correct.

Following the independent completion of the questionnaires by the Deputy Principal and the Autism facility manager, the researcher then met with the individuals separately to ask about changes needed to the questionnaire. In both instances the information was recorded on a form and later used to adjust the questionnaire. The data obtained from the pilot study were used to finalise the instrument and to address the following to ensure validity:

- What changes needed to be made to the design of the questionnaire and to the content of the questionnaire
- If any questions were offensive to the participants
- If any questions were misleading or ambiguous
- If instructions to complete the questionnaire were clear (Gomm, 2008)
- If the time taken to complete the questionnaire fell within the goal time of 10-20 minutes (Eiselen & Uys, 2005).

The pilot study revealed that changes were not needed to the content of the questionnaire.

The questions were not found to be offensive or misleading but one question, question 21. a) was found to be unclear. The time estimated to complete the questionnaire remained unchanged, although 10 minutes to complete the questionnaire pertained to schools which did not have learners with HFA / AS enrolled. Approximately 20 minutes pertained to schools which had experience with learners with HFA / AS and would therefore take longer to record their experiences than schools which did not have learners with HFA / AS enrolled. Results from the pilot study are represented in the Table 3.4 below.

Table 3.4 : Changes made to the questionnaire following the pilot study

Areas for possible changes	Changes made	Changes specified
Content changes	none	n/a
Offensive questions	none	n/a
Misleading or ambiguous questions	none	n/a
Unclear instructions	yes	Question 21. a) examples were given for clarity to assist participants in completing this question
Time to complete the questionnaire	none	n/a

The reliability of a study explores the extent to which the study can be replicated over a similar setting under similar circumstances and achieve the same results. That is, the study must be consistent and dependable over time (Cohen, Manion & Morrison, 2007). A questionnaire was used for this study but due to time and budget restraints, it was not possible to design an equivalence study to test reliability or to use the test- retest method to establish reliability. This is one of the limitations of this study. Engelbrecht et al. (2001) collected data from 10 schools where children with Down syndrome were educated in a mainstream school and proposed that it would not be improbable for their findings to be transferable to other schools in South Africa practicing inclusion. Likewise, due to the relatively new approach to inclusion in general in South Africa and the inexperience of mainstream educators in the field of ASD, it is possible that a study of this nature done in other school districts in KwaZulu-Natal may reveal similar results.

Validity of this study was also enhanced as the target area from which data were collected comprises schools from varying economic and social standings. This means data collected from other regions is likely to yield similar results to the target area for this study as this target area is not unrepresentative of other urban school districts.

3.4.6 Data analysis

The purpose of the survey was to obtain an overview of the current situation regarding barriers to admission to mainstream education for children with HFA / AS to schools in selected circuits of the Umlazi school district.

The quantitative data collected by closed questions in the questionnaire were represented using descriptive statistics (Babbie & Mouton, 2007). The data collected were captured and subsequently analysed using the Statistical Package for Social Sciences (SPSS version 19), with the assistance of Mrs Fikile Nkwanyana Biostatistician / Lecturer College of Health Sciences University of KwaZulu-Natal. Due to the low response rate of the survey, it was not possible to perform statistical tests with the quantitative data. The qualitative data collected by open questions in the questionnaire were represented as themes and tabulated.

3.5 Phase 2: Focus group interview

A qualitative approach was selected for this stage due to the smaller number of participants and the type of data being collected; i.e. the perspectives and experiences of the participants (Babbie & Mouton, 2007). A focus group can be used in research as a standalone method or as part of a mixed methods approach to bring greater depth of knowledge to a study (Vaughn, et al., 1996). The experiences and viewpoints of parents of children with HFA / AS to barriers to admission to mainstream education for their children were explored in Phase 2.

3.5.1 Target population

The participants for Phase 2 were parents of children with HFA / AS who had experienced barriers in admitting their children into mainstream government schools in two circuits of the Umlazi school district as well as parents with children with HFA / AS who have successfully enrolled their children into mainstream schools. The participants resided in the target area.

3.5.2 Participant selection criteria and description

The selection of participants for a study is an essential part of the research and selection should be made according to the relevance of the participants to the study (Stewart, 2007).

Selection criteria are presented in Table 3.5 below.

Table 3.5: Selection criteria for participants in the focus group and motivation therefore

Selection criteria for participants in the focus group	Motivation for inclusion in the study
<p>Participants must be parents or guardians of a child or children with HFA / AS</p>	<p>Parents of children with disabilities other than HFA / AS were not included in the focus group as this study focused on barriers to mainstream education for children with HFA / AS. Parents or guardians are the persons responsible for ensuring the children in their care get an education (South African Department of Education, 2005). They will therefore have firsthand knowledge of the process of school enrolment for their children.</p>
<p>The parent or guardian must have attempted to enrol or have enrolled the child or children with HFA / AS into a mainstream primary school</p>	<p>Parents who are homeschooling their children or whose children are attending special needs schools and had not attempted to mainstream their children with HFA / AS were not included in this study. These parents would not have gone through the process of attempting to enrol their children with HFA / AS in a mainstream school and would therefore not be able to contribute to the discussion questions on the topic.</p> <p>The parents in this study are those who desire their children with HFA / AS to be educated in a mainstream school (Fein & Dunn, 2007). In addition parents who have not attempted to enrol their children with HFA / AS into mainstream schools will not have firsthand knowledge of barriers to mainstream education for children with HFA / AS.</p>

<p>The enrolment or attempted enrolment of the child or children with HFA / AS into a mainstream school must have occurred in the past 5 years.</p>	<p>Including only parents with children with HFA / AS who have enrolled or attempted to enrol their children in the current year would have greatly reduced the participants available for the focus group (Babbie & Mouton, 2007). A time frame of enrolment or attempted enrolment in the past five years was therefore chosen.</p>
<p>The child must have been between the ages of 4.5 years and 12 years at the time of application to a mainstream primary school.</p>	<p>Learners can enrol for grade R between the ages of 4.5 years and 5.5 years (KZN Department, of Education, 2010). Children should complete grade 7 at age 12, with the exception of children who have repeated a year or years during primary school education (South African Department of Education, 1996b).</p>
<p>The parents must have enrolled or attempted to enrol their children with HFA / AS in the selected circuits of the Umlazi school district.</p>	<p>This study focused on barriers to mainstream education for children with HFA / AS in two selected circuits of the Umlazi school district. Therefore data collected from participants in Phase 2 needed to be from these areas.</p>

Five participants comprised the focus group (see section 3.5.3 sampling technique for how participants were recruited) all were women who were parents of children with HFA / AS. All had enrolled or attempted to enrol their children into mainstream government schools in circuits of the Umlazi school district. The children of the participants ranged in age from six to twelve years old. All children had a diagnosis of Asperger's Syndrome (HFA / AS) and had been diagnosed by a range of professionals including paediatric neurologist and psychologists. The children ranged in school grades from Grade R to Grade 7 and the current educational settings for the children were mainstream government schools, home school and a special needs school. The number of school applications made at mainstream government

schools ranged from one to four, with one participant not specifying the number of applications made. This information is presented in Table 3.6 Below.

Table 3.6: Biographical information of focus group participants

Participant	Age of child	Gender of child	Diagnosis of child	Diagnosed by	Grade of child	Current school setting	School applications made
1. Mother	11	Male	Asperger's Syndrome	Psychologist Neurologist Speech therapist	5	Mainstream government school	4
2. Mother	12	Male	Asperger's Syndrome	Paediatrician Psychologist Doctor (GP)	5	Mainstream government school	1
3. Mother	6	Male	Asperger's Syndrome	Paediatrician Neurologist	R	Home school	Not specified
4. Mother	12	Female	Asperger's Syndrome	Paediatrician Neurologist Psychiatrist	7	Special needs school	3
5. Mother	9	Female	Asperger's Syndrome	Psychologist	2	Home school	1

Three to four or three to six focus groups are recommended for a study (Onwuegbuzie & Collins, 2007; Stewart, 2007). However, considering the current study followed a mixed methods design, only one focus group was conducted (Stewart, 2007). Additionally one of the purposes of the focus group was to explore and exchange ideas from the participants on overcoming barriers to admission to mainstream schooling for children with HFA / AS therefore, a single focus group was sufficient (Vaughn, et al., 1996). Since this was a mixed methods study, it was not necessary for the sample sizes of the two components of the study (quantitative and qualitative, i.e. Phase 1 and Phase 2) to be of the same size (Creswell & Plano Clark, 2007).

The focus group comprised five participants and although this was one participant short of the recommended number of six participants (Vaughn, et al., 1996; Stewart, 2007;

Tashakkori & Teddlie, 2010) the data collected were rich enough for a successful focus group as stated by the focus group facilitator (Vaughn, et al., 1996; Stewart, 2007). Other factors which could limit the success of a focus group with participant numbers fewer than six are unstimulating discussion and the danger of one participant dominating the conversation (Vaughn et al., 1996; Stewart, 2007). In this case neither of these factors were realised as the topics of discussion were of deep importance to the participants and therefore the discussion was lively and meaningful. The skill and experience of the focus group facilitator in leading focus groups in the past ensured the discussion was balanced between participants (Vaughn et al., 1996). Benefits of numbers less than six in a focus group are that the discussion is deeper and that each participant has more opportunity to contribute their unique perceptions to the discussion (Vaughn et al., 1996). Focus groups as small as two participants (Peek & Fothergill, 2007) or three participants (Pugsley, 1996) have formed part of studies.

3.5.3 Sampling technique

Participants in a study must be both willing to be involved and be able to contribute to the data needed to fulfil the research goal of the study (Stewart, 2007). Additionally the participants must be representative of the population being studied. Purposive sampling was therefore used to select participants for this phase of the research; the focus group interview (Stewart, 2007). The purpose of this portion of the study i.e. exploring the experiences parents of children with HFA / AS have had in enrolling or attempting to enrol their children into mainstream primary schools therefore determines the participants (Babbie & Mouton, 2007; Creswell & Plano Clark, 2007). Participants were recruited from local Autism support groups and organisations for parents of children with ASD. To contact parents on data bases from local Autism support groups and Autism organisations, the organisations were contacted telephonically and by electronic mail and the purpose of the study and the focus group was explained (Stewart, 2007). A request was made for an email to be sent out by the

organisations and support groups to people on their data base inviting participants who have children with HFA / AS to join the focus group. The email included contact information about the study and the researcher. Persons responding favourably to the request for participants then contacted the researcher directly regarding involvement. The researcher then emailed or phoned the potential participants to determine if they met the criteria for the group by asking several questions about the child's diagnosis and school enrolment (Stewart, 2007). Once it was established that the criteria were met, the researcher emailed a letter of information about the study as well as an invitation to the participant which contained details about location and times (Stewart, 2007). (See Appendix E for copies of the letter of information and invitation to the focus group).

One support group was an online *facebook* group. For this group the administrator of the group was contacted via *facebook* and permission to post on the group's *facebook* wall was requested. Following permission, information was posted and potential participants were requested to contact the researcher via email. Again potential participants were screened for suitability following which an invitation containing details of the location and times of the group was emailed. A *whatsapp* support group was notified following similar methods.

Several potential participants contacted the researcher independently of the support groups' assistance. As information about the study became known in the Autism community parents of children with HFA / AS forwarded the letter of information about the focus group to other parents of children with HFA / AS of their own accord. These parents, who were informed by other parents of children with HFA / AS, then made direct contact with the researcher.

3.5.4 Data collection method

A focus group was used as the data collected related to the same issue to which the participants in the focus groups were linked, i.e. admission to or attempted admission to

mainstream education for their children with HFA / AS and the associated barriers.

Therefore, topics discussed were common to all participants in the focus group. Thus the focus group was an effective use of the researcher's time (Vaughn, *et al.*, 1996). Additionally the dynamics of a group discussion provided immediate clarity on the comparison of participants' views rather than the deduction of such views from separate interviews or questionnaires (Babbie & Mouton, 2007; Stewart, 2007). Data was collected by means of a facilitator conducting the focus group. The focus group facilitator was a senior academic holding a Ph D in Social work research. She was informed about the project several months before the focus group was held and she had done her own reading on the topic of HFA / AS before agreeing to be involved in the research. The researcher was not present during the focus group discussion.

3.5.4.1 Data gathering instrument

A short biographical questionnaire was administered to the group with the participants recording their answers on the questionnaire. Thereafter an interview schedule was used by the focus group facilitator to orally present issues to the group participants for discussion (Gomm, 2008). (See Appendix E for copy of biographical questionnaire).

The interview schedule for the focus group was developed from the data obtained from the questionnaire used in Phase 1, completed by the senior staff members of the schools in two circuits of the Umlazi district. The information collected regarding barriers to mainstream education for children with HFA / AS and the possible conditions needed to overcome these barriers were the source of the interview schedule. These data were used to construct the interview schedule to assist in addressing the aim and objectives presented in Chapter One (Vaughn *et al.*, 1996). Ten open ended questions (Stewart, 2007) with follow up probe questions as necessary were used (Babbie & Mouton, 2007). The order of the questions ensured that the most critical data were collected first and more general questions were

presented later in the discussion (Stewart, 2007). Additionally, since the topic was emotionally provoking, questions were ordered as to not exhaust participants emotionally, staggering questions which may have provoked strong feelings with those which were more emotionally neutral (Stewart, 2007). The construction of the interview schedule was submitted to the researcher’s supervisors for approval and correction before being finalised for the focus group (Stewart, 2007). The focus group facilitator was presented with the interview schedule two weeks before the focus group met to ensure that the facilitator was familiar with the questions for discussion and to give opportunity for the facilitator to ask for clarity in any areas (Stewart, 2007). (See Appendix E for the interview schedule). The basis of the questions, the study objective met by using the questions and the motivation for the questions are presented in Table 3.7 below.

Table 3.7: Questions for focus group, the aim of the study it addresses and the motivation for inclusion in the focus group

Question	Study objective addressed	Motivation
<p>1. Characteristics of HFA / AS</p>	<p>To explore schools’ perceived barriers to mainstream education for children with HFA / AS</p>	<p>Misunderstanding about a condition was seen to be a barrier to inclusive education for children with special needs in the study by Pivik et al., (2002).</p> <p>Likewise parents’ understanding / misunderstanding of the condition will affect which schools they approach for admission. “High Functioning” is not an official term for diagnosis (APA, 2000, WHO, 2012) but is used extensively by teachers, doctors and therapists to describe the level of performance a child with ASD displays. (Autism Society of America, 1998). “High Functioning” can therefore be used subjectively, with professionals (Whitby & Mancil, 2009) and communicated partially to parents. Mainstream schooling is not appropriate</p>

		<p>for all children with ASD (Schopler & Mesibov, 1992; Whitby & Mancil, 2009). However, one of the benefits of mainstream schooling is the social exposure available to children with HFA / AS (Attwood, 2007; Fein & Dunn, 2007). Social exposure is important to children with HFA / AS as social deficits are one of the characteristics of HFA / AS (Dodd, 2005).</p> <p>The question was asked to allow for comparison between data collected from Principals / Deputy principals and Head of Departments about their understanding of HFA / AS.</p>
<p>2. Experiences of parents to admit their children with HFA / AS into mainstream government primary schools</p>	<p>To explore reasons for refusal to admission into mainstream schools for children with HFA / AS</p> <p>To explore the experiences of admission or attempted admission to mainstream education for parents of children with HFA / AS</p>	<p>Parents are responsible for ensuring their children receive an education (South African Department of Education, 2005; Yssel et al., 2007). They will therefore have firsthand knowledge of the process of school enrolment for their children.</p> <p>Barratt (2005) outlines how some parents find it necessary to conceal the child's diagnosis in order to get an educational placement for their children.</p> <p>The question allowed for comparison between data collected in Phase 1 from principals / Deputy principals / Head of Departments about admitting children with HFA / AS into their mainstream government primary schools.</p>
<p>3. Screening processes used by mainstream government primary schools to admit children with HFA / AS</p>	<p>To explore reasons for refusal to admission into mainstream schools for children with HFA / AS</p> <p>To explore schools' perceived barriers to mainstream education for</p>	<p>Reviewing the methods used to screen children for admission will reveal if the schools had an accurate understanding of what HFA / AS is. Not all children with ASD are suited to mainstream schooling (Schopler & Mesibov, 1992; Whitby & Mancil, 2009).</p>

	<p>children with HFA / AS (as experienced by parents) To explore the experiences of admission or attempted admission to mainstream education for parents of children with HFA / AS</p>	<p>Since parents hold the responsibility of finding an educational placement for their children (South African Department of Education, 2005; Yssel et al., 2007), they will have firsthand knowledge of the screening processes used at the mainstream government primary schools they enrolled their children at or attempted to enrol their children at.</p> <p>Parents' responses to the screening processes will contribute to data on their experiences in enrolling or attempting to enrol their children in mainstream government primary schools (Barratt, 2005).</p> <p>The question will allow for comparison between data collected from Principals / Deputy Principals / Head of Departments about the screening methods used in the admission process of children with HFA / AS into mainstream government primary</p>
<p>4. Teachers' experiences of teaching children with HFA / AS, as reported by parents</p>	<p>To explore the encounters of schools which admit children with HFA / AS (as experienced by teachers reports to parents)</p> <p>To explore reasons for refusal to admission into mainstream schools for children with HFA / AS</p>	<p>This question was asked as the experiences teachers have had with learners with HFA / AS in their classes in the past could influence their attitude towards repeating the process in the future (Ainscow & Haile-Giorgis, 1998; Education Review Office, 2010). This question explores what teachers have reported to parents about their experiences in order to compare to the data collected from schools on the same topic.</p> <p>Barriers such as lack of staff training and difficult behaviour from learners with HFA / AS (Barnard et al., 2000) as well as bullying (Pivik et al., 2002) were reported to parents by teachers of children with HFA / AS in mainstream schools (Harrington, 2011).</p>

		<p>Parents report that teachers withhold information about educational supports needed for their children with Asperger's Syndrome and that teachers' attitudes affected the child accessing necessary help (Harrington, 2011).</p>
<p>5. Best learning environment for children with HFA / AS</p>	<p>To explore reasons for refusal to admission into mainstream schools for children with HFA / AS</p>	<p>This question explores parents' views on placement within the schooling options offered in South Africa (Yssel et al., 2007). In a study by Reichart, et al. (1989) all parents of children with special needs and 92% of parents of neurotypical children reported that a child with special needs benefitted emotionally from a mainstream placement.</p> <p>This question addresses the aim of exploring reasons for refusal to admission into mainstream schools for children with HFA / AS in that if a Principal does not feel mainstream schooling is the best placement for a child with HFA / AS, then the child will not easily be accepted into that mainstream government primary school.</p> <p>Walton et al. (2009) in their study on inclusion found that how the school was structured, for example, in terms of support staff, positively affected inclusion. However, the study involved private schools which they note have small classes.</p>
<p>6. Factors needed to facilitate suitable education for children with HFA/ AS in mainstream government primary schools</p>	<p>To explore reasons for refusal to admission into mainstream schools for children with HFA / AS To explore possible ways barriers to admission to mainstream schools for children with HFA / AS may be overcome</p>	<p>Roberts (2007) in her study on inclusion notes the need for the child with HFA / AS to have a personal facilitator to assist the child. Parents would be responsible for the financial implications of hiring a facilitator to fill this need (Yssel et al., 2007). Additional support in the form of specialist staff (such as remedial teachers or psychologists) was also</p>

		<p>noted to be necessary for the educational success of learners with HFA / AS (Walton et al., 2009). In the USA parents are included in Individual Educational Plan (I.E.P.) meetings with professionals who work with their special needs children (including HFA / AS). This is to establish the best educational practice for their children (United States Department of Education, 2004). Each I.E.P. is unique depending on the needs of the child. The South African Department of Education (2010) realises the importance of a flexible teaching curriculum for successful inclusion.</p> <p>Parents have reported that open communication between themselves and teachers is an essential factor for successful mainstream education for children with Asperger’s Syndrome (Harrington, 2011).</p> <p>New ideas may be presented by parents on additional factors needed to facilitate suitable education for children with HFA / AS in mainstream government primary schools.</p>
<p>7. Parent involvement at schools to support mainstream education at government primary schools for children with HFA / AS</p>	<p>To explore possible ways barriers to admission to mainstream schools for children with HFA / AS may be overcome</p>	<p>Yssel et al. (2007) and Koegel et al. (2011) raise the unique challenges South African parents face in finding suitable education for their children with HFA / AS. They mention the success of the learning experience for these children is dependent on parental involvement at the child’s school, along with other factors, as does Harrington (2011). Parents may need to be prepared to offer additional educational support at home to facilitate a mainstream placement (Harrington, 2011; Siewe, 2012). Lack of parental involvement can result in misunderstanding and stress between parents and educators</p>

		(Kujwana, 2008). Schetter and Lighthall (2009) note that parents experience lowered stress levels when involved with the education of their children with ASD.
8. Education White Paper 6 and HFA / AS	To explore possible ways barriers to admission to mainstream schools for children with HFA / AS may be overcome	<p>The Education White Paper 6 (South African Department of Education, 2001b) is an official government document and understanding of how this special needs document should be implemented in a school will influence parents' actions in terms of making an application for their child with special needs (specifically HFA / AS for this study) into a mainstream government primary school.</p> <p>The Education White Paper 6 (South African Department of Education, 2001b) outlines that one of the conditions needed in overcoming gaps with special needs learners in mainstream schools is teacher support and training. Parents' understanding of this point could influence which mainstream government primary school parents approach to enrol or attempt to enrol their children with HFA / AS. i.e. a parent may be more likely to make an application at a mainstream government primary school where teachers have received training on ASD.</p> <p>South African parents who were aware of the child's rights insisted the mainstream school in the area accept their children. Those who were not aware of their rights accepted whatever outcome the school decided (Swart et al., 2004; Yssel et al., 2007).</p>
9. Additional barriers	To explore reasons for refusal to admission into mainstream schools for children with HFA / AS	To give the parents of children with HFA / AS an opportunity to raise any additional information regarding barriers to admission to mainstream

	<p>To explore possible ways barriers to admission to mainstream schools for children with HFA / AS may be overcome</p> <p>To explore the experiences of admission or attempted admission to mainstream education for parents of children with HFA / AS</p>	<p>government primary schools for their children, which may contribute to the study.</p>
<p>10. Open question for further input from parents</p>	<p>To explore reasons for refusal to admission into mainstream schools for children with HFA / AS</p> <p>To explore possible ways barriers to admission to mainstream schools for children with HFA / AS may be overcome</p> <p>To explore the experiences of admission or attempted admission to mainstream education for parents of children with HFA / AS</p>	<p>To give the parents of children with HFA / AS an opportunity to raise any additional information related to barriers to admission to mainstream primary schools for children with HFA / AS.</p>

3.5.4.2 Data collection process

Potential participants were contacted via telephone or email regarding the study. Incentives offered to potential participants were transport cost being covered, a free DVD on ASD in South Africa (Welcome to the Journey, Autism Action: raising awareness) and refreshments during the focus group (Stewart, 2007). These were specified on the invitation along with the start and finish time of the group meeting. Child care during the focus group was offered for parents who had expressed limitations of attending the focus group due to child care issues (Stewart, 2007).

Eight people confirmed their willingness to participate in the focus group. The researcher contacted each of the eight participants again two days before the group met and was given reconfirmation of their attendance (McNamara, n.d.). A list of discussion topics was distributed to the participants five days prior to the assembly of the group to provide the participants opportunity to consider the views they would present during the focus group (McNamara, n.d.). (See Appendix E for a copy of the letter sent to participants containing discussion questions). On the day the focus group met, two participants cancelled their participation and a third person did not arrive. It is not unusual for one to two participants not to arrive for a focus group (Vaughn, et al., 1996; Stewart, 2007) and it is recommended that one additional participant be secured before the assembly of the group (Vaughn, et al., 1996; Stewart, 2007). In this case an additional two members were confirmed. However, three did not participate. It was decided nevertheless to go ahead with the focus group (Vaughn, et al., 1996).

The focus group facilitator outlined the purpose of the study and of the use of the focus group to achieve the goals of the study before the discussion began (Vaughn et al., 1996). Informed consent was obtained in writing from the participants, using an informed consent form. Each participant filled in an informed consent form and submitted it to the focus group facilitator before discussion in focus group began (Creswell & Plano Clark, 2007). (See Appendix F for a copy of the informed consent form). Participants were informed that they may withdraw from the focus group at any time without penalty. The focus group facilitator presented members of the focus group with the short biographical questionnaire before the discussion began; thereafter the open-ended questions as listed on the interview schedule were used for discussion (Vaughn, et al., 1996) (See Appendix E for a copy of the interview schedule). The focus group was held in a community centre within the target area for the schools; that being one of the circuits of the Umlazi district. The venue was air-conditioned and comfortable

creating an intimate setting for the discussion of a topic which was of emotional significance to the participants (McNamara, n.d.; Vaughn, et al., 1996). The discussion lasted 1.5 hours (McNamara, n.d.; Vaughn, et al., 1996; Stewart, 2007).

During the focus group responses to the discussion questions were recorded using digital video and audio recording (digital video recorder model: Canon Legria FS06 and audio recorder Echo Smartpen) to ensure quality (Babbie & Mouton, 2007; Creswell & Plano Clark, 2007). This was done by the focus group facilitator. The recordings were later transcribed by an outside source and were analysed by the researcher.

It should be noted that since the researcher has had personal experience with her child and her clients with HFA / AS being excluded from mainstream education, there was potential for researcher bias (Maxwell, 2005). Additionally, considering the researcher works as a behavioural therapist in the target area she may have had contact with some of the participants by means of support group attendance or direct therapy with participants' children. This potential contact could have limited the discussion, adding to the need for a focus group facilitator to conduct the focus group. Researcher bias was addressed by the questions for discussion in the focus group being reviewed by the researcher's supervisors before they were presented to the focus group and by utilising a focus group facilitator to conduct the focus group. An academic who was experienced in conducting focus groups was selected to facilitate the focus group to ensure correct discussion techniques were used and data were accurately collected (Vaughn et al., 1996; Stewart, 2007). The facilitator, being a senior academic, had practice in handling sensitive discussions as well as collecting the data within the time restraints of the meeting (Stewart, 2007). Additional discussion on how researcher bias was addressed can be found in section 3.7.1. Personal considerations.

3.5.5 Pilot study

3.5.5.1 Validity and reliability testing:

When collecting qualitative data, reliability is determined by assessing if the data given by the participants are credible and is also enhanced by using external reviewers in handling the data (Creswell & Plano Clark, 2007). This was achieved in this study by using a focus group facilitator during the focus group to collect data. According to Tashakkori and Teddlie (2010), the function of a pilot study is to pre-test the instrument and to become familiar with any apparatus needed to collect data and to gain experience in interviewing techniques. It is part of the development of the research. Therefore a pilot study was also used for Phase 2 of the study, the focus group interview schedule.

The short questionnaire which was used in the focus group was administered to a parent of a child with HFA / AS who was not in the target area before the focus group met. The list of discussion topics was likewise presented to the parent for review. The parent noted that the completion of the biographical questionnaire took less than five minutes and all questions were easy to read. None of the questions were offensive or confusing (Stewart, 2007). The discussion questions were also noted to be easy to understand being without offense or confusion. The data obtained from the pilot study were evaluated to further develop the instrument by determining the following:

Short biographical questionnaire

- What changes need to be made to the design and content of the short questionnaire
- If any questions were misleading or ambiguous
- If instructions to complete the questionnaire were clear
- If any questions were offensive to the participants (Gomm, 2008)

Interview schedule

- What changes need to be made to the discussion questions on the interview schedule
- If any questions from the interview schedule were offensive (Stewart, 2007).

Additionally a pre-test of the recording equipment was done to determine the adequacy of the video and audio recording equipment. This was done in the room used for the focus group three days before the focus group was held. A meeting was in progress for another event in the room and permission was granted for the researcher to record part of the meeting to use as a test of the recording equipment. The video recording equipment was used as well as two audio recording devices. One audio device was found to be ineffective with the recording being unclear; the second device was therefore selected. This was the Echo Smartpen. These elements are represented in the Table 3.8 below:

Table 3.8: Changes made to biographical questionnaire and interview schedule following the pilot study

Areas for possible changes	Changes made	Changes specified
<u>Biographical questionnaire:</u>		
Content and design changes	none	n/a
Misleading or ambiguous questions	none	n/a
instructions	none	n/a
Offensive questions	none	n/a
Time to complete the questionnaire	Less than 5 minutes	n/a
<u>Discussion topics:</u>		
Discussion questions	none	n/a
Offensive questions	none	n/a
Adequacy of recording equipment	none	n/a
Digital video recorder	none	n/a
Audio recorder	Echo Smartpen selected	n/a

Rigour was addressed by only the researcher coding the transcripts to ensure consistency as well as understanding that the data obtained from discussion were not converted for analysing statistically (Tashakkori & Teddlie, 2010). Trustworthiness was focused on by considering the following areas as they pertained to the data obtained from the focus group:

Prolonged engagement -with a view to reaching data saturation.

Persistent observation- identifying the fundamental themes and considering them from several different perspectives.

Triangulation-using the short questionnaire, the interview schedule and later comparing the data from the descriptive survey questionnaire (Phase 1) as well as using the researcher's personal essay on her experiences on the topic (autoethnography), which was written before the data from Phase 1 and Phase 2 were received.

Referential adequacy-using a digital video recorder as well as an audio recorder for the focus groups.

Member checks- Confirming data with the participants of the focus groups to ensure accuracy in the data and the interpretation thereof (Babbie & Mouton, 2007). Two participants had omitted the number of schools at which attempted applications had been made for their children with HFA / AS. They were contacted for clarity; one did not know the number of schools approached the other gave the number of three schools. Participants were also contacted regarding the questions about the screening process and types of educational settings most suited to learners with HFA / AS. Participants confirmed that the information they had given was accurate and that they had no further information to contribute.

3.5.6 Data analysis

Thematic analysis was used to analyse the data from the focus group interview schedule to establish common trends amongst the participants regarding the barriers to admission to schooling for children with HFA / AS. Their experiences and perceptions of the topic were used to establish themes (Creswell & Plano Clark, 2007). Themes which arose from the data once transcribed were coded accordingly (Creswell & Plano Clark, 2007; Gomm, 2008). The researcher established the themes by reading the transcription from the recorded focus group discussion until saturation point was reached. The researcher then drew together common connections within the text. Concepts which appeared frequently in the text were marked accordingly and were categorised manually on a hard copy of the transcription. After

commonalities were identified within the text, a list was compiled of all emergent categories, for example, the impact HFA / AS has on parents. The list of themes was then examined and related themes were arranged together. Themes which were similar in nature or which were not frequently represented were either combined or used as subthemes. Software programmes were not used to analyse the data due to the small number of focus group participants. Additionally the researcher needed rapid and in depth familiarisation with the data from the focus group as she was not present during the focus group having utilised a facilitator. .

3.6 Autoethnographic essay

The researcher, in contributing data to the study by means of the autoethnographic essay, was a participant in the study. The data she contributed was not only as an involved parent of a child with HFA / AS but also as behavioural therapist specialising in Autism Spectrum Disorders. She treats children who have ASD, including HFA / AS and trains teachers in effective strategies on educating learners with HFA / AS (in addition to ASD in general). In addition she trains facilitators to work in schools to assist learners on the Autism Spectrum. The mainstream setting for learners with HFA / AS is therefore very familiar to her.

Her experiences of enrolment and attempted enrolment in mainstream schools involve her son with HFA / AS who is now 13 years old. Enrolment experiences started when he was aged five and involved 11 schools. Both private and government schools were approached and she had experiences of rejection and admission to both types of schools.

The autoethnographic essay was analysed thematically. The themes were established by the researcher reading the text to saturation point, then drawing together common links within the text. Concepts which were repeated in the text were marked and categorised manually on a hard copy of the essay. Following the identification of commonalities within the pages of the text, a list was made of all emergent themes, for example, conflict. The list of themes was

then reviewed and themes which were related to one another were grouped together.

Commonalities which were infrequent or similar in nature were either combined or used as subthemes. In this way the below list of themes and subthemes was developed. Additionally the autoethnographic essay was analysed by an external source (See Appendix G for copy of external analysis).

3.7 Data integration

The results from the survey, Phase 1 descriptive survey questionnaire, were compared to the data received from Phase 2, focus group interview schedule and with the researcher's personal experiences as a parent of a child with HFA and a professional working with children with ASD including those with HFA / AS following the autoethnographical method (Holstein & Gubrium, 2008). Following the compilation of data from Phases 1 and 2, comparative analysis was used to determine if the barriers to admission to mainstream education for children with HFA / AS as expressed by senior school staff members in the survey were congruent with the experiences of parents with children with HFA / AS in enrolling or attempting to enrol their children into mainstream schools. This information was also contrasted with the autoethnographical material presented from the researcher's personal essay. Common themes identified between Phases 1 and 2 were used to examine the data presented in the essay. Data according to the selected themes were contrasted with descriptive data section by section interspersing narrative and tables (Tashakkori & Teddlie, 2010).

3.8 Ethical considerations

The ethical responsibility of the researcher should include ensuring dignity of participants in the study and truthful account to the public of the results of the study (Creswell & Plano Clark, 2007; Gravetter & Forzano, 2010). This was achieved in this study by submitting the proposal for this study to the Humanities and Social Sciences Research Ethics Committee of

the University of KwaZulu-Natal (Westville) to obtain ethical clearance for this study (Creswell & Plano Clark, 2007; Delpont & Fouche' 2011). The clearance number issued by the committee is: HSS/0008/013M (See attached copy of the letter in Appendix B). In addition permission was requested from the KZN Department of Education in order to administer the questionnaire to primary schools in the selected circuits, within the Umlazi district.

For recruitment of participants for the focus group, permission was requested from the administrators of support groups for parents of children with HFA / AS. Three participants withdrew from participating in the study the morning the focus group was held due to unforeseen personal arrangements conflicting with the time the group was to meet.

Cancellation held no consequence for these participants and there was no penalty to their lack of participation (Delpont & Fouche' 2011; Johnson & Christensen, 2012).

General sensitive and humane treatment of participants, as well as honest representation by the researcher are underlying premises in collecting data from human participants. In addition, participation must be voluntary and informed consent is essential (Delpont & Fouche', 2011). For all participants, senior school staff and focus group participants, informed consent was obtained so participants were aware of what was expected of them when participating in the study and how the information they gave would be used (Bradburn, Sudman & Wansink, 2004; Delpont & Fouche', 2011). The focus group participants were made aware that the focus group discussion would be recorded using a digital video camera and an audio recorder. All involved in the study were informed that their identities as well as the identity of the schools would be kept confidential and data used in the study would be presented without reference to any personal details due to the sensitive nature of the study (Delpont & Fouche', 2011; Babbie, 2009). Participants were made aware that they were able

to withdraw from the study at any time, without penalty, should they wish to discontinue their involvement in the research (Delpont & Fouche', 2011; Johnson & Christensen, 2012).

The option of receiving feedback about the study was given to the schools and focus group participants. In such cases, following the conclusion of the study the contact details of the schools and focus group participants concerned will be retrieved from the locked storage device by the researcher and the results of the study will be forwarded to those schools and individuals. A copy of the report will be sent to the KZN Department of Education as per the request from their research department. This will address the social responsibility of informing the participants about the results of the study they participated in (Gravetter & Forzano, 2010; Delpont & Fouche', 2011). The benefit of the study to the participants was the opportunity to express their experiences in regards to school applications for children with HFA / AS as well as to receive feedback in the longer term, which could assist in altering acceptance policy for learners with HFA / AS in the future. Data collected via electronic means are stored on a password protected computer (Reynolds, Woods & Baker, 2007) and data collected in hard copy are stored in a locked container at the Department of Health Sciences of the University of KwaZulu-Natal. Both sets of data will be destroyed by means of a paper shredder or deletion respectively after five years (Sheehy, Nind, Rix, & Simmons, 2005).

3.8.1 Personal considerations

As a parent of a child with HFA / AS and as a therapist working with children on the Autism spectrum, the researcher recognises her potential for researcher bias. Her personal experiences with exclusion from mainstream schools for her son as well as the exclusion from mainstream schools for children on the Autism spectrum whom she treats could be contributing factors for bias in conducting this study (Maxwell, 2005). She presented this potential influence for continued review to her supervisors. This was addressed in the

following ways: The pilot study ensured that the questionnaires to be completed by senior management staff of the mainstream primary schools were objective (Tashakkori & Teddlie, 2010). Researcher bias was addressed in the selection of participant schools in that all mainstream primary schools in two circuits of the Umlazi district were invited to participate in the study. No schools were preselected (Babbie & Mouton, 2007).

To address researcher bias in selecting the participants for the focus group, all local independent Autism organisations and all support groups, including the researcher's support group, were approached to recruit participants for the study. The interview schedule, the list of discussion questions and short biographical questionnaire for the focus group were presented to the researcher's supervisors for review before they were presented to the focus group. The biographical questionnaire and list of discussion questions were also piloted before the focus group was held. This addressed any subjectivity in the questions. In addition, the focus group was led by a focus group facilitator and not the researcher.

In analysing data from the questionnaires, researcher bias was attended to by examining the data according to the set categories presented in Table 3.2 in section 3.4.4.1., Data gathering instrument. These categories were approved by the researcher's supervisors and a biostatistician and were derived from concepts in the literature (See Table 3.2). Data from Phase 2 were analysed in similar categories as monitored by the researcher's supervisors. The autoethnographic essay was written by the researcher before any data from Phase 1 or Phase 2 had been collected. It was analysed by a third party, (a senior academic) as well as the researcher to avoid researcher bias.

As mentioned in section 3.3., Research methodology, data were collected from Phase 1, Phase 2 and from the ethnographic essay. These sources ensured triangulation which additionally contributes to overcoming researcher bias (Babbie & Mouton, 2007). All areas of this

research were monitored by the researcher's supervisors to determine if the researcher was being subjective in any way. Additionally, the researcher applied the concept of reflexivity to the research, understanding her relationship with the topic of research in this study. Her expertise in the field of ASD was a contributing factor to the data in this study (autoethnographic essay) and the processing of it. She considered the cycle of knowing the topic and processing new information related to the topic on an ongoing basis (Shacklock & Smyth, 1998).

3.9 Summary of Chapter Three

In this chapter the aim and objectives of the study were presented. The mixed methods approach of research methodology for this research study was explained. The two phases of the study were described, the quantitative element- Phase I: A descriptive survey questionnaire, where data was descriptively analysed and the qualitative element- Phase 2: A focus group where data were thematically analysed, along with the data presented in the autoethnographical essay written by the researcher. The selection criteria for the populations and participants, the sampling techniques, the methods of data collection and the necessary materials to collect for each of the phases were outlined. The pilot study was presented as well as the data analysis. In addition the ethical considerations for the study were exposed.

“The pages of my books all had numbers on them and I felt happy surrounded by them, as though wrapped in a numerical comfort blanket. Long before I could read the sentences on the pages, I could count the numbers. And when I counted, the numbers would appear as motions or colored shapes in my mind”

*Daniel Tammet- Adult with Asperger’s Syndrome
Taken from “Born on a blue day”, 2006, p. 24*

CHAPTER FOUR: RESULTS AND DISCUSSION

4.1 Introduction

The results of the research study are presented and discussed in this chapter. Results of the survey are presented in two formats, quantitatively with tables and figures for closed ended questions and qualitatively for open ended questions, with reference to themes which emerged. The evaluation of the results is discussed with reference to literature and other research.

The results of the focus group are presented according to themes which emerged following the transcription and analysis of the data. Results are discussed with reference to parental experiences in other countries as well as parental experiences in other parts of South Africa.

The results of the autoethnographic essay are presented in a table as an overview then discussed according to emergent themes. An integration of results from the three data sources is presented in this chapter, in response to the aim and objectives of the study. These are discussed with reference to the literature on the topic and government policy.

4.2 Results: Phase 1

The goal of Phase 1 was to give an overview or broad brush stroke of the current status of admission to mainstream primary schools in two circuits of the Umlazi school district. Of the 154 schools in the target area 153 questionnaires were sent out via email, the South African postal service or were hand delivered. One school had neither email address, postal address

nor active phone number as supplied by the KZN Department of Education district office.

Efforts were made by the researcher to contact the school via a non profit organisation which works with the school; however, the delivery of a questionnaire was not achieved.

4.2.1 Distribution and return of questionnaires

Of the 153 questionnaires distributed, 28 were returned, giving a low return rate of 18% (Babbie & Mouton, 2007). Reasons for this low rate were varied and are discussed below and presented in Table 4.2 Only 15 of the 20 hand delivered, four of the 26 posted and eight of the 106 emailed questionnaires were completed. One questionnaire was completed during a telephonic conversation. Forty- two questionnaires were returned undeliverable although they had been sent to the email addresses provided. These figures are presented in Table 4.1 After waiting two weeks the researcher re-emailed the questionnaires to the schools which had not returned the questionnaires. One principal completed the questionnaire over the telephone.

Twenty-two schools declined participation in the study for reasons such as being too busy, not being interested in the study or being short staffed. One school reported having email problems and therefore was not able to return the questionnaire via email. As a result of the follow up telephone calls, 26 schools requested the questionnaire be re-emailed. Follow up telephone calls after the resending of the questionnaires however, did not result in the questionnaires being completed. At 35 schools the Principal, Deputy Principal or Head of Department was not available and the secretary agreed to deliver a message requesting the senior management staff's participation in the study and the return of the questionnaire.

Likewise, with these schools, even when follow up calls were made following the messages, the schools did not return the questionnaires. Lastly, 35 schools had invalid or unavailable phone numbers. Repeat follow up telephone calling was done up to four times. For all incorrect email address and phone numbers the researcher attempted to find correct contact information via internet searches.

Table 4.1 below shows the various distribution methods used for the questionnaires, as well as the returns per method. It can clearly be noted that the low response rate to the electronically sent questionnaires contributed greatly to the overall low response rate of Phase 1. Reasons given by potential participants for non participation leading to a low response rate are recorded in Table 4.2 and responses given to the follow up phone call requests to complete questionnaires are recorded in Table 4.3 below.

Table 4.1: Methods of distribution of questionnaires and return of questionnaires

	Number distributed	Number of hand collected returns	Number of posted returns	Number of email returns	Number of telephonic returns
Hand delivered	20	8	7	0	0
Posted	26	0	4	0	0
Emailed	106	0	0	8	0
Telephonic	1	0	0	0	1
totals	153	8	11	8	1

Table 4.2: Reasons for low response rate

Reasons for non returns	Number
Can't help	5
Too busy	7
Not interested	6
Short staffed	3
Email is down	1
Undeliverable emails	42
Total	64

Table 4.3: Follow up attempts to collect data

Responses to follow up phone calls	Number of responses
Email resend requested	26
Invalid phone number or no phone response	34
Faxed questionnaire requested	3
Principal, Deputy Principal or Head of Department not available (message left)	35
Totals	98

It was interesting to note that the schools which responded quickly to the returning the completed questionnaire (approximately a week) were those schools who already had learners with HFA / AS in their schools and wanted to express their experiences. Those schools which needed follow up to complete the questionnaires and took an extended time to return the questionnaires were those schools which did not have learners with HFA / AS and indicated on the questionnaire that they felt mainstream placement was not a suitable learning environment for learners with HFA / AS. This suggests that the lack of willingness to participate was perhaps linked to something greater (Babbie & Mouton, 2007) than being the lack of willingness to enrol children with HFA / AS in those schools.

4.2.2 Biographical information of senior management staff members participating in the study

As noted in section 3.4.4, the questionnaires were completed by senior management staff of schools in two circuits of the Umlazi district. The majority of the participants (89.2%) were

Principals, 1.1% were Deputy Principals and 1.1% were Heads of Department. Table 4.4 below shows the representation of staff positions in the study.

Table 4.4: Positions held by senior staff members who completed the questionnaire

Position held at the school	Principal	Deputy Principal	Head of Department	Principal in conjunction with teacher	Total
Number	20	3	3	2	28

The senior management staff who completed the questionnaires ranged in age from 34 years to 64 years with the average age being 54.3 years. The number years of teaching experience ranged from 14 years to 43 years with the average number of years of teaching experience being 31.7 years. In Geduld’s study (2009) she revealed that senior management staff who were close to retirement were not open towards inclusion. In this study in selected regions of the Umlazi school district, six participants were over 60 years old, two expressed that mainstream schooling was the setting most suitable for learners with HFA / AS. The remaining four senior staff members felt remedial schools and special needs schools would be the best placement for these learners’ needs. Of the 22 remaining senior staff members who were between the ages of 34 and 59, 12 felt mainstream schooling was not the best placement, three felt a mainstream placement was best, one participant omitted to answer the question, two expressed that the school most suited to a learner with HFA / AS would vary from case to case and four participants said training and support would be needed for a mainstream placement. The correlation between age and negative views toward inclusion were therefore inconclusive in this study. Due to the low response rate of the study these results cannot be used to infer patterns. This is represented in Figure 4.1 and Figure 4.2 below.

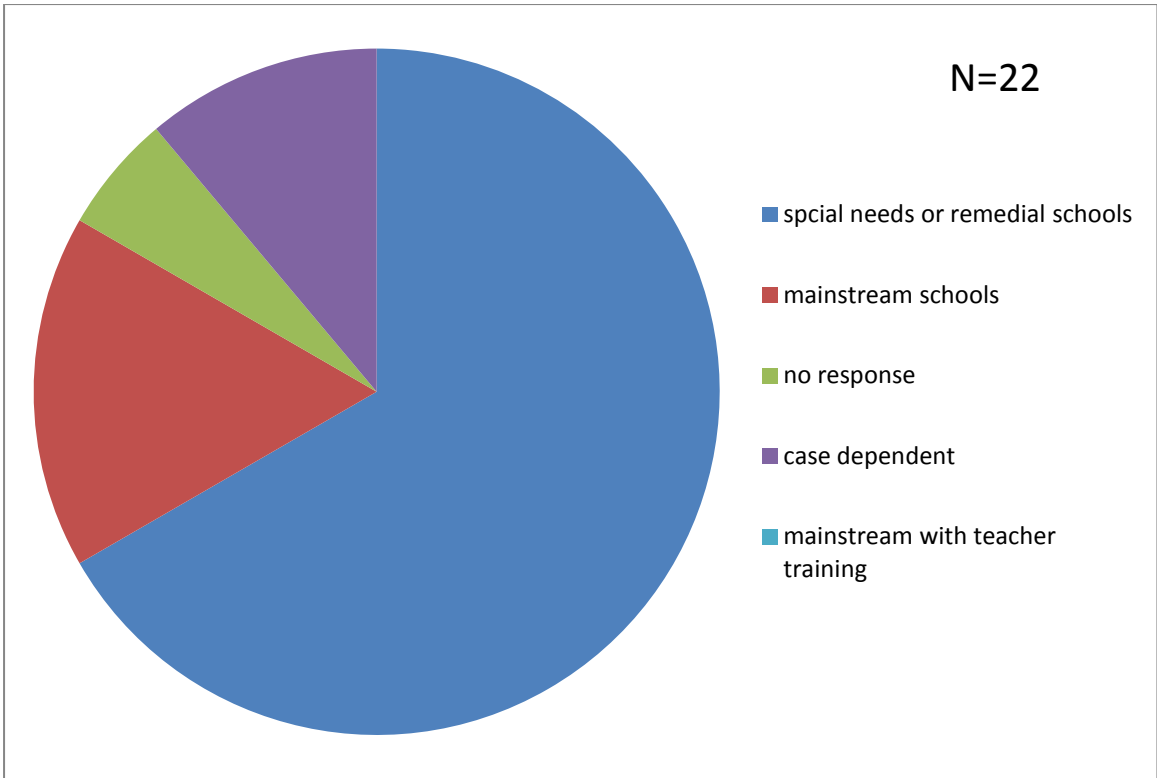


Figure 4.1: Views of senior staff members aged 34-59 on inclusion for learners with HFA / AS

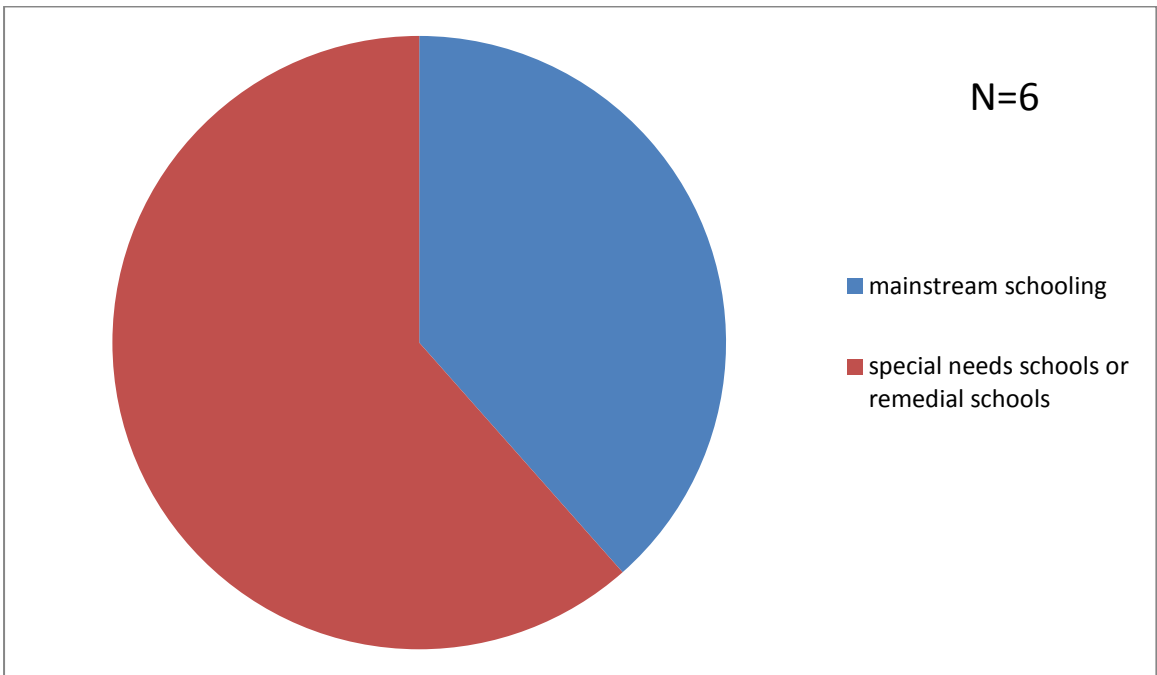


Figure 4.2: Views on school placement, senior staff members aged 60+

The range in years of teaching experience and breakdown of positions held by the senior management staff at the schools in the target area did not impact the degree of training on HFA / AS the participants had received during their teaching qualifications. Of the 28 senior staff members who participated in the study, 23 had not received any instruction on HFA / AS during their teacher training. Two participants reported that HFA / AS had been “only mentioned”, one participant reported that very little instruction was given in part of a Psychology Diploma, one participant noted a section in inclusive education and classroom management included HFA / AS and lastly one participant reported that the condition was covered in a Special Needs Certificate. This means 82.1% of the senior management staff reported that their teacher training qualification did not include any instruction on the education of learners with HFA / AS. A further 7.1% reported that the condition was only mentioned briefly and 3.6% reported that very little was included. These make a total of 92.8% of senior management staff members who had not received training to equip them on educating learners with HFA / AS. Only 7.2% reported that the condition had been covered and that was by means of a special needs certificate and section on inclusion and classroom management. This is in agreement with the finding from the study on inclusion ASD done in schools in Gauteng (Roberts 2007). The importance of senior staff members knowing about HFA / AS and how to educate learners who have the condition is that the senior management staff are responsible for admissions. Being unfamiliar with the condition could therefore be a barrier to admission for learners who have HFA / AS Figure 4.3 below illustrate these data.

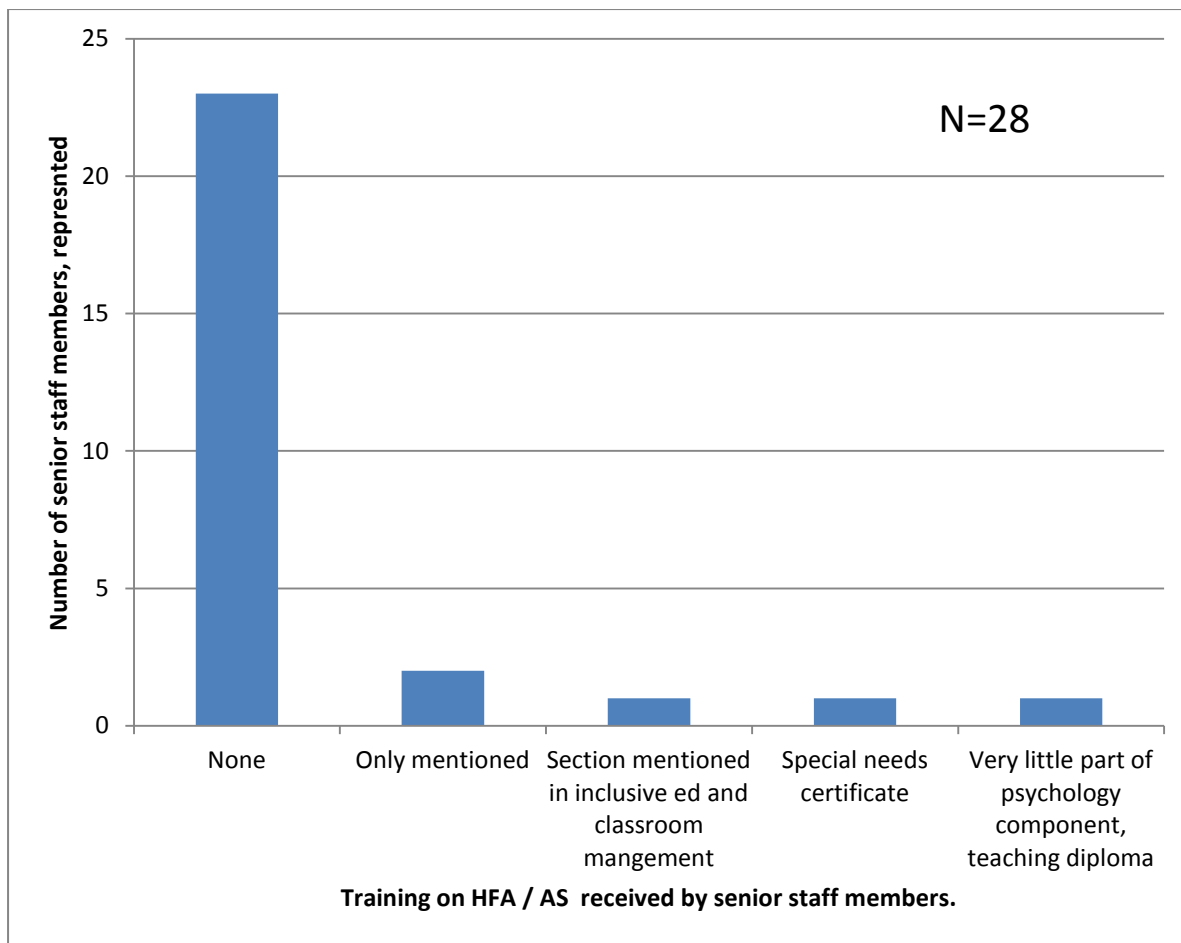


Figure 4.3: Training received on HFA / AS by senior management staff of schools in the selected circuits of the Umlazi district during teaching qualification

Horrocks et al. (2008) suggests that factors such as age, years of teaching experience and training in the field of ASD positively affect the placement recommendations for learners on the Autism spectrum (including HFA / AS) into mainstream schools. The converse would presumably also hold true with the lack of teaching experience and lack of training in the field of ASD negatively affecting placement recommendations for children with HFA / AS into mainstream schools. In this study eight of the 28 schools said mainstream education was the learning environment most suited to children with HFA / AS, with only two of the eight schools having attended workshops on HFA / AS presented by organisations independent from the South African Department of Education or KZN Department of Education. Thus,

71.4% of schools in this study felt mainstream schooling was not the environment most suited to learners with HFA / AS. Of the schools in this study, 92.8% had not received any formal training on how to teach children with HFA / AS, which is in support of Horrocks et al. (2008).

All schools reported that no ongoing training (by means of seminars, workshops or conferences) on HFA / AS was provided for senior management staff or teaching staff since their teaching qualification had been completed. The Education White Paper 6 (South African Department of Education, 2001b) outlines how ongoing training and professional support is needed for successful inclusion of learners with special needs into mainstream schools. In countries such as Australia (Government of South Australia, 2006), The United Kingdom (Department for Education, UK, 2011) and the United States of America (United States Department of Education, 2004), educators are provided with training to equip them with skills to work with children with HFA / AS. The Education White Paper 6 (South African Department of Education, 2001b) does recognise that to achieve the objectives outlined in the paper, there will be financial implications for the government budget.

4.2.3 Biographical information of participant schools

All schools participating in the study were mainstream primary government schools. Being primary schools they offered varying ranges of grades from Grade R to grade 7. The majority of the schools, 71%, offered Grade R along with other grades. This is in line with the Education White Paper 5 (South African Department of Education, 2001a) where the South African Department of Education is including Grade R in the formal schooling years. An aim set by the South African Department of Education in the Education White Paper 5 (South African Department of Education, 2001a) was to have all children who started Grade 1 by 2010 attend a grade R year before starting Grade 1. In the KwaZulu-Natal Department of

Education Annual Report 2010/2011 (2011a) this was said to be achieved in excess of 85%.

The breakdown of grades offered is presented in Figure 4.4 below.

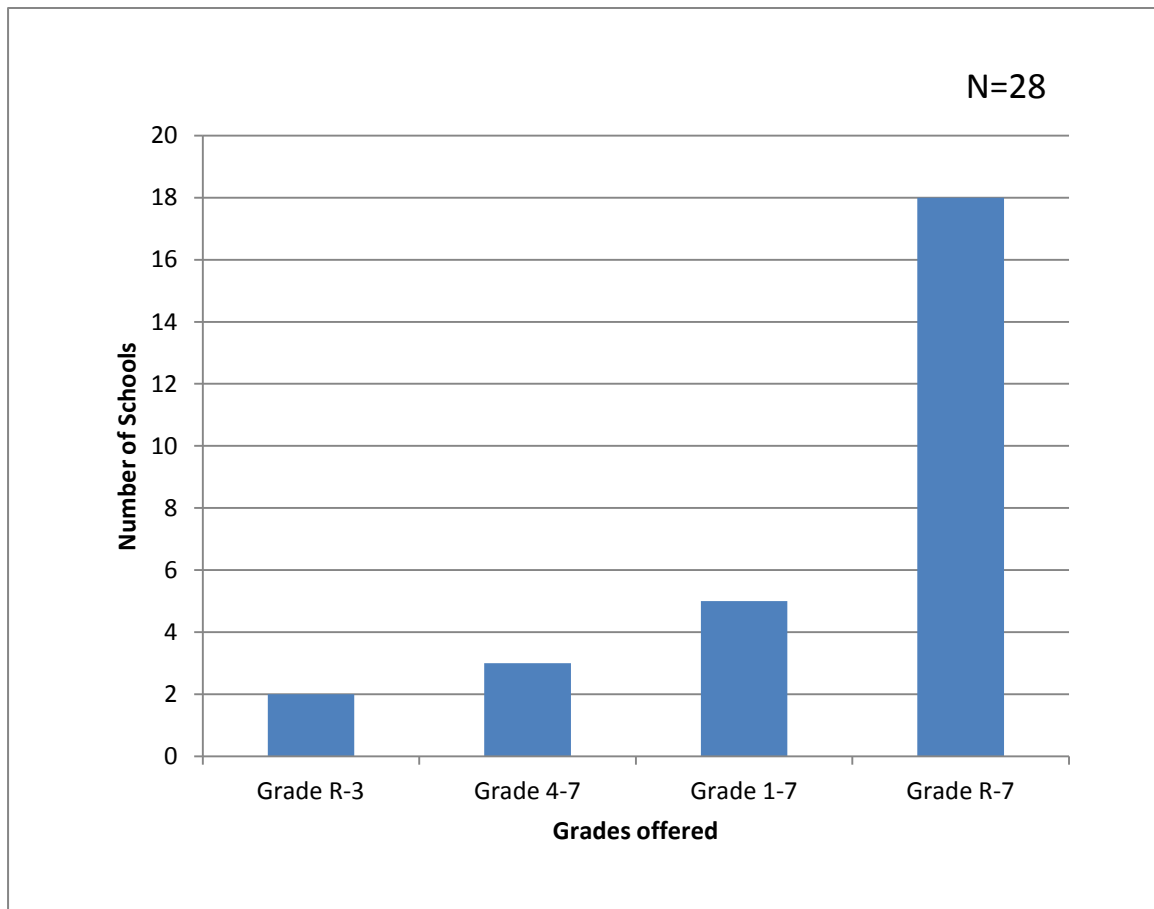


Figure 4.4: Grades offered at participant schools

The schools represented a range of number of children per class and per school. The differences in the numbers reported per school can be seen in the light of the number of grades offered in the Figure 4.4 above. Schools offering grade R to Grade 7 will therefore have greater number of learners in the school than schools offering only Grade 1 to 3 or Grade 4 to 7. The number of grades offered however, would not necessarily affect the number of children per class. Figure 4.5 below shows that the majority of schools in this study had between one and 30 children per class. This made up 46.4% of the total.

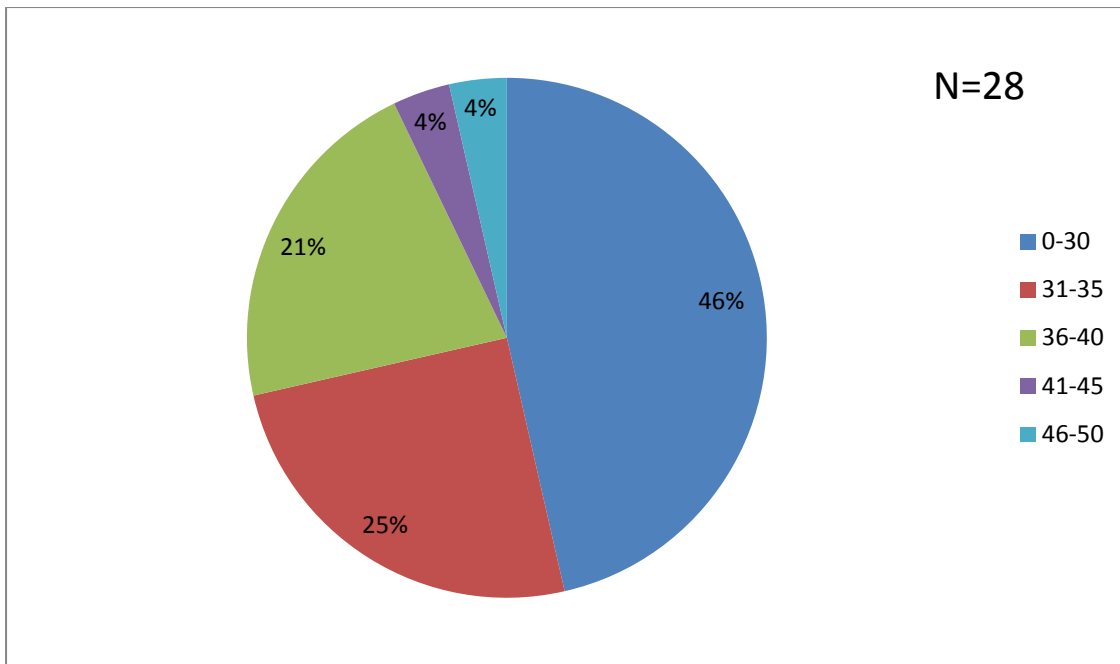


Figure 4.5: Number of children per class

The smallest class recorded was 15 and the largest was 50. Low numbers of learners per class has been noted to positively affect inclusion (Simpson et al., 2003; Roberts, 2007; Walton et al., 2009). In this study the school which had the lowest number of learners per class (15) did not feel mainstream schooling was the best educational placement for children with HFA / AS. Of the total number of schools in this study which did feel mainstream placement was the most suitable setting for children with HFA / AS (eight of 28 schools) three schools had 40 learners per class and one school had 38 learners per class. These relatively large numbers are surprising in the light of the literature reviewed. However, it should be noted that these four schools do not currently have any learners diagnosed with HFA / AS enrolled at their schools and had not had any enrolled in the past five years. Their first hand experience of the conditions and the associated challenges such as behavioural and sensory difficulties in the classroom (Fein & Dunn, 2007; Roberts 2007; Autism Speaks, 2012) may therefore be limited.

As seen in Figure 4.6 below, the majority of schools were able to accommodate between 501 and 750 learners. This made up 42.8% or 12 of the 28 schools in the study. The range of number of learners per school was from 120 to 1179.

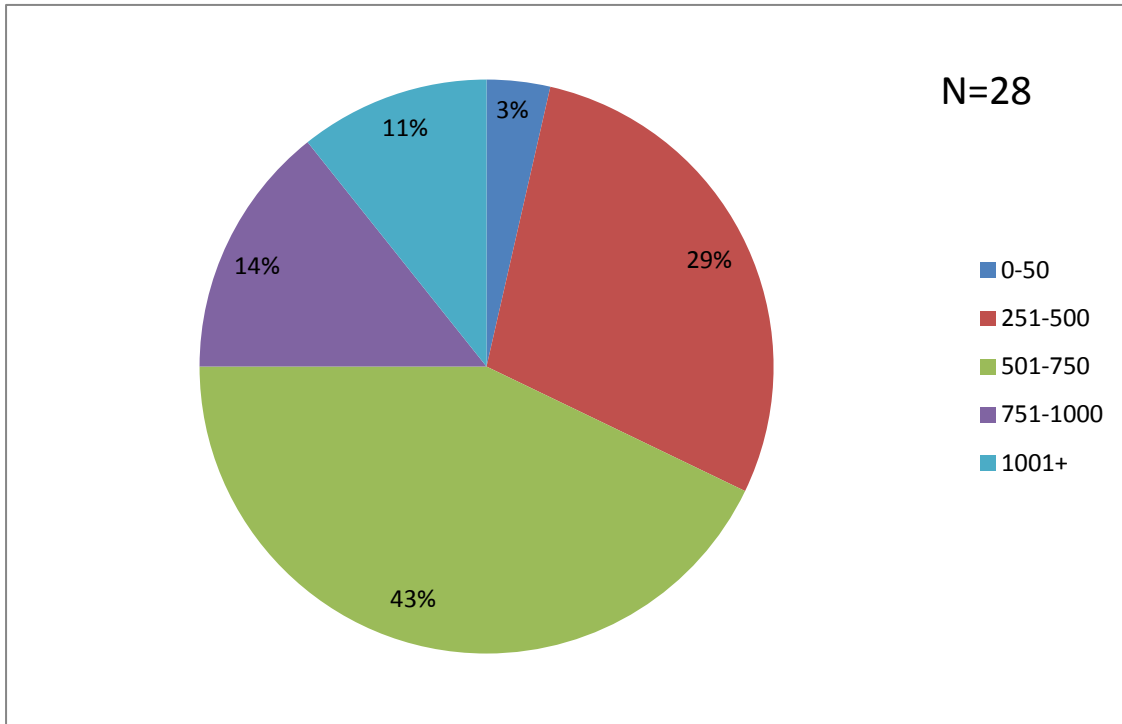


Figure 4.6: Number of children per school

Some schools employed class assistants and support staff, those being remedial teachers, speech therapists, occupational therapists and psychologists. If a school employs additional staff members, how many are employed and how the payment of the staff is funded is presented in Tables 4.6 and Table 4.7 below.

Table 4.5: Number of schools employing class assistants and support staff

	No support staff or class assistants	Only class assistants	Only support staff	Both class assistants and support staff	Total
Number of schools	14	4	3	7	28

N=28

Fourteen of the 28 schools or 50% of schools had neither class assistants nor support staff employed. Seven schools had both class assistants and support staff. Eleven of the 28 schools in the study employed class assistants with a total number of 66 class assistants working at the 11 schools. Ten schools reported having support staff, however, only six schools specified numbers, giving a recorded total of 18 support staff. Four schools did not specify the number of support staff employed. The importance of support staff and mainstream education for learners with HFA / AS will be further discussed in section 4.3.9.

Table 4.7 below shows that four schools fund the payment of class assistants themselves and two schools rely on parents of learners to fund the class assistants. Of the six schools which employed occupational therapists, all were funded by parents, as were the speech therapists who were employed at five schools and the psychologists which were employed at four schools. Six schools employed remedial teachers, these staff were funded by the schools' own fund raising initiatives. None of the class assistants or support staff were funded by the government. This does not follow the guidelines outlined in the Education White Paper 6 (South African Department of Education, 2001b) where the staff who are needed to support educators in inclusive education are supposed to be provided by the government. This puts an additional financial burden on the parents of children with special needs (including HFA / AS) which parents of neurotypical children do not have to consider (Matthews & Matthews, 2012). In contrast to parents of children on the Autism spectrum in the USA, parents of children with the same condition in South Africa, have a greater financial responsibility (Yssel et al., 2007).

Table 4.6: Numbers of funding sources for class assistants and support staff

Source of funding	Class assistants	Occupational therapist	Speech therapist	Remedial teacher	Psychologist
School funded	4	0	0	6	0
Parent funded	2	6	5	0	4
Government funded	0	0	0	0	0
Totals	6	6	5	6	4

N=14

The aim of this study was to determine and explore barriers to admission to mainstream primary schools for children with High Functioning Autism / Asperger’s Syndrome in two circuits of the Umlazi school district. The objectives used to address this aim for Phase 1 are presented below. Results from Phase 1, Phase 2 and the autoethnographic essay will be integrated in section 4.7.

4.2.4 Objective 1: To explore reasons for refusal to admission into mainstream schools for children with HFA / AS

4.2.4.1 Application declined

Of the 28 schools which participated in the study only one school stated that an application for a child with HFA / AS was declined. The reasons given for the declined application were that the school staff members were not trained to teach a child with HFA / AS, and that the staff members did not know what HFA / AS was as well as that the class sizes were too big to accommodate the learning styles of a child with HFA / AS in that school. This school had an average class size of 28 learners. Lack of staff training does form a barrier to mainstream education for children with HFA / AS (Barnard et al., 2000; Roberts, 2007; Walton et al., 2009). However, training itself is not always sufficient for inclusion to be successful.

Carrington (1999) reveals that attitudes as barriers to inclusion are best changed with hands

on guidance and practical help in implementing the training, and not in training alone (Roberts, 2007).

The senior staff member completing the questionnaire also stated

'We can assist [with the education of children with HFA / AS] to start but have little success after grade three'.

Reasons were not given as to why the school had little success with learners with HFA / AS after Grade 3. This school had accommodated four learners with HFA / AS in the past five years, so it was concluded that their intention was to mainstream children with HFA / AS and follow the Education White Paper 6 (South African Department of Education, 2001b) but did not feel they could repeat the experience, particularly after grade 3. Presumably learners with HFA / AS would be admitted into grades one to three.

The principal goes on to say that their past experiences of learners with HFA / AS were difficult for teachers, that the teachers did not grow as a result of having learners with HFA / AS in their classes and that other learners were *'Sometimes distracted'* by the learners with HFA / AS who *'require extra attention'*. It would seem that the school's past experiences with learners with HFA / AS influenced the lack of willingness to admit future learners with HFA / AS. This may have been as a result of lack of support from the district support teams. This supports the findings of Ainscow and Haile-Giorgis (1998) and the reported information from the Education Review Office (2010) in New Zealand. These sources report that past experiences of educating children with HFA / AS can influence the attitudes of educators' attitudes towards repeating the process in the future, be those positive or negative experiences.

4.2.4.2 Schools without learners with HFA / AS enrolled

Twenty-one schools reported that they did not currently have learners with HFA / AS in their schools and expressed various reasons why this was the case: Eighteen schools said no applications were made for children with HFA / AS to attend their schools. Since inclusive education is relatively new in South Africa (South African Department of Education, 2001b), it is possible that there are parents who are unaware that their children with HFA / AS may attend mainstream government schools. The South African Broadcasting Corporation (2012) reported that it is not known where all learners with ASD are as not all are accounted for in schools. It is also possible that parents may have concealed the child's diagnosis (Barratt, 2005) in order to enhance the possibility of the child attending a mainstream school. Alternatively, some children may not have received a diagnosis of HFA / AS at the time of enrolment. Children with Asperger's Syndrome are usually diagnosed between the ages 8 and 12 years old (Attwood, 2007; Schetter & Lighthall, 2009) and in some cases at 5 years old (Exkorn, 2005). Since learners can enrol for grade R between the ages of 4.5 years and 5.5 years (KwaZulu-Natal Education Department, 2010), it is possible that some children are currently in mainstream schools, without the schools or their parents being aware of the condition. This would also account for the 12 schools which reported that they suspect they have children with HFA / AS in their school but that the children are undiagnosed. This was expressed by two schools:

'Diagnosis of HFA not part of entrance criteria so learners may be undiagnosed in our school'

'We may have undiagnosed learners with HFA / AS and not know'

The presence of learners with HFA / AS or learners suspected to have HFA / AS will be further discussed in objective 4 below and represented in Table 4.6 and Table 4.7.

The additional barriers to admission to mainstream primary government schools for children with HFA / AS as reported by eight schools which did not have learners with HFA / AS enrolled were that they did not know what HFA / AS was and that their staff were not trained to educate learners with HFA / AS. The unique presentation of each child with ASD (Jordan 2001; McAfee, 2002) and in particular HFA / AS can cause misunderstanding about the condition and the abilities of those affected by it. Research has shown that misunderstanding about the condition can cause confusion about educational placement for those who are affected by it. (Schopler et al.,1998; Jordan, 2001; Volkmar & Klin, 2005). It could be assumed that if educators do not know what HFA / AS is, the schools would be reluctant to enrol the learners affected by the condition. In addition if educators have not had access to training on how to teach learners with HFA / AS, reluctance to enrol these learners is understandable. Roberts (2007) and Walton et al., (2009) make note of this reality in their studies on inclusion in schools in South Africa and it proves to be a difficulty internationally, even where countries have more experience with inclusion than South Africa does (Jordan, 2012).

Three schools said their classes were too big to accommodate the learning styles of learners with HFA / AS. This is a reality noted by Simpson et al. (2003), Roberts (2007) and Walton et al. (2009). Two schools found that the social difficulty children with HFA / AS experience formed a barrier to enrolment as did senior staff members' attitudes towards bullying. Senior staff members at two schools expressed that the anticipation of learners being bullied by neurotypical learners was a barrier to admission for learners with HFA / AS. It would stand to reason that the bullies should rather be disciplined for interfering with learners with HFA / AS than preventing the admission of learners with HFA / AS into mainstream schools for fear of bullying. Bullying was also experienced in Singapore (Barratt, 2005) and the reason given was that there is a social stigma and embarrassment associated with special

needs. Children on the Autism spectrum in Singapore are often kept at home and neurotypical learners were therefore unfamiliar with the condition. This resulted in the learners with ASD becoming targets for bullying. This being the case increased inclusion correctly handled would decrease bullying. These two factors can be addressed together as both are related to one of the elements of the triad of impairments of ASD and HFA / AS, that being social challenges (Dodd, 2005; Roy et al., 2006; Wing, 2006). In order to assist children with HFA / AS in this area, adjusting the curriculum to include social skills teaching is recommended (Simpson et al., 2003 Attwood, 2007). The implementation of such a program would be contingent on staff being trained on how to teach the new material. According to the Education White Paper 6 (South African Department of Education, 2001b), this training should be provided by the district support teams. The lack of staff training was raised by schools as an area of challenge. Two schools reported that their past experiences of enrolling children with HFA / AS were problematic. It could be suggested that the lack of staff training could contribute towards the poor past experiences, as teachers who are not equipped are likely to find the experience stressful.

The last reason given by schools as to why there were no learners with HFA / AS enrolled, was that the parents of the children with the condition were potentially too demanding. Considering that some teachers have been noted to withhold information from parents of children with HFA / AS about what supports are needed for their children with HFA / AS in their classes (Harrington, 2011), it could be understood that the parents have to be assertive in the school setting. Research shows (Yssel et al., 2007; Koegel et al., 2011) that for a child with special needs to succeed in a mainstream placement the parents need to be actively involved in the child's education. Parents who understand the principle of involvement for their children's educational success, are likely to be outspoken in their dealings with the

schools their children with HFA / AS are enrolled in. These reasons are represented in Figure 4.7 below.

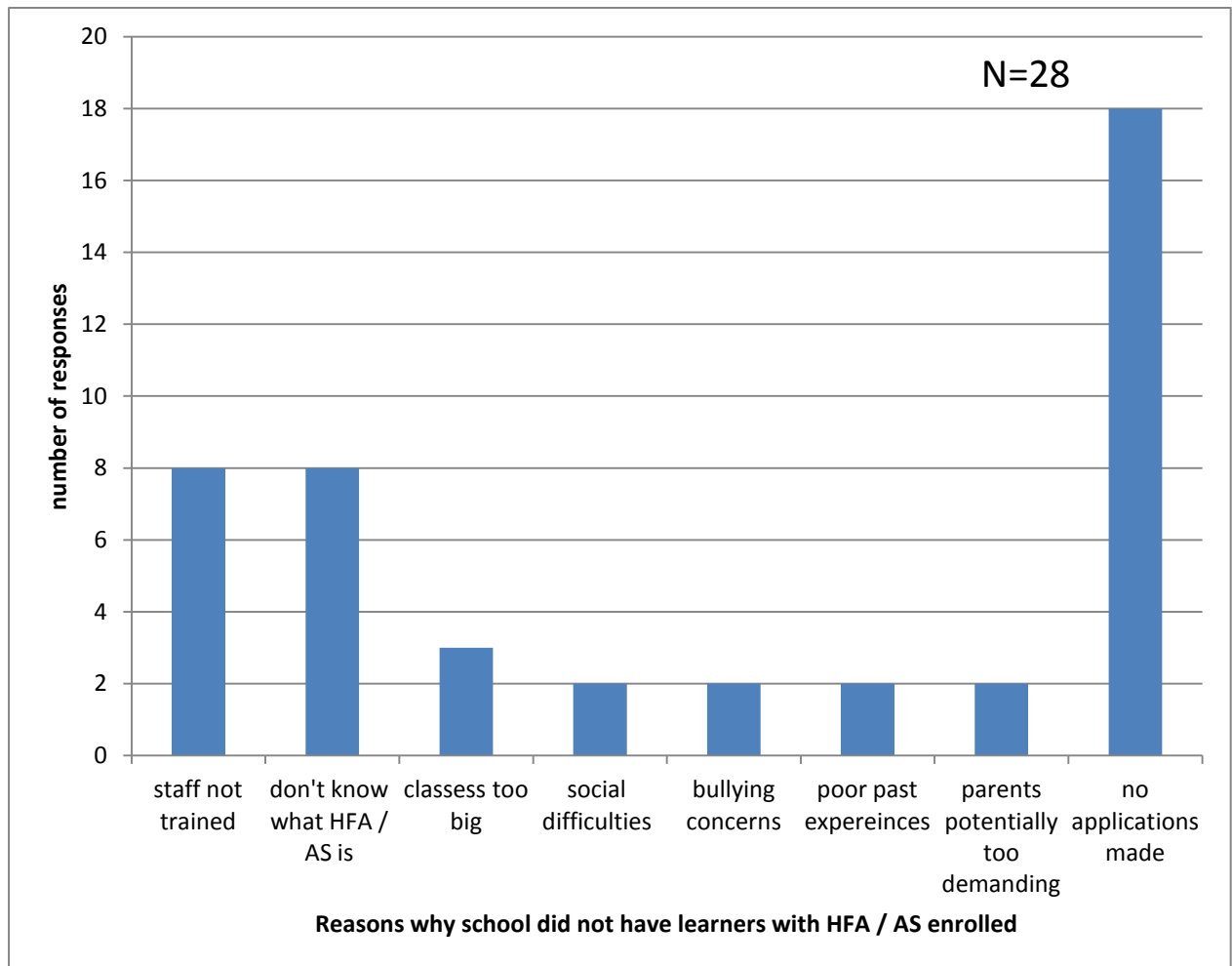


Figure 4.7: Reasons given by schools why they did not have learners with HFA / AS enrolled

Specific recommendations on dealing with the barriers will be presented in Objective 6 of Phase 1 and revisited in section 4.3.9 where the results will be integrated with results from Phase 2 and the autoethnographic essay.

4.2.5 Objective 2: To explore schools' perceived barriers to mainstream education for children with HFA / AS

Attitudes towards inclusion can impact the expectation educators have about special needs learners, including those with HFA / AS (Carrington, 1999; Walton, 2002) and their acceptance into mainstream schools (Education Review Office, 2010). Additionally the understanding about a condition can influence how educators respond to special needs learners as noted by Anthony (2009). In Anthony's study (2009) cultural beliefs contributed towards the attitude that LSEN were unable to learn and that witchcraft was responsible for how the child presented. In this study negative attitudes about inclusion were revealed but they related mostly to misunderstanding about characteristics of HFA / AS rather than causation of the condition. Cultural beliefs such as witchcraft being responsible for HFA / AS were not revealed in this report.

Senior management staff in school environments set the attitudinal tone for the school (Williams, 1983). In addition they are responsible for the staff morale and enthusiasm at their schools (Coleman, et al., 2003). How these senior management staff members understand HFA / AS and the relating attitude about HFA / AS is therefore important when considering the barriers to mainstream education for children with HFA / AS. Senior management staff in the two circuits of the Umlazi school district in this study were therefore presented with a list of characteristics from which to identify HFA / AS as part of the questionnaire. This was to explore the level of understanding of the condition amongst the senior management staff who would be responsible for the acceptance or rejection of children with HFA / AS into their schools. Four schools felt that children with HFA / AS were unable to learn supporting Anthony's finding (2009). One school stated:

'[Children with HFA / AS] can't learn without meds'

This however, is in contradiction to the DSM-IV (APA, 2000) and ICD-10 (WHO, 2012) where one of the criteria for a diagnosis of Asperger's Syndrome is no cognitive delays. That is the person with HFA / AS presents with peer level cognitive skills, implying that children with Asperger's Syndrome (HFA) are indeed able to learn. It could be that the senior staff members were referring to Classic Autism where medication can be prescribed for calming purposes, or for Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder where medication can be prescribed to assist with attention (Autism Speaks 2013). Eight schools recognised this characteristic noting that children with HFA / AS do have peer level cognitive skills and 17 schools indicated that HFA / AS is characterised by high intelligence. This can be the case (Exkorn, 2005; Wing, 2006; Schopler & Mesibov, 1988) and individuals with HFA / AS are well able to make contributions to our society (Attwood, 2007). Foley-Nicpon et al. (2012) note how individuals with HFA / AS can have superior intelligence and be regarded as "gifted". The importance of recognising the intelligence at school level they suggest is so that the learners can be stimulated in the learning areas they excel in. Schools which are able to identify the strengths of learners with HFA / AS and develop those strengths would benefit themselves as schools for interschool competitions such as maths Olympiads. Examples of such competitions are The Horizon Mathematics Competition (Horizon Educational Trust's Schools, 2013) and the Conquesta Mathematics competition (Conquesta Olympiads, 2007) which are conducted in KZN. Foley-Nicpon et al., (2012) note that attention is typically given to the child's areas of weakness but not the areas the learner excels in. This is representative of the Medical model of education (Landsberg et al., 2005) which is active in many mainstream government schools due to the gap in policy in the Education White Paper 6 (South African Department of Education, 2001b) and its implementation. It would be understandable that schools which felt that children with HFA / AS were unable to learn may be reluctant to enrol them. Therefore, the perceived barrier of

the inability of children with HFA / AS to learn may prevent learners with the condition (who are indeed able to learn, APA, 2000; WHO, 2012) from accessing a mainstream education.

Fourteen schools felt children with HFA / AS are unable to communicate. This characteristic does not apply to HFA / AS but rather to Classic Autism (APA, 2000; Autism Society, 2013c), as persons with HFA / AS have language skills which are typically developed, such as peer level grammar and vocabulary (Autism Society of America, 1998; Volkmar & Klin, 2005; Noterdaeme et al., 2010). Their means of social communication, such as conversation skills, however, are impacted as is the ability to easily interpret non verbal language (Wing, 2006; Shane, 2012).

A further 13 schools felt learners with HFA / AS were unable to follow instructions. While it is true that persons with HFA / AS can have inflexible behaviour, respond better to routines and have difficulty dealing with change (McAfee, 2002; Wing 2006; Schetter & Lighthall, 2009) the inability to follow directions does not form part of the characteristics of HFA / AS (APA, 2000; WHO, 2012). Since persons with HFA / AS do have a deficit in Theory of Mind (McAfee, 2002; Schmidt et al., 2011) (See section 1.8.2) and have a literal understanding of language (Shane, 2012), how instructions are interpreted may not be as the staff member intended them to be carried out. Understanding that instructions should be given in a non-ambiguous way would assist in dealing with this issue. Likewise, strategies in dealing with inflexible behaviour related to instructions are beneficial in assisting persons working with learners with HFA / AS and there may also be the need for a trained class assistant to give support in such circumstances (Roberts, 2007; Koegel et al., 2011). Self injury and violence were perceived as part of the condition by eight schools, with one school expressing

'[Children with HFA / AS are] very physical'

Persons with HFA / AS are not inherently violent and no connection has been found between ASD and planned violence (Autism Society, 2013d). Any possible aggressive behaviour observed in individuals with HFA / AS is typically a reaction to a situation (Autism Society, 2013d). Aggression may therefore possibly be present in a situation where a child feels threatened. The perceived barrier of violence being problematic at schools can be overcome by staff members understanding that the child will not plan violence. Additionally understanding the child's emotional needs could also eliminate any potential reactions. Knowing how to handle such situations again raises the issue of staff training. Only six schools identified poor imaginative skills as a characteristic of HFA / AS whereas limitations in imaginative skills form part of the triad of impairments (Exkorn, 2005; Wing, 2008). This characteristic would not necessarily be problematic for all teachers, for example maths teachers or history teachers. So, although there was a lack of knowledge amongst school staff about poor imaginative skills, it would seem it would not be a barrier to admission to mainstream primary schools. Learning problems were noted by 13 schools however, learning difficulties do not form part of the criteria for HFA / AS (APA, 2000; WHO, 2012). Principals perceiving the above characteristics as indicators of HFA / AS could therefore put potential school applicants for children with HFA / AS at a disadvantage, by assuming incorrect information about the condition.

Twenty schools correctly identified the following characteristics of HFA / AS: poor social skills (McAfee, 2002; Volkmar and Klin, 2005; Attwood, 2007), behavioural difficulties (McAfee, 2002; Wing 2006; Schetter & Lighthall, 2009), sensory issues (Dunn et al., 2002; Schetter & Lighthall, 2009; Autism Speaks, 2012) and emotional outbursts for small incidents (Schopler & Mesibov, 1992; McAfee, 2002). Other characteristics which were correctly identified from the list presented were: difficulty making eye contact (Dodd, 2005;

Center for Disease control, 2010) by seventeen schools, obsessive interests (APA, 2000; Dodd, 2005; Center for Disease control, 2010; WHO, 2012) by 18 schools and self stimulatory behaviour (e.g. rocking) (APA, 2000; WHO, 2012) mentioned by 14 schools. Poor concentration (McAfee, 2002; Whitby & Mancil, 2009) was correctly identified by 12 schools from the list provided in the questionnaire. Poor concentration could be linked to the sensory issues and obsessive interests persons with HFA / AS can experience which may be distracting and stressful to the learners (McAfee, 2002; Schmidt *et al*, 2011). The DSM-IV (APA, 2000) notes that those with HFA / AS can be preoccupied by intense interests or parts of objects this may lead to a drop in concentration in classroom topics. These characteristics would make for problematic teaching if the teachers were not trained (Roberts, 2007). The perceptions of the senior management staff, in these cases would be accurate, and these characteristics were noted by the majority of the schools, that being 60.7% to 71.4% of the schools in this study.

Twenty schools said the inability to make friends is characteristic of the condition. Although social deficits do form part of the diagnosis of HFA / AS (APA, 2000; WHO, 2012), persons with the condition are not unable to make friends but rather need to be taught how to make friends (Simpson *et al.*, 2003; Attwood, 2007). This relates back to the need for teacher training to equip school staff in managing learners with HFA / AS and implementing social skills curriculum (Attwood, 2007). Some learners with HFA / AS can experience difficulty in reading comprehension, which was recognised by only five schools. This characteristic only becomes evident as the school years progress (Whitby & Mancil, 2009), so may not have been observed by those completing the questionnaire. This difficulty is related to the social deficit of the condition where the learner is often required to interpret someone else's point of view (Theory of Mind) in comprehension exercises (McAfee, 2002; Schmidt *et al*, 2011).

The flipside of poor social skills is that persons with HFA / AS are typically very honest as they struggle to deceive others (Attwood, 2007); only five schools recognised this positive aspect of the condition.

Seven schools recognised the good maths skills of persons with HFA / AS (Baron-Cohen, et al., 2005). It is noted that persons with HFA / AS can achieve well in “techheavy” industries as adults as they are skilled in information technology and computer related pursuits (Shane, 2012). These types of activities require effective skills in mathematics. Ten schools, however, did recognise the attention to detail learners with HFA / AS have, this could also relate to the success many persons with HFA / AS have in areas of technology as adults.

Three schools recognised the individuality of learners with HFA / AS,

‘[The characteristics] depends on each child’

‘Not all [characteristics] apply to all children with HFA / AS’

‘[The characteristics] don't necessarily apply to all children with HFA / AS’.

These expressions, recognising that each child with HFA / AS presents differently could positively affect future enrolment of children with HFA / AS even if past experiences of children with the condition were not positive. The Education White Paper 6 (South African Department of Education, 2001b) reveals the importance of dealing with each child with special needs individually, mentioning that stereotyping will also negatively impact inclusion.

The information regarding characteristics of HFA / AS as reported by 25 of the 28 schools in the study is represented below in Figure 4.8. Three schools omitted the section on the characteristics of HFA / AS in the questionnaire.

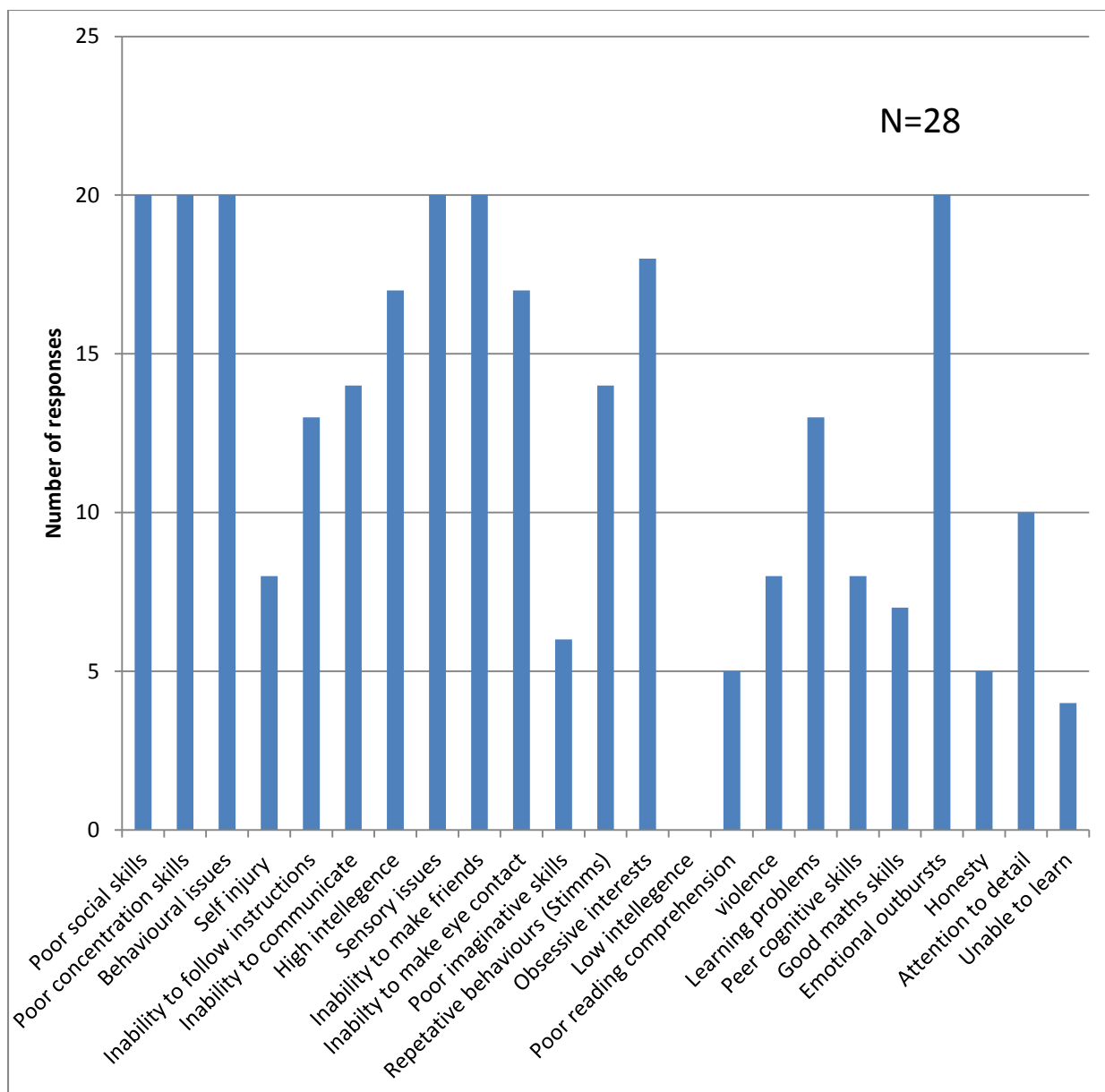


Figure 4.8: Characteristics of HFA / AS as reported by schools in the selected circuits of the Umlazi district

4.2.6 Objective 3: To explore the experiences of admission or attempted admission to mainstream education for parents of children with HFA / AS

This objective was not addressed in Phase 1 of the study. Please see Phase 2 section 4.4.1 where this aim is addressed.

4.2.7 Objective 4: To explore the encounters of schools who admit children with HFA / AS

Sixteen of the 28 schools reported that they had learners with HFA / AS currently enrolled in their schools or had had learners with HFA / AS enrolled in their schools in the past five years. The experiences the teachers had of having learners with the condition in their classes as reported by the senior staff members are discussed in this section.

Eleven schools reported that it was a difficult experience for the teachers. One school reported it was not difficult for the teachers and four schools reported that they did not know if the experiences were difficult for the teachers or not. Several reasons were given for the difficulty the teachers experienced. These were categorised into two main groups: 1. Lack of staff training and 2. Class size / the need for individual attention for the child with HFA / AS. Only one school reported that

'[The teacher] is managing well. No serious problems experienced'

4.2.7.1 Staff training

The lack of staff training was raised by seven of the eleven schools which reported that the experience of having learners with HFA / AS in their classes was difficult for the teachers. This was in line with the literature where teachers felt unprepared in teaching children with HFA / AS in other parts of South Africa (Roberts, 2007; Walton et al., 2009). The Education White Paper 6 (South African Department of Education, 2001b) acknowledges the need for training and teacher support. The teachers of the schools in the study had not received any direct training, nor any support from district support teams as mentioned in the Education

White Paper 6 (South African Department of Education, 2001b). They expressed the following.

'Couldn't always cope with the demands of the child',

'Didn't know how to handle the learner',

'Educators need to be aware of outbursts and lashing out at other learners',

'No expertise to deal with and assist children with HFA / AS '

'No training to deal with behaviours of ASD',

'Not correctly trained',

'Teachers not fully equipped to handle learners'

'Very little or no experience with the conditions listed'

'Teachers are not informed about these learners and their symptoms.'

The desire for further training was also expressed by one school with

'We need to be better informed'.

4.2.7.2 Class size / individual attention

The issue of small class sizes also appears in the literature (Simpson et al., 2003; Roberts, 2007; Walton et al., 2009), with the authors noting that small classes assist with dealing with difficult behaviour (which is mentioned in the above quotes) as well as with giving more attention to learners with HFA / AS. This aspect of individual attention is given in support of home schooling (Schetter & Lighthall, 2009) and flexischooling (Lawrence, 2012). These options are not available to all parents as financial sacrifice is involved since one parent would not be able to earn if teaching the child at home (Schetter & Lighthall, 2009). A difficulty experienced by teachers in working together with parents of LSEN specific to the South African context, is that there are those parents who are illiterate or have low education

(Kujwana, 2008). These parents would not be equipped for homeschooling or flexischooling.

The schools' experiences are recorded below.

'[Teachers are] not always able to give individual attention',

This was stated in consideration of other learners as indicated below;

'Teachers have to spend extra time with learner with ASD =less time for other learners who need help',

'They [learners with HFA / AS] are very demanding, and find it difficult to share equipment, cards and the educator with the other learners.'

One school expressed their experiences positively saying

'[Teaching children with HFA / AS is] time consuming but once in routine gets easier.'

Twelve of the sixteen schools which currently had learners with HFA / AS enrolled or had done so in the past five years reported that having a child with HFA / AS in the class was a drain on the teachers' time. This made up 75% of the schools who had learners with HFA / AS currently enrolled at their schools or who were enrolled in the past five years. Three schools reported that they did not know and one school expressed that it was not a drain on the teachers' time. There were two positive comments expressed.

'Children are never a drain'

'Can be draining but when done with heart, can be rewarding'.

The reasons given for the drain on the teacher's time was again related to the other learners, as expressed below.

'Academic time is taken from other learners'

‘Teachers often have to spend extra time with the learner with AS, depriving other learners of the teacher’s time if they happen to struggle with the concept-especially if it is a “busy” class in general’

This need could be met by means of a class assistant or facilitator, (United States Department of Education, 2004; Barratt, 2005; Fein & Dunn, 2007; Koegel et al., 2011), so that the education of the neurotypical learners in the class is not negatively affected.

Twelve of the sixteen schools reported that having a child with HFA / AS was a growing experience for the teachers and an opportunity for the teachers to gain experience in working with children with HFA / AS. Hands on experience was noted as beneficial in generating a positive attitude of educators towards working with learners with HFA / AS (Carrington, 1999). The hands on experience was recommended by means of the guidance of professionals.

4.2.7.3 The experience of neurotypical learners educated alongside learners with HFA / AS

There were mixed comments by the schools towards the experience of the neurotypical learners who were in the same class as the learners with HFA / AS. It was seen as an opportunity for the neurotypical learners to understand those who are different, that is, those who have HFA / AS, by 75% of the schools. These schools had learners with HFA / AS currently enrolled or had learners with HFA / AS enrolled in the past five years. The schools felt that:

‘Everyone needs to be accepted for who they are and we need to teach empathy, care and understanding’

‘[Inclusions gives learners the] opportunity to help and take care of each other’

‘Children learn patience and acceptance’

‘[The neurotypical learners] were most sympathetic’

‘[The neurotypical learners learned that] different doesn't mean wrong’

This reflects the view Temple Grandin (2012) (famous adult on the Autism Spectrum) has about herself saying that she is different but not less and it relates to the uniqueness persons on the Autism spectrum display (Jordan 2001; McAfee, 2002). Inclusion can have benefits for both the learner with HFA / AS and the neurotypical learner (Simpson et al., 2003; Fein & Dunn, 2007; Yssel et al., 2007) in terms of peer tutoring and the development of social skills. One school reflected this sentiment saying:

'Children with HFA / AS are special and have lots to teach others'

Reichert et al. (1989) found that all parents of children with special needs children in their study and 92% of parents of neurotypical children felt it was beneficial for the two groups of children to be educated together. Teachers in this study who expressed concern for the neurotypical learners said that the neurotypical children had found the learners with HFA / AS challenging as expressed in the following quotes.

*'[Neurotypical learners] find these children [with HFA / AS] difficult',
[but] after explanation they try to understand'
'...do find behaviours disturbing and are unsure how to cope'*

The teachers went on to say that the neurotypical learners found the learners with HFA / AS particularly difficult if there were outbursts and especially if these outbursts were

*'Violent',
'Some learners found this traumatic'.*

It should be considered if the learners who were violent were correctly diagnosed with HFA / AS or if there were other contributing factors (Autism Society, 2013d). At two schools the

neurotypical learners appeared to be accepting early on but not continuously. The drop in acceptance contributed to disruptions caused by the learners with HFA / AS as indicated by the quotes below.

'Initially yes'

'Certainly at foundation phase they [learners with HFA / AS] are accepted [by their neurotypical peers]. At senior primary [grade 4-7] this is not the case'

In contrast to the above quotes, another school reported that younger learners were not able to understand the learners with HFA / AS.

'Lack of understanding from younger learners'

A positive attitude towards HFA / AS by the senior management staff members in schools is essential in influencing how the neurotypical learners feel about the learners with HFA / AS and for inclusion to be successful (Carrington, 1999; Anthony, 2009). This was expressed by one school which said

'[We have] no problems [with other learners] we encourage acceptance'

This positive attitude can contribute to positive outlooks by the neurotypical learners. It is understandable that it would be difficult for the educators to see inclusion as positive and express this positively to neurotypical learners if the teachers do not have training or support.

Again reflecting on teacher training three schools said that learners with HFA / AS can be disruptive or distracting to other learners in the class and that having a learner with HFA / AS can slow down the teaching of the class. This principle can apply to any learners with special needs and is not exclusive to HFA / AS.

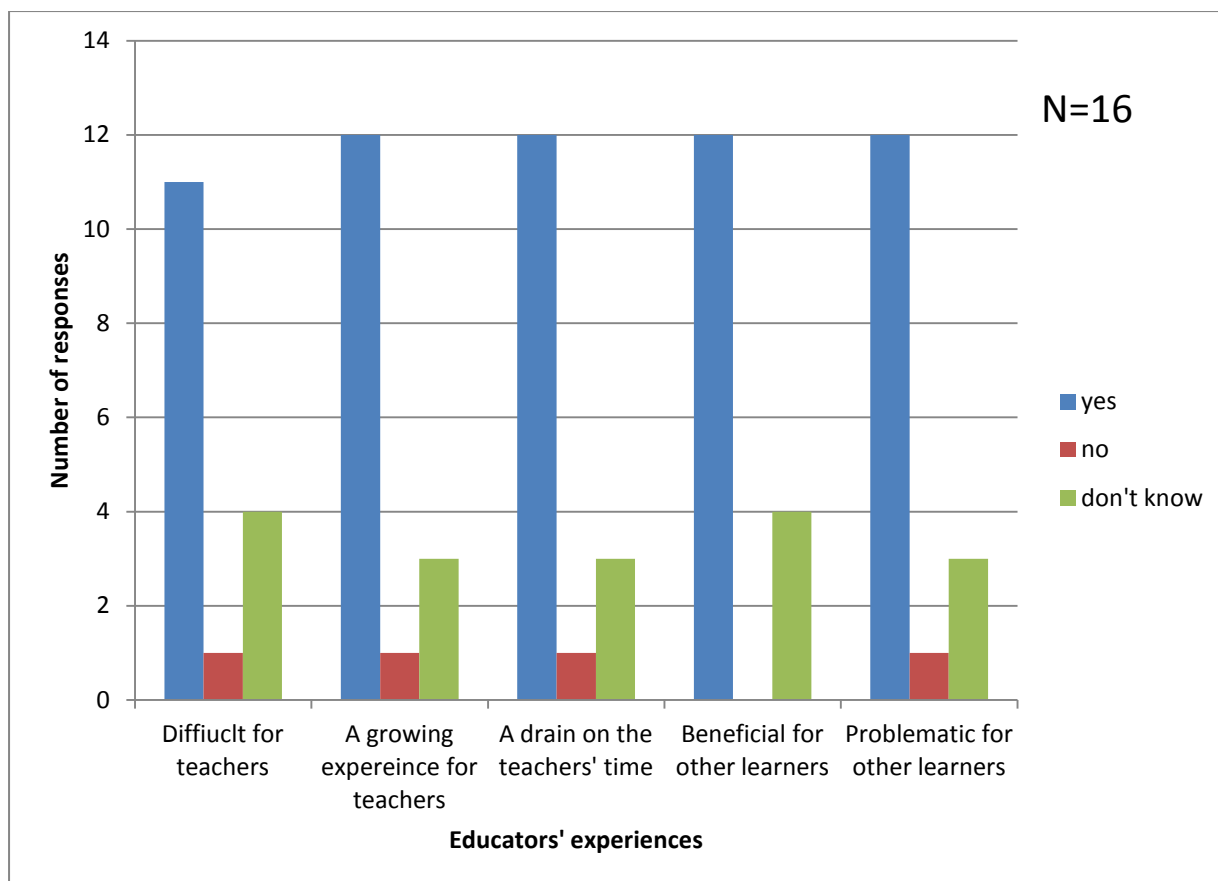


Figure 4.9: Educators' experiences of teaching children with HFA / AS

Figure 4.9 shows the mixed views teachers had about teaching learners with HFA / AS, as reported by senior staff members in mainstream schools. While it was difficult for the teachers, the majority of teachers also felt it was a growing experience and while it was a drain on the teachers' time which impacted other learners, the experience was felt to be beneficial for the neurotypical learners in most cases.

Geduld (2009) and de Nysschen (2008) outline that teaching a learner with ASD (including HFA / AS) can be emotionally draining and they suggest options to support teachers. These include support groups, networking with other teachers working with learners on the spectrum, shortened school day hours and taking time off as needed.

4.2.8 Objective 5: To determine the current numbers of children with HFA / AS admitted into mainstream primary schools in a specific population

Due to the low response rate of 18% (Babbie & Mouton, 2007) it was not possible to determine the current numbers of children with HFA / AS in the two circuits of the Umlazi school district being studied. However, totals of learners with HFA / AS were collected from the 28 schools which participated in the study. These are presented in Table 4.6 below. There are currently no data bases of number of children with HFA / AS in mainstream schools in the target area to refer to. It was thus hoped that this study would add to knowledge in this regard.

It is interesting to note that a total of 11 learners were identified as undiagnosed but suspected to have HFA / AS. An additional four schools reported that they suspected there were learners with HFA / AS in their schools who were not diagnosed however, the number of learners were not specified. This could relate to the age of diagnosis for children with Asperger's syndrome of between 8 and 12 years old (Attwood, 2007; Schetter & Lighthall, 2009). In some cases learners with Asperger's Syndrome are diagnosed as early as five years (Exkorn, 2005) but this is less common. This means there could be learners in the schools who did not have a diagnosis at the time of enrolment as learners can enrol for grade R between the ages of 4.5 years and 5.5 years (KwaZulu-Natal Education Department, 2010). These learners may then have been observed to have some characteristics of HFA / AS by the teaching staff as the child got older. The numbers below were compiled from 13 schools which indicated that they did have a learner or learners with HFA / AS enrolled at their schools. The average number of learners with HFA / AS per school in this study was 1.5, with the range being one to three.

Table 4.7: Current numbers of learners enrolled with HFA / AS reported by schools in the study

Condition	Numbers
HFA	1
PDD-NOS	0
Asperger's Syndrome	7
Suspected HFA / AS but undiagnosed	11
Total	19

N=28

Nine schools indicated that they had learners in their schools in the past five years who were undiagnosed but suspected to have HFA / AS but numbers were not specified. The difference in numbers of learners with HFA / AS who were currently enrolled at schools in the target area and those enrolled in the target area in the past five years was only two learners. It should be noted that in both time periods there were unspecified numbers of learners who were undiagnosed but suspected to have HFA / AS. The number of schools between the two time periods differed by three schools with the lower number of schools (13) being the current number. Sixteen schools reported that they had learners with HFA / AS or suspected HFA / AS in their schools in the past five years. The numbers are indicated in Table 4.9 below. This drop in numbers of schools with learners with HFA / AS is surprising considering the rise in number of children with ASD, including HFA / AS (Whitby, et al.,

2009; Autism Society, 2011 Centre for Disease Control, 2012a). Possible reasons for learners not being admitted into mainstream schools were discussed in sections 4.2.4 and 4.2.5.

Table 4.8: Numbers of learners enrolled with HFA / AS in the past five years as reported by schools in the study

Condition	Numbers
HFA	3
PDD-NOS	0
Asperger's Syndrome	15
Suspected HFA / AS but undiagnosed	3
Total	21

N=28

4.2.9 Objective 6: To explore possible ways barriers to admission to mainstream schools for children with HFA / AS may be overcome

4.2.9.1 Attitudes

Overcoming the attitudinal barriers to mainstream education for children with HFA / AS can be dependent on the outlook of the senior management staff at the primary schools (Walton, 2002). The Social Ecological model of education described by Landsberg et al. (2005) notes that for inclusion to be successful attitudes have to change. This is addressed in the Education White Paper 6 (South African Department of Education, 2001b) where the need for training at schools at management level is mentioned in reference to revising current school programmes. Changing of a person's attitude is not a simple process however; having a national policy in place can start in reversing the educational norms and expectations of the

past. Therefore, for schools to overcome this barrier they would need to recognise the stance the government takes on this issue, “ While special schools provide critical education services to learners who require intense levels of support, they also accommodate learners who require much less support and should ideally be in mainstream schools” (South African Department of Education, 2001b, p. 21) and “Specifically admission policies will be revised so that learners who can be accommodated outside of special schools and specialised settings can be accommodated within designated full-service or other schools and settings” (South African Department of Education, 2001b, p. 27). It should be noted that only three of the schools in the study stated that they did not have any understanding about the Education White Paper 6 (South African Department of Education, 2001b). The remaining 25 schools all had varying levels of understanding about the document meaning inclusion of special needs learners into mainstream schools. In Uganda, policy changes were made to include learners with disabilities into mainstream schools. The implementation of the policies were difficult despite the legislation as many families, government officials and disability organisations were unaware of the new legislation (Mittler, 2003). In this study the majority of the senior staff members were aware of the inclusion policy, yet were not in favour of it. The South African Department of Women Children and People with Disabilities, in their Annual performance plan fiscal year 2012-2013 document (2012), states that the department strives for the equalisation of opportunities for persons with disabilities. The equal opportunity desired for children with HFA / AS is for mainstream schooling. The Annual performance document (2012) goes on to say that attention will be given to effective service delivery for persons with disabilities. While the service delivery is still lacking in support of teachers at mainstream schools who teach learners with HFA / AS, the presence of this attitude in national policy indicates the desire to up hold the rights of persons with disabilities including HFA / AS.

Attwood (2007) describes how knowledge changes attitudes, and we could assume the missing part to changing the attitudes of senior management staff is that the means to implementing the policies put forward in the Education White Paper 6 (South African Department of Education, 2001b) are not yet realised.

4.2.9.2 Educator support

Dealing with challenging behaviours such as inflexibility (Wing 2006; Schetter & Lighthall, 2009), difficulty dealing with change (McAfee, 2002), self stimulatory behaviours (APA, 2000; WHO, 2012) and emotional outbursts (Schopler & Mesibov, 1992), associated with HFA / AS, can be difficult for a teacher especially of a large class. Approximately a third (32.1%) of schools in the study reported that they would enrol learners with HFA / AS if the learners did not have behavioural issues (including repetitive and stereotypical behaviours). This would seem discriminatory since behavioural difficulties are part of the diagnosis of ASD (and thus HFA / AS) (APA, 2000; WHO, 2012) and form part of the triad of impairments (Exkorn, 2005; Wing, 2008). This barrier can be overcome by means of class assistants (Koegel et al., 2011) or personal facilitators (Roberts 2007) for the child with HFA / AS. The role of a class assistant is to aid the teacher in the classroom in a general sense with learners and class activities. The role of a facilitator is to be a personal aid to a learner with special needs, including HFA / AS. These facilitators and class assistants who should be trained in working with learners with HFA / AS (Koegel et al., 2011) would assist the teacher with the child with HFA / AS should a difficulty with behaviour arise. In this study, 50% of schools recognised the need for class assistants to overcome this barrier, saying they would enrol learners with HFA / AS if they had class assistants. The need for the parents of the child with HFA / AS to provide a personal facilitator for the learner to enable enrolment was noted by 28.5% of the participant schools. This would impact the personal finances of the parents

of the child with HFA / AS which goes against the charter rights for persons with Autism as reflected upon by Matthews and Matthews (2012).

An additional area of support needed for the educators is in dealing with the sensory issues the learners with HFA / AS may experience. In excess of half of the schools in this study, 57.1%, felt that they would be able to enrol learners with HFA / AS if support staff were employed at their schools (psychologists, occupational therapists, speech therapists and remedial teachers). Walton et al. (2009) agree with the need for support staff however, how the support staff are funded is not noted. Of the schools who reported they did have support staff working at their schools, all were personally funded by the parents of the children who needed access to them. Fourteen schools reported that they employed either class assistants, support staff or both (See Table 4.6 and Table 4.7). Of these 14, three reported that a mainstream school is the setting most suited to educate learners with HFA / AS, three reported that mainstream schools with support (i.e. class assistance or support staff) is the best setting, three reported the best educational setting for a child with HFA / AS depends on the how the child presents with one of those three schools adding that the support the teacher is given is also important. One school said mainstream education with teacher training would make the best setting. Therefore in this study, 10 of the 14 schools (71.4%) which had class assistants or support staff felt mainstream education was the best placement for learners with HFA / AS.

Overcoming this barrier to acceptance to mainstream government primary schools for children with HFA / AS is addressed within the Education White Paper 6 (South African Department of Education, 2001b). Educator support by means of district professional support teams is outlined. Teachers are due to receive support services by trained personnel to assist learners with a “full range of learning needs” (South African Department of Education, 2001b, p. 25). However, the implementation of this goal was not realised by the schools in

this study. Teachers in Malaysia (Yoke, 2010) and in KZN (de Nysschen, 2008) reported that increased work load in terms of paper work affected their attitudes towards teaching with learners with ASD. Providing teachers with support in practical areas such as administration would provide more time for teachers to concentrate on teaching. This could be achieved by means of parent volunteers or collaborative involvement from other teachers. These could be the physical education teachers, librarians or music teachers who do not have the added demands such as setting and marking exams. Additionally teachers could provide each other support by means of weekly meetings to share ideas and problem solve in areas involving HFA / AS. This form of collaborative teaching (Yoke, 2010) could increase a teacher's confidence and reduce stress. de Nysschen (2008) revealed that stress levels are high for educators working with learners with HFA / AS. Support would be needed for the educators on an emotional level as well in order to promote successful inclusion. For this support groups were suggested as well as shorter school days and increased communication with the parents of learners with ASD as well as time out from the learners and increased physical activity.

4.2.9.3 Finances

More than half of the schools in this study, (57.1%) reported that they would enrol learners with HFA / AS if they had more government funding. In this study some schools had overcome the barrier of financial limitations to enrolling learners with HFA / AS themselves by means of fund raising or by the parents of the children affected paying for class assistants, support staff and facilitators. Although this method goes against the charter rights for persons with Autism as mentioned by Matthews and Matthews(2012), it is a reality for the current educational options within South Africa. This option therefore excludes all families of children with HFA / AS who are not in a financial position to pay for the personnel needed to help their children in the school setting or for the training of such staff.

The Education White Paper 6 (South African Department of Education, 2001b) outlines the need for educator support to facilitate successful inclusion. The practicality of the implementation of the policies in the document however, are not yet a reality as evidenced by 100% of the participant schools reporting that they have not had training provided by the government on HFA / AS but that they would like training on the topic. In Ghana (Anthony, 2009) similar financial issues exist with policy existing to include all learners with non-severe disabilities into mainstream schools (Government of Ghana, 2003) but means to do so being absent. Due to the high expense of special needs education, financial priority has not been given to implement the policies. The difficulty in providing suitable education for learners with ASD in Ghana is that structures are not presently in place for these learners and they are therefore not in school. Numbers of learners needing special education are therefore not determined and the ripple effect is that these learners are not budgeted for in planning for special needs education (Anthony, 2009). The problem therefore perpetuates itself.

4.2.9.4 Training

The lack of staff training in the field of HFA / AS was presented repeatedly as a difficulty by the schools. Of the participant schools, 100% reported that no training had been provided by the South African Department of Education. Some school staff had attended training seminars on HFA / AS which had been provided by private organisations, which typically are not free of charge. This made up 17.8% of the participant schools, leaving 82.2% of the schools in the study having received no input about HFA / AS, about characteristics, teaching methods or classroom management for learners with HFA / AS. This regards workshops or seminars teaching staff have attended at some point during their teaching career. It does not represent instruction on HFA / AS included in the teaching qualification, as reported by senior management staff of the schools and recorded in section 4.3.1.2 where 92.8% of the senior management staff reported that no instruction on the topic was provided in their

teacher training qualification. It was evident that the schools felt unprepared to educate learners with HFA / AS as 100% of the participant schools reported that they would like to receive training in HFA / AS.

The Education White Paper 6 (South African Department of Education, 2001b) states that the classroom teacher is the main resource in the successful implementation of inclusion and that the skills of the educators (including senior management staff) will need to be further developed and new skills will need to be learned in order for inclusion to be successful in South African schools. This exemplifies the Social Ecological model of education (Landsberg et al., 2005) which would be beneficial to learners with HFA / AS. The Education White Paper 6 (South African Department of Education, 2001b) goes on to say that the teachers' needs will be reviewed and structured programmes will be put into place in order to meet the needs of the educators in successfully implementing inclusive education. In this study the lack of provision in this area remains a barrier to admission to mainstream education for children with HFA / AS in primary schools.

For schools to overcome this barrier without the presence of the district support teams, they could collaborate with other schools in the areas and hold brainstorming sessions. Teachers from different schools could share their experiences and difficulties and together reach solutions which would be beneficial for all school staff attending the meeting (Yoke, 2010). These types of meetings could be held on a regular basis and would not have any financial impact on the schools. The resource being used would be the time needed to meet. Guest speakers from Autism organisations such as Autism South Africa and Action in Autism could be invited to address the specific issues the teachers are facing in the classroom. Both organisations are non profit and do not charge for their services. Areas to address which would be helpful to teachers could be behaviour management, visual support and I.E.P to name a few (de Nysschen, 2008). In the absence of professionals available to teach on the

topic of HFA / AS, use could be made of the training available on the internet, for example the CARD organisation or by means of DVDs available for purchase on line or through Autism resources centres.

4.2.9.5 Curriculum and teaching technique adjustments

Just less than half (46.4%) of the schools in this study reported that they would accept learners with HFA / AS into their schools if they assessed the child to be suitable for their schools. This would indicate that the schools were still employing the Medical model of education (Landsberg et al., 2005; Jordan, 2008), where the child has to “earn” the right to be accepted into that school by fitting into how the school has always operated. The Education White Paper 6 (South African Department of Education, 2001b) outlines the implementation of the Social Ecological model (Landsberg et al., 2005) where the curriculum and teaching methods are to be adjusted to meet the needs of the learners saying: “In mainstream education, priorities will include multi-level classroom instruction so that educators can prepare main lessons with variations that are responsive to individual learner needs; co-operative learning; curriculum enrichment; and dealing with learners with behavioural problems” (South African Department of Education, 2001b, p. 18). Overcoming this barrier again relates to finances and teacher training in order for the educators to be trained to adjust the curriculum to accommodate learners with HFA / AS.

4.2.9.6 Class sizes

Behavioural difficulties can be challenging for an educator of a large class. Two schools expressed this issue by saying ‘*[inclusion] does not work in huge classes*’ and ‘*Does not work in classes greater than 30*’. This is linked to the need for educator support by means of a class facilitator or class assistant, which therefore relates to the barrier of finances, as provision would be needed for the payment of such staff. In this study some schools had overcome this barrier themselves by means of fund raising or by the parents of the children

affected paying for the support staff. One school had a 'Support Unit' (SU) which catered for a maximum of 14 learners per grade. This school had overcome the barrier of class size by creating an SU for each grade. This catered for the individual needs of children with special needs in general, which included HFA / AS. This again would require finances to achieve. In Malaysia the Persons with Disabilities Act (Government of Malaysia, 2008) entitled children with disabilities including ASD equal opportunity to attend mainstream schools. The mainstream classes had approximately 50 learners per class and the practical implementation of the Act led to special classes being instituted at the mainstream schools. These classes had special education programmes for learners who were not able to perform academically in mainstream classrooms. They were effectively remedial or special needs facilities at a mainstream school. While this method would be beneficial for learners with cognitive difficulties, learners with HFA / AS do not have cognitive challenges (APA 2000; WHO, 2012) and would benefit from mainstream curriculum. A combination for the two methods, that is, small classes with mainstream curriculum would be most effective as demonstrated by one school in the Umlazi district which had successfully implemented this combined approach to LSEN. The factors expressed in this section (section 4.2.9.) which schools stated as necessary for acceptance of learners with HFA / AS into their schools are represented in Figure 4.10 below.

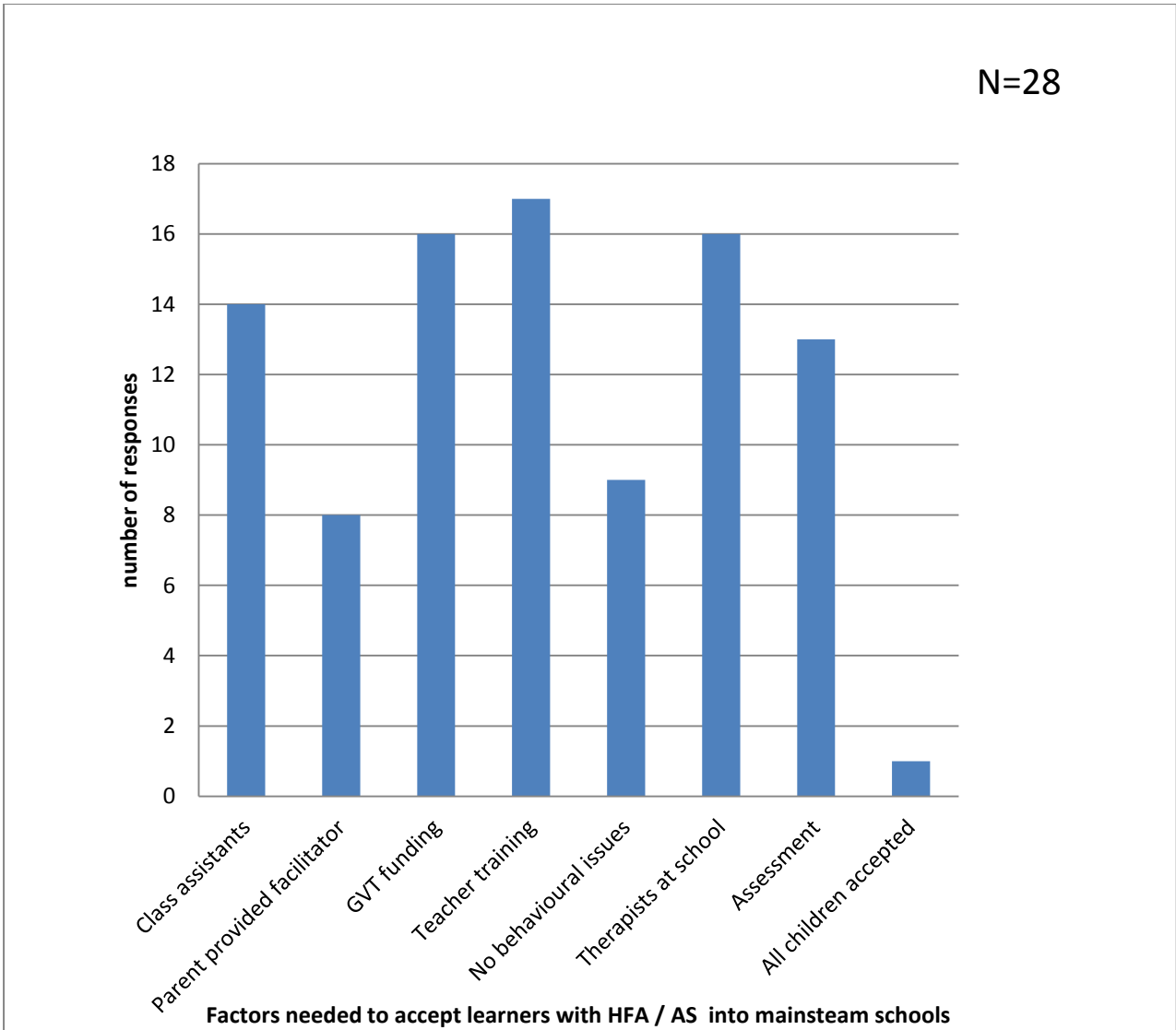


Figure 4.10: Factors needed to accept learners with HFA / AS into mainstream schools

It is interesting to note that 13 schools required an assessment of children with HFA / AS who would like to enrol at their schools. When schools were asked what type of screening method was used, 20 schools reported that they do not have a screening method and a maximum of eight schools had specific requirements used for screening. These were an interview with the parents, an interview with the child, a performance test for the child, a report from the previous school, an observation of the child’s behaviour and one school

required reports from any specialists the child had seen for example psychologist or speech therapist. These are represented in Figure 4.11 below.

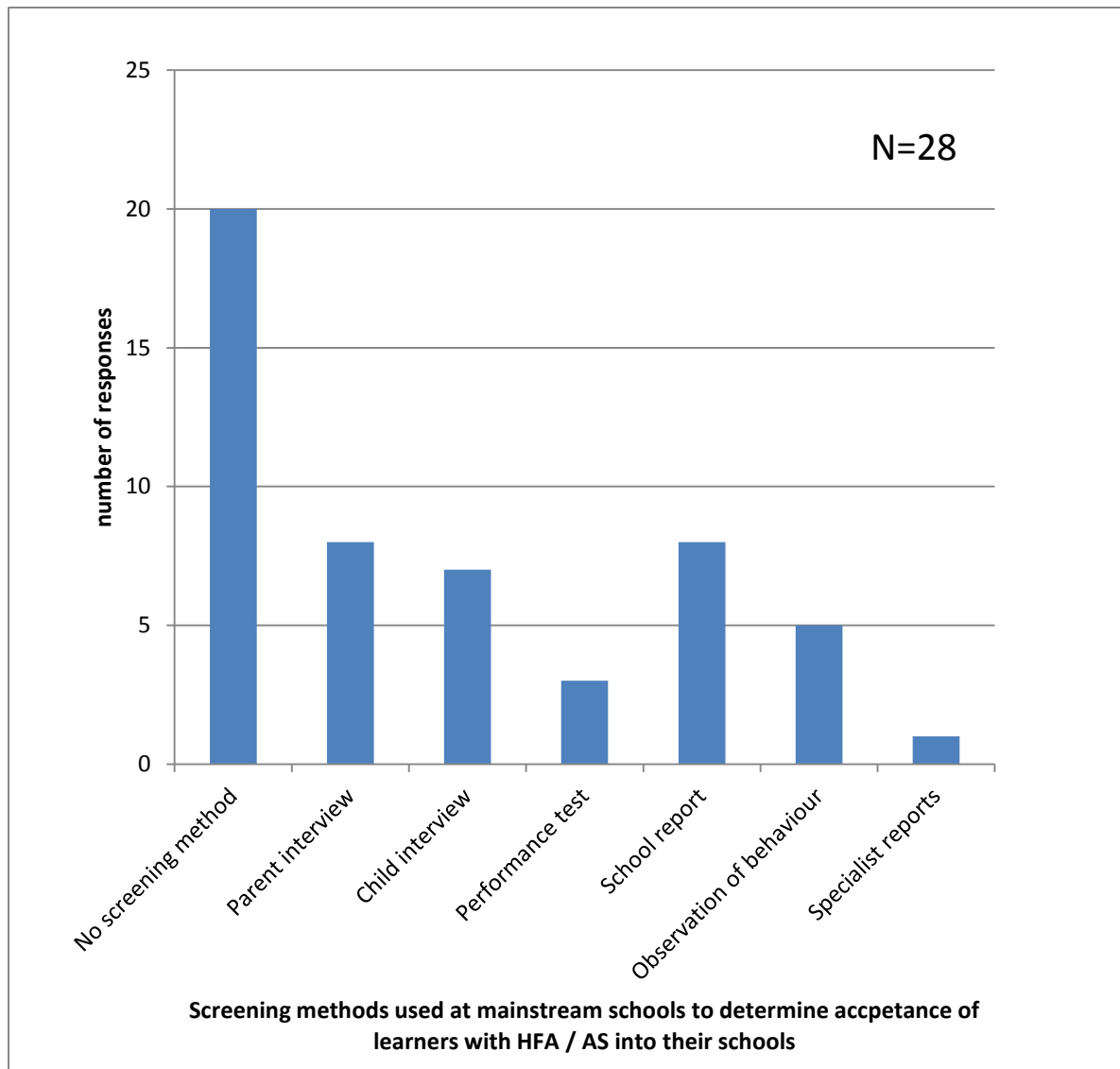


Figure 4.11: Screening methods for acceptance into mainstream schools for children with HFA / AS

Three schools required a performance test and eight required a report from a previous school in order to determine if they would admit a learner with HFA / AS into their schools. The use of a performance test to determine eligibility for a school is however, illegal according to the Rights and responsibilities of parents, learners and public schools: Public School Policy Guide (South African Department of Education, 2005). It would seem there is a need to

address the lack of standardisation of the admission process for learners with HFA / AS as in this study schools accepted or rejected learners with HFA / AS based on the subjective views of the senior management staff. Screening tool such as The High-Functioning Autism Spectrum Screening Questionnaire (ASSQ) which was developed for use with school aged children (Ehlers, Gillberg & Wing, 1999) could be utilised in the South African context to determine the appropriateness of learners on the Autism Spectrum for mainstream schooling. Learners who do not fall within the High Functioning range as determined by the screening tool, could then be referred to special needs schools where their needs would be better attended to. It is suggested that the district support teams take this responsibility. In Ghana, similar difficulties exist with a poor screening system in place and confusion amongst school staff as to the steps involved with referral of learners with special education needs including those with HFA / AS. A lack of standardisation was also reported (Anthony, 2009).

In addition to the data processed from the questionnaires already being discussed in this chapter, the qualitative data is represented in Table 4.10 below.

Table 4.9: Themes arising from open ended questions

<p>Lack of staff training</p>	<p>‘Very difficult for the teachers to provided specialised teaching..... for HFA / AS as there is no trained support structure in place’</p> <p>‘Definitely a need for HOD’s or managers to be trained in this regard’</p> <p>‘[for inclusion to be successful] educators would need training’</p> <p>‘Teachers are not fully equipped’</p> <p>[Teachers were] not sufficiently trained to deal with the behaviours of these learners’</p> <p>‘[Teachers were] not correctly trained’</p>
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<p>Willingness to teach children with HFA / AS or accommodate them in mainstream classes</p>	<p>‘Training on the above would be fantastic. This would go a long way- to us being in a better position to help children with HFA’</p> <p>‘Educational class assessments: child may not be able to be tested as other children’ [would need alternate testing methods]</p> <p>‘adapt teaching strategies to assist them[learners with HFA / AS]’</p> <p>‘[Teaching a child with HFA / AS] encouraged you to try and test new ideas and teaching styles’</p>
<p>Consideration of neurotypical learners</p>	<p>‘[Neurotypical learners] did not always understand fully all the circumstances and medical background’</p> <p>‘[Having a child with HFA / AS in the class] took away academic time from the other learners’</p> <p>‘[Neurotypical learners] have found these children [learners with HFA / AS] very difficult after explanation have found the learners do try to understand and make allowances’</p> <p>‘[learners with HFA / AS were] often disruptive’</p> <p>‘some learners found this traumatic’</p>
<p>Positive teaching experiences</p>	<p>‘[The teachers] learned from the different situations that occurred’</p> <p>‘New challenges- new learning experience [for teachers]’</p> <p>‘We have learned so much over the years’</p> <p>‘It takes you out of your comfort zone, leads to research and increased knowledge’</p> <p>‘Teachers have enjoyed the challenge’</p>
<p>Negative teaching experiences</p>	<p>‘[The teachers] could not always cope with the demands of the child’</p>

	<p>‘with so many children you are constantly on the back foot unless you have support’</p> <p>‘Difficult to handle these learners’</p> <p>‘Time consuming’</p>
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4.2.10 Summary of Phase 1

Phase 1 revealed that there are a small number of schools in the two circuits of the Umlazi school district which do enrol learners with HFA / AS. The majority of the schools were not in support of mainstream education for learners with HFA / AS, rather suggesting special needs schools or remedial schools as the teachers in the mainstream schools were not trained to teach learners with HFA / AS. Only approximately one third of the schools which currently had learners with HFA / AS enrolled, reported that mainstream schooling was the educational setting most suited to learners with the condition. Approximately two thirds of the schools reported that no applications were made at the schools by learners with HFA / AS. This may be due to the late age of diagnosis of the Asperger’s Syndrome (Attwood, 2007; Schetter & Lighthall, 2009) or the difficulty in the diagnosis itself (Whitby & Mancil, 2009). It can be inferred that since the majority of the schools were not in support of mainstream education for HFA / AS, that a diagnosis may be a barrier to admission (Barratt, 2005).

It was revealed that there was misunderstanding about HFA / AS amongst senior staff members of the schools and that Classic Autism was confused with HFA / AS in some cases. The changes in the DSM –5 regarding Asperger’s Syndrome and Autism Spectrum Disorders (APA 2013) may cause further confusion for schools and increased difficulty regarding admission for learners. Learners who are High Functioning but are now diagnosed with Autism Spectrum Disorder, may have applications declined based on the assumption that they have Classic Autism. In contrast those who will be diagnosed with Social (pragmatic)

Communication Disorder (APA, 2013) may have an advantage regarding admissions as no connection with ASD is made.

Schools expressed that they would enrol learners with HFA / AS if certain criteria such as teacher training and government funding were met. The results from Phase 1 will be integrated with the results from Phase 2 and the autoethnographic essay in section 4.7.

4.3 Results: Phase 2

The aim of Phase 2 was to address Objective 3 and Objective 6 of the study. These are:

Objective 3: To explore the experiences of admission or attempted admission to mainstream education for parents of children with HFA / AS and Objective 6: To explore possible ways barriers to admission to mainstream schools for children with HFA / AS may be overcome. A focus group was utilised for this purpose. The participants fulfilled all the selection criteria for participation in the study as outlined in Chapter Three. Despite efforts made to recruit participants, there was a lack of volume in responsive participants. This lack could be attributed to families feeling that the educational problem is far reaching and a discussion group would not change the attitudes of schools. Perhaps this could be seen as a waste of the parents' time. Parents who did attend were all vocal and proactive regarding their children's education. Absent participants could perhaps be those who did not have assertive personalities and had accepted the educational limitations without resistance. All participants requested feedback on the study following the completion of the research project, which indicated that they regarded the study as important. The biographical information of the group is presented in Table 3.7 section 3.5.4.2. above.

The five participants in the study had enrolled or attempted to enrol their children with HFA / AS at different schools in different areas within the district of Umlazi. Despite the differences in enrolment locations, there was commonality among their experiences. Four themes

emerged, each with subthemes: Theme 1: The lack of knowledge of school staff about HFA / AS, with three subthemes; 1.1. The uniqueness of a child with HFA / AS. 1.2. The dissatisfaction of parents with the screening process for enrolment of their children with HFA / AS into mainstream schools and 1.3. The lack of knowledge [the parents had] about the Education White Paper 6 (South African Department of Education, 2001b).

Theme 2: Conflict between school staff and parents, consisted of three subthemes, 2.1. Inflexibility of school staff [which caused conflict], 2.2. Attitudes of school staff towards inclusion [which caused conflict] and 2.3. Desire from parents for unity between themselves and those involved with their children [to overcome the conflict].

Theme 3 emerged as the impact HFA / AS has on parents. The three subthemes are: 3.1. Emotional indicators for parents of children with HFA / AS, 3.2. Dissatisfaction with schooling options or experiences and 3.3. Views on suitable school settings for learners with HFA / AS.

The fourth and last theme emerging referred to: Views on how to overcome the barriers to mainstream education for children with HFA / AS. This theme has five subthemes or concepts, those being: 1. Small classes, 2. Class assistants, 3. Teacher training/experience in HFA / AS, 4. Change in attitudes [of school staff and parents of neurotypical learners] and 4. Accommodations [in the classroom]. These themes are presented in Table 4.11 below and discussed thereafter.

Table 4.10: Themes arising from the focus group

<p><u>1. Lack of Knowledge of school staff about HFA / AS</u> 1.1. Uniqueness of a child with HFA / AS 1.2. Dissatisfaction of parents with screening processes for enrolment of their children with HFA / AS into mainstream schools 1.3. Knowledge of the Education White Paper 6</p>
<p><u>2. Conflict between school staff and parents</u> 2.1 Inflexibility of school staff 2.2. Attitudes of school staff towards inclusion 2.3 Desire from parents for unity between themselves and those involved with their children</p>
<p><u>3. The impact HFA / AS has on parents</u> 3.1. Emotional indicators for parents of children with HFA / AS 3.2. Dissatisfaction with the gaps in the current schooling system as experienced by parents 3.3. Views on suitable school settings for learners with HFA / AS</p>
<p><u>4. Views on how to overcome the barriers to mainstream education for children with HFA / AS</u> 4.1. Small classes 4.2. Class assistants 4.3. Teacher training/ experience in HFA / AS 4.4. Change in attitudes 4.5. Accommodations</p>

4.3.1 Results and discussion of Phase 2

To illustrate the results of the focus group, direct quotations from the focus group participants are presented. Codes P: 1 to P: 5 are used to refer to the participants, codes C: 1 to C: 5 are used to refer to the participants' children and S:1 to S: 5 are used to refer to schools. Codes are used to ensure the confidentiality of the information. Parents not only expressed their view verbally but also by means of volume and tone of voice. The difference in tone and volume was evident when the participants were referring to difficulties encountered with mainstream school staff. It was also evident when the participants agreed with each other on a topic or wanted to express understanding of one another's experiences.

4.3.2 Theme 1: Lack of Knowledge of school staff about HFA / AS

The lack of knowledge of HFA / AS amongst school staff of mainstream government schools was raised repeatedly by the participants during the focus group. Parents expressed their concerns about the lack of knowledge the teaching staff and school management staff, who came into contact with their children with HFA / AS, had about the condition. They felt that limited training given to the school staff contributes to this lack of knowledge amongst school staff. Swart et al. (2004) and Yssel et al. (2007) report that even though there has been progress in South Africa in terms of understanding inclusive education by means of the Education White Paper 6 (South African Department of Education, 2001b), parents still lack confidence in the education system due to the lack of training educational staff have received in this field. This is illustrated below in the comments made by focus group participants, who comment that teachers are untrained and are unaware of the condition.

P: 5 'She [the teacher] said, well there's no teachers that are trained to help the child'

P: 3 'They [the teachers] don't seem to have the whole concept of Autism and what Autism brings to the table'

Two of the participants expressed how they had met with the teaching staff to discuss the needs of their children with HFA / AS but were informed that the teachers were not able to assist the children. The significance of the parents meeting with the school staff is that the parents desire to be part of the solution and support of the educators who work with their children. This will be discussed further in Theme 2 subtheme 3 below: Desire from parents for unity between themselves and those involved with their children. The Education White Paper 6 (South African Department of Education, 2001b) outlines how training of teachers for efficiency in inclusion will be provided by the South African Department of Education.

However, this has not yet been realised at the schools which the participants had encountered.

P: 5 in the quote below refers to her child's behaviours (meltdown) which the teacher does not know how to handle. Emotional outbursts can be presented by people on the Autism spectrum (Schopler & Mesibov, 1992; Autism Society of America, 1998; McAfee, 2002) so the teachers' concerns are valid if training has not been provided to deal with the behaviours mentioned.

P: 5 'When we were given the diagnosis that my little one has Asperger's and I went back to the school and I told them. I spoke to the teacher and the teacher said they can't cope with that...and I said, what do you mean you can't cope? She said to me they don't have teachers that are trained to deal with kids that have got Asperger's or that are on the Autism spectrum because they don't know how to deal with the child if they have a meltdown.'

P: 4 'We had parent interviews to explain all the problems and they couldn't cope'

The reports from the participants about teachers being underprepared for educating learners with HFA / AS reflect the experiences of teachers in other parts of South Africa when working with learners with HFA / AS (Roberts, 2007; Walton et al., 2009). The participants did not direct any negative emotion towards the teaching staff but rather empathised with the teachers, knowing that the teachers have not been exposed to training and therefore felt fearful of teaching learners with HFA / AS because they were ill-equipped. The dialogue below illustrates this idea.

P: 1 'And that's the frightening thing to be a teacher because you're afraid'

P: 2 'Ja, you can't cope, Ja'

P: 1 'It's not that you [the teacher] don't want to be, whatever. It's that you can't, you feel ill-equipped to deal with it'

Participant 4 and Participant 1 took the empathy a step further, suggesting that parents need to be considerate in dealing with the teachers. The importance of this again reflected the

desire from the parents to be supportive of the teachers and be in unity with the school staff. This point will be revisited in Theme 2, subtheme 3: Desire from parents for unity between themselves and those involved with their children. The importance of this is that the parents recognised that the teachers are not the policy makers and that the teachers are in need of support in the absence of the district support teams which should be assisting the teachers (South African Department of Education, 2001b). Parents are therefore understanding of the teachers' position within a system which is inefficient in serving their children with HFA / AS. The participants expressed that their own conduct should be positive towards the teachers, as illustrated in the quotes below.

P: 4 'I just want to say, as parents we need to not be negative to the school, we need to understand it is difficult for them, it's hard for them, they can't always be...'

P: 1 'Absolutely, yes we have to try be neutral, yes and listen to the message with calmness and think that persons taken the trouble...'

4.3.2.1 Subtheme 1.1: The uniqueness of a child with HFA / AS

Part of the difficulty teachers face in working with children with HFA / AS is that each child on the Autism spectrum presents differently (Jordan, 2001; McAfee, 2002). Therefore, each child needs to be handled according to how the triad of impairments are represented in that child. The participants in the focus group understood this concept well, going on to realise that the teachers' lack of understanding of the characteristics of the condition can contribute to causing barriers to mainstream education for their children with HFA / AS. Parents, as a result of living with a child with HFA / AS, recognised the individuality of their children. The teachers unfortunately, who had not had training or experience in HFA / AS would be at a disadvantage in knowing how to approach teaching a child with HFA / AS. The participants expressed how the uniqueness of each child should be taken into account by those who interact with the child as shown below.

P: 3 *'Autism what they read in the textbook is not the autism that each child presents. And just because you have read something about it doesn't mean that you know my child'.*

P: 5 *'Society can't expect kids to conform, you know, to be the same all the time. You know everybody is different; everybody is unique in their own special way'*

The lack of understanding school staff had about the uniqueness of each child with HFA / AS could influence the screening process employed at the schools to determine a child's suitability for the school. The assumption could be made by the school staff that all children with HFA / AS present in the same way and therefore limit access to the mainstream school to future learners based on how past learners presented. This introduces the following subtheme which addresses the screening processes at mainstream schools for learners with HFA / AS.

4.3.2.2 Subtheme 1.2: Dissatisfaction with screening processes for enrolment of children with HFA / AS into mainstream schools

The focus group participants felt that the process employed at the mainstream schools to determine their children's suitability for education at those schools did not take the uniqueness of the child into consideration (Jordan, 2001; McAfee, 2002). Not all children on the Autism spectrum are suited for mainstream education (Schopler & Mesibov, 1992; Whitby & Mancil, 2009). It would stand to reason then that the South African Department of Education, by means of district support teams (South African Department of Education, 2001b), would set in place a suitable screening method to determine which children could be accommodated within mainstream education and those which cannot. The focus group participants reported that the school management staff did not have effective screening methods in place when considering their children with HFA / AS for the mainstream

placement. The process was experienced as vague or non-existent by the parents as demonstrated below.

P: 3 'That they [school management staff] are not quite sure, like bring your son then we can look at him. Looking at my son in that moment, in that instant is not telling you about my son'

P:2 'Basically ...the deputy principal basically said, due to his behaviour on that day they felt that he needed to go to...'

C: 4 'My child wasn't screened at all.... He [the principal] said what do you feel and I said are you willing to accommodate these x, y, z and he said yes and he promptly left within six months...and she basically sat on a beanbag and was screened by her behaviour on the beanbag and the hand holds and she was an angel, so they were like yes okay. Once the problems had happened and we made application elsewhere obviously. That suspension from the meltdowns followed her and no one was prepared to give her a screen'

The participants in this focus group felt the need for a better screening process, unlike parents in Ghana, who were resistant to screening processes for their children in fear of labelling and rejection (Anthony, 2009). The South African's Schools Act (South African Department of Education, 1996b, Chapter 2 point 6 says "In determining the placement of a learner with special education needs, the head of department and principal must take into account the rights and wishes of the parents of such a learner". To achieve this goal school staff would do well to collaborate closely with the parents of the child with HFA / AS in order to understand the child and the child's needs. In terms of the screening process this could include a more extended method, allowing the child opportunity to familiarise him / herself with the environment or possibly screening the child in an environment which the child is comfortable with (Walton et al., 2009). It appears from the comments of the participants that a once off screening interview is insufficient in determining the child's suitability for the school.

To better the screening process for learners with HFA / AS, it would be important that the senior management staff have an understanding about the condition as misunderstanding

about a condition has been shown to be a barrier to inclusion (Pivik et al., 2002). Should schools be familiar with the main characteristics of HFA / AS, most importantly peer level language, peer level self help skills and peer level cognitive skills (APA, 2000; WHO, 2012) the contemplation of applications for learners with HFA / AS would be more defined. There is a disagreement amongst professionals in the definition of HFA / AS and as a result some professionals resort to developing their own definitions of Asperger's Syndrome (Whitby & Mancil, 2009). The gap between understanding HFA / AS and utilising a suitable screening process for school entry could be addressed by means of the professionals who would make up the district support teams recommended by the Education White Paper 6 (South African Department of Education, 2001b). The High-Functioning Autism Spectrum Screening Questionnaire (ASSQ) (Ehlers et al., 1999) is a 10 minute screening questionnaire developed for use by teachers and parents for the screening of learners who are suspected to have HFA / AS in order to give the learners the best educational support. The ASSQ was found to be successful screening tool and since it is easy and quick to utilise could be a possible option for use by the district support teams in the Umlazi school district. The significance of using a standard screening tool and utilising the district support teams would be that consistency in screening would be achieved amongst schools in a common area. Learners would not be admitted or rejected by schools based on subjective opinions but rather by a standard measure. Additionally families would not be impacted financially (Matthews & Matthews, 2012) as the district support teams would be employed by the South African Department of Education and the parents would not be charged for this service. The current implementation of this ideal is unfortunately not yet realised by district support teams.

4.3.2.3 Subtheme 1.3: Knowledge of the Education White Paper 6

With the exception of one participant in the focus group, the parents were unaware of their children's rights to mainstream education, as expressed in the Education White Paper 6

(South African Department of Education, 2001b). The participants stated openly that they did not know what the document was about as illustrated below.

P: 3 *'I have no idea of even what Paper 6 is'*

P: 1 *'Well I know what's floating around'*

P: 5 *'Neither do I, I don't know what Paper 6 is'*

Participant 4, who was a special needs teacher herself, as well as being a parent of a child with HFA / AS, knew the contents of the Education White Paper 6 (South African Department of Education, 2001b). She expressed that knowledge of the document was insufficient in gaining a mainstream placement for a learner with HFA / AS as the implementation of the Education White Paper 6 (South African Department of Education, 2001b) had not yet been achieved.

P: 4 *'Very big leverage [if you as a parent are familiar with the Education White Paper 6]. Can I just say, it's all very well to have the leverage but if the, if you, and you know why Paper 6 means inclusion and it states exactly what they need to do and what they, if you, if it, you can fight and fight and fight and...it's in paper, it's not in practice. It is a start'.*

Specific to the South African context, studies have shown that awareness of the child's rights have influenced the parents' responses to schools' decisions about enrolment for the child with special needs (Swart et al., 2004; Yssel, et al., 2007). Parents who were unaware that the child should be allowed to enrol at a mainstream school accepted the schools' decisions about placement; whereas parents who knew the child was entitled to be enrolled at the school insisted that the school accept the child's application. Likewise in Uganda the implementation of inclusion policies was difficult as parents were unaware of the new legislation for their children to attend mainstream schools. Additionally some government

officials and disability organisations were unaware of the inclusion policies adding to the delay of realising the goals of inclusion (Mittler, 2003). In this focus group parents experienced conflict with the schools but only one participant (P: 4) involved the KZN Department of Education to ensure her child received a school placement. Similarly in the UK, parents reported that they were unaware of their children's educational rights at the time of diagnosis and that this excluded the child from the educational services to which the child with HFA / AS was entitled (Harrington, 2011). Likewise in Singapore parents were not aware of the services their children with ASD (including HFA / AS) were entitled to and schools did not inform the parents of the options available for these learners (Barratt, 2005).

4.3.3 Theme 2: Conflict between school staff and parents

Four of the five participants expressed conflict in some form when dealing with mainstream school staff with reference to their children with HFA / AS. This was experienced during the admission or attempted admission process or following enrolment. Considering that the right to education is a basic constitutional right in South Africa (Constitution of the Republic of South Africa, 1996) and that, "The rights and wishes of learners with special education needs, must be taken into account at the admission of the learners to an ordinary public school" (Admission Policy for Ordinary Public Schools, South African Department of Education, 1996a, p. 4) it does seem unreasonable that parents of children with HFA / AS experienced conflict in attempting to access education for their children who have the cognitive ability to learn in a mainstream setting (APA, 2000; Whitby et al., 2009; WHO, 2012). The parents' struggles are presented in the quotes below.

P: 4 *'With a battle she was accepted in a junior primary school with the diagnosis'*

P: 5 *'So they accepted her but they said if we have any problems with her they would let me know and basically we had an on-going battle with them ever since and that is why I decided to take her out of the school'*

P: 2 *'It was the whole battle now to find a place and only a government school'*

One participant had a positive experience in the admission process and it would seem the school involved put into practice the above mentioned government documents. She reported that the school had a positive attitude towards her child and welcomed him into the school. It appears that this school took into account the positive attributes a child with HFA / AS has to offer a community (Attwood, 2007) and embraced inclusion. This is demonstrated below.

P: 1 'The government school said, well they made me feel very welcome, I was amazed you know. They came and said we would love to have him, we think he's got a nice report, he looks like he'll be an asset to the school, we think he'll be happy here and that's what we care about the most, the kids'.

4.3.3.1 Subtheme 2.1: Inflexibility of school staff

Participants whose children were able to secure placements in mainstream government schools, reported difficulties experienced in terms of the school staff being inflexible with the needs of their children with HFA / AS. The inflexibilities included dealing with sensory issues, school routines and accommodations in the school setting. The sensory element refers to the need for breaks when the learner with HFA / AS has experienced too much sensory input. The sensory input can be experienced through any of the senses; this input which is not problematic for neurotypical persons can come in the form of loud noises, crowded setting, temperature change or strong smells to name a few (Fein & Dunn, 2007). It may also refer to planning breaks deliberately to avoid distress before the learner with HFA / AS experiences it. P: 5 below attempted to achieve this with the school her child attended by being allowed to sit outside assembly to avoid the noise. An assembly setting can be challenging for a child with HFA / AS as the sensory input of noise in the form of group singing or clapping can be impacting and disturbing to the child on the Autism spectrum (Dunn et al., 2002; Dodd, 2005; Schetter & Lighthall, 2009; Autism Speaks, 2012). Some schools in the USA have been known to have “meltdown” areas where learners with HFA / AS can go if they feel over

stimulated from sensory input (Palmer, 2010). This is usually more common in special needs schools but the participants suggest this is not unreasonable for mainstream schools to implement. Additionally since persons with HFA / AS have social deficits (McAfee, 2002; Volkmar & Klin, 2005; Attwood, 2007), he / she is unlikely to feel “different” about sitting outside assembly and being allowed to read a book during that time as mentioned by the teacher in P: 5’s quote below. Inflexibility regarding classroom adjustments and sensory issues were also raised during the discussion as demonstrated by P: 4. Both quotes below emphasise the inflexibility participants experienced at the schools.

P:5 ‘The teacher battled with routine in that all the children go to assembly, when we have our staff meeting, your child cannot be made to feel different and sit outside with a book.

P: 4 ‘The meltdown, the sensory disorder and there was no accommodation. Her private psychologist visited the school and said there was no reason why she can’t mainstream. We had a lady who trains facilitators come look at having a facilitator come there; they wouldn’t allow that at the government school. ...the school just needs to make a few adjustments to accommodate her, and they were not big adjustments they were small adjustments, Anyway long story short, she was suspended twice, then asked to leave’

The need to address flexibility is that the relatively small changes do not directly affect education but rather if the issues are handled correctly would make teaching easier as outbursts would be reduced. Should a school system recognise the needs of learners with HFA / AS within a mainstream setting, inflexibility can be reduced by setting policies in place to allow for adjustments. This was noted by Rix, Sheehy, Fletcher-Campbell, Crisp and Harper in the Continuum of Education Provision for Children with Special Education Needs (Review of international policies and practices, 2013) where the importance of addressing the individual needs of the learner was expressed. This flexibility is with reference to the 55 countries reviewed and the 10 countries which were examined in greater detail (Victoria, Australia; Cambodia; Nova Scotia, Canada; Cyprus; Italy; Kenya; Lithuania; Scotland;

Norway; and Japan). The flexibility included adaptable schedules, teachers' aides and adjusted teaching (Rix et al., 2013). It was assumed that flexibility was needed for successful inclusion. The participants continued along these lines expressing that the teachers want all the children to do the same thing, not realising the individual challenges a child with HFA / AS experiences (Jordan, 2001; McAfee, 2002). The participants referred to the school routines and neurotypical learners, which indicates the structure of the school seems to take preference to the learning needs of the individual which is in contradiction to the Education White Paper 6 (South African Department of Education, 2001b) and the Social Ecological model of education (Landsberg et al., 2005). The inflexible attitudes are reported below.

P:1 'See they [teachers] don't want to do something that all the children can't do because they've got this belief that all children want to do the same which I don't know whether that's got evidence to it'

P: 4 'So it's the non-conforming to the school regulation and routines that the school battled with'

Participant 1, who mentioned previously that she had a positive school enrolment experience, noted that the school did take the sensory issues into account when dealing with her child.

One would assume that the school which was favourable to her son's placement had considered the implications of his needs at the school, as indicted below.

P: 1 '...different teachers will be different. Like if it's too noisy you don't have to come to the gala or go sit quietly. They let you off quietly when it's not a big story in front of the whole class sort of thing'

This sentiment of sensitivity of the school to her son's sensory needs was unique amongst the experiences reported by the other focus group participants who reported that allowances were not made for sensory issues as illustrated below.

P: 4 'Mine didn't, mine had to go sit at sports day'

Participant 1's positive experience with flexibility from the school staff involving sensory issues for her child, however, was not extended to flexibility with other issues in the classroom. This inflexibility regarded the parent's provision of a facilitator which she wished to share with another learner in the class. This request was denied by the school even though the provision of the facilitator could be seen as being to the teacher's advantage. The parents of the child with HFA / AS were offering to give the teacher more support in the classroom with another learner who needed assistance, at no extra cost to the school or the other child's family. The attitude teachers hold towards making inclusion workable and smooth for those affected has been noted to affect the educational experiences and enrolment of learners with special needs (including HFA / AS) in mainstream schools (Carrington, 1999; Education Review Office, 2010). The parent's experience is recorded below.

P: 1 'So could she [a classroom facilitator] not just get him going [the child with HFA / AS] and then as you suggested (P:4) get the next one going maybe and if the facilitator was happy to do that, you know, work between two and float and it was completely... the school said absolutely no, it can't be, my facilitator must not interfere with someone else'

In the USA the provision of a classroom assistant (aide) is considered part of inclusion depending on the needs of the child (United States Department of Education, 2004). In Yoke's study (2010) in Malaysia teacher's class assistants or facilitators (aides) were also reported for some learners with ASD. Having a classroom assistant is beneficial for both the learner with HFA / AS as well as for the teacher, provided the assistant is trained. Inflexibility is an outward indicator of negative attitudes towards inclusion, because if school staff do not feel a child is suited to mainstream schooling as in Malaysia (Yoke, 2010), Ghana (Anthony, 2009) and Singapore (Barratt, 2005) the desire to help the learners achieve in that school will be absent and expectations will be low (Anthony, 2009).

4.3.3.2 Subtheme 2.2: Attitudes of school staff towards inclusion

The attitudes teachers and school staff hold towards their roles in an inclusive school setting are important in ensuring the learners within that school setting achieve maximum success. Teachers need to not only gain information about the topic but also be willing to make changes (Koegel et al., 2011). The attitudes of teaching staff are seen to be influenced by the attitudes held by senior staff members at the school (Williams, 1983; Coleman et al., 2003), meaning that if a senior school staff member has a negative attitude towards inclusion, the teaching staff are likely to adopt that same attitude. The same would apply to a positive outlook demonstrated by the senior staff members. The focus group participants recognised this concept, identifying the headmasters and headmistresses of the schools as critical people in establishing a favourable school ethos towards HFA / AS. This is illustrated in the quotes below.

P: 2 'It starts for me, it starts, currently where my son is he has been, he was written off, my son was written off by the headmaster and the head of department... I was so shocked when I found out that the head of department wasn't interacting with him'

GF: 'So where does that positive attitude start?'

P: 1 'The headmistress...you see they started with a positive attitude so they didn't see it was going to fail. They thought it would, they wanted it to work so from the word go'

P: 4 'but the headmaster that took then took over...., as soon as the word was mentioned he closed. We can't cope with that so your whole screening process is almost null and void because once you mention, their skewed view of Autism and Asperger's and High Functioning...'

The significance of the attitudes of the headmistresses or headmasters is important considering that they are gatekeepers to admitting learners into their schools, along with Deputy Principals and Head of Departments (KZN Department of Education, 2010). Should the senior staff members be resistant to inclusion and express negativity towards inclusion, other teaching staff are likely to adopt the same views (Williams, 1983; Coleman, et al.,

2003). Should finances allow, senior staff members would benefit from interaction with their counterparts in countries where inclusion is established, such as the USA (United States Department of Education, 2004) and Australia (Government of South Australia, 2006) as a means to promote positive attitudes towards inclusion. The participants went on to note that teachers could still hold opposing attitudes towards inclusion even if the principal is favourable to inclusion. There could be those who follow policy if directed to do so by a senior staff member but may not internalise the change, as illustrated below.

P: 3 'Some teachers would do it [training] because that's the kind of teacher they are whereas another teacher is only going to be doing what they get told to do by the...'

P: 2 'By the headmaster, exactly'

Participants expressed that the attitudes of the teachers changed positively as a result of exposure to HFA / AS during the year. This could then open the door for inclusion a little wider for future learners with HFA / AS (Ainscow & Haile-Giorgis, 1998; Education Review Office, 2010). The significance of this is that attitudes can change and that the barrier of attitudes to admission to mainstream schooling for learners with HFA / AS can be overcome. To achieve this teachers need to be willing to try and give the learner with HFA / AS an opportunity to learn in their classrooms. Additionally senior staff members need to be positive about inclusion and offer support and understanding to the teachers, realising the teachers are the ones who carry the responsibility for the child's learning despite not being trained to work with learners with HFA / AS. The positive change in attitudes of the teachers as experienced by the participants are recorded below.

P: 5 'She [the teacher] realised ...that all kids are not the same. Kids have different problems. You get different types of children with different things and she's learnt that, in the bit of time that C:5 was in her class and me working with her and explaining things to her, she realised that you know, when a child has a problem in that area or the child has that kind of problem there are ways you can deal with it'.

P:1 'what I think has worked in my school is that when he arrived and they [senior school staff] accepted him in right in the beginning...every Friday after school, they had a staff meeting... there were two of us [with children with HFA / AS] and they invited us and we came from very different ways from which we handled the whole, you know, the therapies that the children [with HFA / AS] were following, we were completely opposite spectrums but they brought both in and they gave the, so the teachers learnt from that approach'

Participants also reported that senior school staff members felt that the parenting skills of the participants were poor. The assumption that how the children with HFA / AS presented was a result of poor parenting skills was a misconception on the part of the senior staff members as hereditary factors and neurobiological aspects are considered to be the causation for ASD (Schopler et al., 1998; Dodd, 2005). It would seem that since the schools were not knowledgeable in the field of HFA / AS as indicated in Theme 1, they would not be in a position to give advice to the parents on the child's condition. Since behavioural difficulties are part of HFA / AS (McAfee, 2002; Wing, 2006; Schetter & Lighthall, 2009) it is also unjustified to assume the child's behaviour is a result of poor parenting skills. The parents reported that the schools felt the children with HFA / AS were undisciplined as indicated below.

P:5 'I honestly told them that she had a problem but I didn't know what it was and they basically said that I was not parenting her correctly that I was too soft with her... They said to me basically that my way of discipline doesn't correspond with the school's way of disciplining the children, my child. At the end of the day, you here to educate her, I'm her mother'

P: 4 .the recommendations [from the school] was that we would comply to the way social services told us to discipline and manage our child at home'

Judgemental attitudes expressed by school staff towards parents can easily cause a parent of a child with HFA / AS to feel offended and contribute toward disunity between school and parents. Parental involvement at an educational level is noted to positively affect inclusion of learners with HFA / AS (Harrington, 2011). An open relationship between school staff and

parents of the child with HFA / AS would therefore be seen as beneficial for the child (Yssel et al., 2007; Koegel et al., 2011). The significance of this is that parents and teachers would be able to give each other support and thus improve the teaching experience of the teacher and therefore positively influence future enrolment of learners with HFA / AS. The focus group participants therefore desired unity between themselves and the staff who work with their children.

4.3.3.3 Subtheme 2.3: Desire from parents for unity between themselves and those involved with their children

Participants in the focus group expressed the desire to have open communication with the school staff who worked with their children with HFA / AS. The participants recognised the principles outlined by Yssel et al. (2007), Koegel et al. (2011) and Harrington (2011), where such an arrangement is beneficial to the child with HFA / AS. One participant described a positive experience with communicative success with a teacher. The teacher gave the parent her cell phone number as well as email address so communication about the child's progress or any difficulties at school could be exchanged. Other focus group participants responded with surprise and support of this experience as it not common place for teachers to give out personal contact information to parents of learners they teach. P: 1's experience is outlined below.

P: 1 'also another thing that's really helped is that first teacher gave me her cell phone number and her e-mail. I didn't abuse it but she would e-mail once a week with any problems she had...she would e-mail and say I just want to let you know, and its followed through with the new teacher, she would email me with any biggie happening at school'

P: 2 'That's great'

P: 4 'Oh my hat, what a blessing!'

The importance of open communication as illustrated by the above quote is that successful inclusion of learners with HFA / AS is possible. Throughout the focus group P: 1 reported the positive experience she had at the mainstream school which her son with HFA / AS attends. Unity and communication are therefore means to overcome barriers to mainstream education for learners with HFA / AS. The unity will only be achieved if attitudes to inclusion of learners with HFA / AS are positive. This will be further discussed in Theme 4: Change in attitudes. The importance of unity was noted by other participants, who expressed the desire to have unity between all professionals who work with their children with HFA / AS in order to achieve successful inclusion. This is demonstrated in the following dialogue.

P: 2 *'Everyone needs to be on the same page'*

P: 3 *'Between the parent and the teacher and the school and the department of education. Everybody'*

P: 4 *'Ja, everybody working together'*

P: 2 *'On the same page'*

P: 3 *'Everyone needs to be, with the psychologist, the, a team'*

P: 1 *'Yes we all agree on the same..... Plenty of communication'*

P: 4 *'Plenty, plenty, plenty'*

Participant 4 went on to introduce the importance of the parents of children with HFA / AS being supportive of the teachers and being partners with them in their children's education. Other participants in the group agreed and contributed to the theme. This was interesting as apart from P: 1 the other parents had not experienced good communication or unity from the schools their children with HFA / AS attended. Regardless, they were able to identify this element as essential along with the need to offer themselves in other supportive roles such as supplying visual aids for their children as noted below.

P: 4 *'As parents I think, whether they reject it or not, what we need to do is we need to communicate, communicate, communicate. We need to involve ourselves, we need to offer our assistance where we can, so much so that visual aids, I offered and I did make for the school ...If we find the right schools or if it comes about that the schools are willing to take and include and are on board that's, we need to, it is new to them, it is hard for them. We need to help make their lives easier...'*

P: 1 *'Yes'*

P: 4 *'You know sort of encouraging, being the cheerleader for this inclusive sort of thing and offering our assistance as much as possible'*

The willingness of the participants to be supportive towards the teachers who work with their children with HFA / AS is admirable, so much so that it is easy to lose sight of the fact the this responsibility and the support of the teachers is not in fact the role of the parents. This responsibility is outlined in the White Paper 6 (South African Department of Education, 2001b) to be held by the district support teams. Their role is to provide learning materials and educational assistance to the teachers in mainstream schools who work with LSEN. If one assumes that parents need to be supportive and involved with those who work with their children with HFA / AS in order for inclusion of learners with HFA / AS to succeed, we immediately place children who do not have this option at a disadvantage. Basic education is a right to every child in South Africa (Constitution of the Republic of South Africa, 1996), not only to those who have parents who have the means and inclination to be involved in their children's education.

Although the participants expressed the desire to support the teachers and have open communication, the reality of finding appropriate education for their children with HFA / AS did have emotional implications for the parents.

4.3.4 Theme 3: The impact HFA / AS has on parents

4.3.4.1 Subtheme 3.1: Emotional indicators for parents of children with HFA / AS

It can easily be understood that the parents could feel anxious about their children's education as they are responsible for ensuring their children attend school (South African Department of Education, 2005). Their anxiety presents itself as parents are insecure if their children with HFA / AS will have continued placement at a school or if they will be able to find a schooling placement at all for the child. The emotional impact for the participants in this focus group therefore related to enrolment, continued placement at mainstream schools and the pressures of homeschooling due to poor mainstream experiences.

P: 2 'We have been told there is no space for him to move from the unit to the, which would be the intermediate kind of phase, and I'm bordering on hysterical about it because they say there is no space'

P: 4 '... at that stage I was beside myself so yes but that was a huge problem like for them to consider'

P:3 'that other 'teacher' who my son is like, you know scarred for life from school, you know, and it puts me, a lot of strain on me as a person, as a mother, teacher everything at once [homeschooling]'

P: 2 'I'm also a single mom so there are quite a lot of confines at the moment'

Once again the stress experienced by the parents should not be present since South African children are entitled to basic education (Constitution of the Republic of South Africa, 1996). Parents should not have to carry the burden of not knowing if their children with HFA / AS will have a mainstream placement from term to school term. The emotional strain experienced by the parents relates to the dissatisfaction the participants felt with the available schooling options in the school district where they live. Processing this stress can be achieved by means of parents attending support groups as is done in Australia (Harrington, 2011),

India (Action for Autism, national centre for Autism) and in other parts of South Africa (Swart et al., 2004) as well as in the greater Durban area (Action in Autism). Although the parents realised the importance of partnering with the school staff who worked with their children with HFA / AS as mentioned in Theme 2, subtheme 3 above, the limitations of the present schooling system were still raised.

4.3.4.2 Subtheme 3.2: Dissatisfaction with gaps in the current schooling system as experienced by parents

The participants felt that their children with HFA / AS fell into a gap in the present educational system. Intellectually the children functioned well (APA, 2000; WHO, 2012) but the social deficits of the conditions (Atwood, 2007) were not accounted for at the mainstream schools. The special needs schools however, did not always provide the cognitive challenge the children with HFA / AS needed. The below discussion between the participants gives evidence that the problem was common. The participants expressed that their children did not fit into mainstream schools and did not fit into special needs schools. This gap in the current education system was an additional factor which gave rise to stress for the parents of the children with HFA / AS as expressed by Participant 2.

P: 3 *'I just find, you know what for me, and this is personal, there's no middle ground. He doesn't fit into special needs, he doesn't fit into mainstream'*

P: 2 *'I went to see S:2 and he went into the kind of mainstream in their school and after two weeks they said socially he doesn't fit, he has to go into the autistic unit. Well, I was devastated because he's extremely intelligent and the children in the class range from Grade 1 intellect to Grade 6 intellect'*

ALL: *'Yes'*

P: 4 *'Yes that's the barrier for us, for HFA and AS'*

P: 5 *'Where does your child fit?'*

P: 3 *'It's one or the other, so where does he fit?'*

P: 4 *'we ended up at a special needs school which was brilliant but they don't really cater for Autism but they have been fantastic, absolutely fantastic and helping her'*

Parents in Singapore experienced frustration with their schooling system in accessing appropriate education for their children. Due to teachers being untrained in mainstream schools to work with learners with ASD, the learners were referred to special needs schools or were kept at home as placements were not available (Barratt, 2005). While at home and waiting for a placement the children fell behind academically and were prevented from social exposure from peers. Due to the gaps in the current schooling system and the stress experienced by the parents, the participants offered their input on the most suitable educational setting for children with HFA / AS drawing from their own experiences.

4.3.4.3 Subtheme 3.3: Views on suitable school settings for learners with HFA / AS

It was generally agreed upon among the participants that learners with HFA / AS do well with one on one attention. The reality of this being achieved in the mainstream environment was discussed amongst the parents. In America this option is available by means of class assistants (United States Department of Education, 2004) and can be achieved by means of flexischooling (Lawrence, 2012) or homeschooling (Schetter & Lighthall, 2009). In the Umlazi school district within the current South African school system, the participants were not convinced it would be possible. This reflects the findings of Swart et al. (2004) and Yssel et al. (2007) where the lack of confidence parents of children with HF A / AS had in the South African education system was noted. In Morocco similar attitudes amongst parents were experienced in response to inclusion. Parents were resistant to admitting their special needs children into schools which had been prepared for inclusion as they were not convinced that the programs at the schools would be beneficial for their children (Mittler, 2003). A specific difficulty discussed in the focus group was that of one on one attention for learners with HFA / AS. Participant 4 raises this in the below quote.

P: 4 *'They [school staff] start to sort of say, oh what does your child need that's extra and added and once you start it's like, oh we've got so many other children to worry about, you know'*

Other participants discussed and agreed on the need for one on one attention for their children with HFA / AS, with participant 3 giving this as the reason she chose to home school her son.

P: 3 *'One on one. Our children need one on one that's the bottom line'*

ALL *'Yes, yes'*

P: 3 *'Our children thrive on one on one attention'*

P: 2 *'Definitely'*

P: 3 *'That's the thing. That's one of the main reasons I chose home-schooling because if my child is, if they doing cooking class, he wants to know why does an onion look like it is, how does it grow, she's not going to stop the whole class of 20 with their cooking lesson to tell my son how this onion has grown and that's one on one. So no'*

Participant 1, who as indicated in above quotes, had a positive experience with mainstream schooling added that there are social benefits to mainstream schooling for learners with HFA / AS which may not be possible with homeschooling. She explains in the quote below how mainstream schooling provides opportunities for social development.

P: 1 *'I'm saying, depending on the child but if the child is in a place where he is now interacting socially, [referring to mainstream schooling] it's an opportunity to have that social interaction, you know'*

This statement from P: 1 reflects views (Attwood, 2007; Fein & Dunn, 2007; Autism Independent, UK, 2010) where the benefits of social modelling are noted as advantageous to learners with HFA / AS in developing their social abilities. This opportunity is absent in the homeschooling environment. The homeschooling option does provide the one on one attention the participants mention, although it does have financial implications for the family as one parent would not be able to earn in order to teach the child at home (Schetter &

Lighthall, 2009). An alternative option is mainstream private schooling or the provision of a personal facilitator to accompany the child in the mainstream classroom. This places an additional financial demand on the parents of the children with HFA / AS and is therefore not available to all families. This method is also opposed to by Matthews and Matthews (2012) in their reflections on The Charter rights of persons with Autism where additional financial costs should not be imposed on families with children with Autism in order to access education for their children. Should a family choose to home school their child with HFA / AS in the presence of suitable mainstream government schooling, one would anticipate the family should be prepared to cover the cost. In the situation where parents are forced to home school their children with HFA / AS due to lack of suitable schooling provided by the government, the additional cost is not justified. The reality of being a parent of a child with HFA / AS in the selected circuits of the Umlazi school district is that personal finances will be impacted. The participants expressed the factors needed for suitable education for their children fell on their own budget and that not all of them could afford the costs involved as illustrated below.

P: 2 'Because I can't afford private school fees I went to see S: 2 and he went into the kind of mainstream in their school'

P: 2 'I mean we could only go to a private school and then I had to raise money in the family to send him, so it was very difficult'

P: 3 'A facilitator would help a lot but it's on the parent's budget. I might be able to afford it but P: 1 won't be able to afford it'

P: 5 'I certainly can't'

P: 4 'I can't'

In countries such as Singapore, parents are responsible for additional support for their children with HFA / AS as is the case in South Africa. In India policy is in place for funding for therapy for a child with ASD up to age three, as well as providing schooling free of

charge after age three. Unfortunately due to the rise in cases of children with ASD (including HFA / AS) not all educational needs for the children are met and parents have to pay for services out of their own finances (Das, 2010). In Denver, USA (Denver Options, 2006) Autism waivers can assist families with children on the Autism Spectrum with special needs with the costs involved up to age six. Thereafter disability grants can be applied for from the government (United States Government, 2013).

4.3.5 Theme 4: Views on how to overcome barriers to admission to mainstream education for children with HFA / AS

The participants, as parents of children with HFA / AS and having enrolled or attempted to enrol their children into mainstream government schools, had experience with the difficulties faced in accessing education for their children. They therefore also had insight into solutions to the areas of challenge. The participants were willing to provide support to the teachers and offer help as needed. This could be by means of better communication with the teachers or extra academic lessons for the child. In addition the parents had suggestions such as smaller classes, class assistants, teacher training, curriculum adjustment, attitude changes and classroom accommodations, all of which are discussed in the literature. These will be discussed below in Subtheme 4.1 to Subtheme 4.5. Participant 3 below illustrates the willingness parents have to provide academic support outside the school setting for their children with HFA / AS. The quote also shows the recognition that that each child with HFA / AS is different and may need different types of support.

P: 3 'Depending on each child. My child, he might need extra speech lessons and that would back up his education, you understand what I'm saying. He might need extra lessons like in maths or something just to, you know and assist him. Ja it depends on each child'

4.3.5.1 Subtheme 4.1: Small classes

The need for more one on one attention for children with HFA / AS was noted by the participants in section 4.4.4.3 above. To make this possible; small classes would be needed. With a small class a teacher would more easily be able to recognise when a child with HFA / AS is in distress as expressed by participant 4 below. The teacher referred to in the quote expresses that she does not have time to assist the child with HFA / AS as she has other children to attend to. The second quote takes into account the possible views of the parents of the neurotypical children in the class.

P: 5 'if you can see a child's starting to stress, you can see a child is starting to get upset, surely you would be able to take the initiative and get up and say listen, what is wrong, what's upset you or can I help you. But she said to me they don't have time for that because they've got so many kids in their class and a certain time to get through their work that they don't have time to even think of trying to help that child and that's the sort of problem area'.

P: 1 'he's got this issue and he's taking up more time...you know there's a there's finance resources they want to spread out evenly and they don't want your child to take up more of the teachers' time than anybody else'

The Education White Paper 6 (South African Department of Education, 2001b) does not make mention of the need for small numbers of learners per class in order for successful inclusion. Simpson et al. (2003) and Roberts (2007) do make note that small classes are advantageous for learners with HFA / AS in assisting with individual learning styles, increased personal attention for the child and for managing any behavioural difficulties. The reality of instituting small classes would be a greater financial output by the South African government. Since small classes are not mentioned in the Education White Paper 6 (South African Department of Education, 2001b) it is unlikely that governmental resources would be directed to supporting small classes at mainstream schools. Another method to overcome the need for one on one attention for learners with HFA / AS could be by means of class assistants or facilitators.

4.3.5.2 Subtheme 4.2: Class assistants / facilitators

Since children with HFA / AS can have emotional over reactions to relatively small incidents (Schopler & Mesibov, 1992; McAfee, 2002), parents felt a break during class time would be beneficial to their children with HFA / AS. The practicality of achieving this would mean an adult would need to accompany the child to leave the classroom for a sensory break. It would be unsafe for a child, who may be as young as 4.5 years in the case of Grade R learners (KwaZulu-Natal Education Department, 2010) to be unsupervised on the school grounds while their classmates were in lessons with the teacher. Teachers recognise this need as expressed in the below quote, where the child would need an adult to accompany her to the field in order to calm down.

P:4 'so her teachers concern was yes we'd like her to be able to go for a walk and go calm down and spin on the field, which is what she does but who is going to watch her?'

The Education White Paper 6 (South African Department of Education, 2001b) does not mention the need for class assistants or facilitators. Class assistants are school staff employed to assist the teacher by means of material preparation for lessons and for support and interaction with all learners in the class. A facilitator is an adult employed specifically to attend to the needs of one or two learners in the class. Class assistants are used in the USA (United States Department of Education, 2004) as well as in selected cases in Malaysia (Yoke, 2010) and are recommended from studies within South Africa (Walton, 2002; Roberts, 2007). To overcome the problem the teacher expresses about of not having someone to accompany the child out the classroom, participant 4 offers the suggestion of a facilitator. Her suggestion is that a facilitator would be employed by the school to assist more than one learner. The advantage of one person being employed for this position is that the financial demand would be lower than employing a facilitator to assist each child in the school who

needs additional help. Participant 4 expresses how her child does not need a facilitator all day and a “floating” facilitator would be sufficient. The benefit of this arrangement would be an efficient use of time and resources. Another benefit mentioned would be increased communication between parents and school and the obvious need for the person to be trained in HFA / AS is stated, as seen below.

P: 4 ‘...my ideal, and I think it’s possible, I don’t think it’s impossible in our country, is to have our children mainstream with accommodation. Whether it be a floating, counselling, facilitator because my daughter does not need a facilitator 24/7. So if your, if the schools now are including children to have a facilitator that sort of maybe gathers them in the morning and says this is your day, this is where I am if you need me, it’s one person’

P: 3 ‘It’s a mode of communication between the school and the facilitator to the children’

P: 4 ‘Ja and it mustn’t be us who has to provide it, you know it can be provided by them and you know, it’s a floating person for all their inclusive children’

P: 5 ‘But it should be someone who is trained to do it’.

The importance of the facilitator being trained as mentioned by participant 5 reflects the findings of Koegel et al., (2011) where class assistants felt ill-equipped to give the teacher support in with learners with special needs. It is insufficient to have an additional person in the classroom if the person is unaware of how to provide the necessary help to the teacher or learner with HFA / AS. Although class assistants and facilitators are not mentioned in the Education White Paper 6 (South African Department of Education, 2001b), training of school staff is noted for the success of inclusive education in South Africa. It could perhaps be motivated that an additional staff member who is trained would be advisable for schools where learners with HFA / AS are enrolled. The below quotes present some of the benefits of a facilitator in mainstream settings for learners with HFA / AS as safety, forming a relationship and as a result the probability of challenging behaviours being reduced. The

significance of the reduction of challenging behaviours is that teaching and learning are not interrupted.

P: 4 'They [learners with HFA / AS] can cope in a mainstream environment without anxiety if they just have support. So ideally it would be just one person on the staff who understands and they feel comfortable going to with their specific need and saying, I'm having a meltdown, I need to go to the safe room and that person sort of saying, okay'

P: 2 'So that's why [a facilitator] someone like that would be so awesome because then that would be a relationship and therefore safety and therefore no meltdowns, probably'

Currently the provision of a facilitator rests on the finances of the parent of the child with HFA / AS. Other professionals who attend to the needs of the child with HFA / AS in a mainstream school are also funded by the parent of the child as seen in the results of Phase 1. In Singapore (Barratt, 2005) support for the child with HFA / AS was also funded by the parents and the parents experienced dissatisfaction with the school system as their children's needs were not accounted for.

4.3.5.3 Subtheme 4.3: Teacher training / experience in HFA / AS

The principle of the need for facilitators to be trained to assist learners with HFA / AS in the class would also apply to teachers (Roberts, 2007). The participants in the focus group recognised this need and provided some suggestions of how to achieve the training.

Participant 2 lists studying, reading, attending workshops and then implementing the strategies in the classroom. These suggestions are all made on the assumption that the teacher initiates the training and wants to attend training. Should a school be resistant to inclusion the suggestions would be invalid. None of the participants made mention of the role of the South African Department of Education in providing the teachers with training or of training coming as mandatory from a governmental level. This could be related to the fact that the majority of the participants were unaware of the policies outlined in The Education White

Paper 6 (South African Department of Education, 2001b) and were therefore unable to refer to the training and support which should be provided by means of the district support teams.

Participant 5 notes how there are teachers who are untrained and participant 2 offers the practical suggestions as shown below.

P:5 '.....If they had the correct staff that were trained, you know, to deal with it, you know, to pick up on these little cues these kids have, you know'.... A lot of the teachers don't, they have got no idea, you know'

P: 2 'Well I think that, I think there are many ways [for the teachers to be trained]. I think that studying, reading, going to workshops and then doing things, workshops in the class and it doesn't need to be a huge thing and it can be something integrated. It can be a theme or whatever, you could do social stories, you know. I think there are many ways'

The emotional needs of the child with HFA / AS (McAfee, 2002) were also recognised by the participants, extending the training needed by the teachers to not only include the academic needs but also the overall needs of the child, understanding that this support would in turn make teaching easier for the educator in the inclusive education setting. The Education White Paper 6 (South African Department of Education, 2001b) does not make specific reference to the emotional needs of LSEN but does mention that inclusion should support a comprehensive range of learning needs. Since emotional difficulties can block learning for children with HFA / AS, it would seem the policy makers of the Education White Paper 6 (South African Department of Education 2001b) were not aware of this need. It could be argued that the correct emotional support for learners with HFA / AS could lead to increased learning. Therefore for effective inclusion for learners with HFA / AS to meet this specific educational need as related to emotional support, an addition to the document may be necessary to include emotional support. Participant 1 below alludes to increased learning by expressing that emotional support for learners with HFA / AS would help with teaching and that children cannot learn if they are anxious. By inference then, attending to the emotional

needs of learners with HFA / AS would have an increase in learning for these children. This is represented below.

P: 5 'Teachers in general are there to teach but at the same time they also there to look after your kids as well, you know and if they aren't trained to sort of pick up, as I say, all the little cues, if this child is starting to have a meltdown, if this one's starting to stress, this ones that, this one you know then you know hopefully they will be able to sort of interfere before it gets out of control, too out of hand'

P: 1 'And that would help with the teaching'

P: 1 'If you that anxious, you can't learn. You've got to be in a calm state to be able to learn'

P: 5 'So their emotional needs are not being met at school you know because I find with kids that have Asperger's it's not a physical, it's an emotional need that needs to be seen to. If they had the correct staff that were trained you know to deal with it...'

To effectively address the emotional and social needs of the learners with HFA / AS, there would then be a need for adjustment to the teaching curriculum (Attwood, 2007). In order for teachers to be trained and to successfully implement new strategies, they would need to be willing to do so. Change in the attitudes of school staff can therefore be seen as a means to overcoming barriers to admission to mainstream education.

4.3.5.4 Subtheme 4.4: Change in attitudes

The participants recognised that not only do the teachers and school staff need to have openness to inclusion and have positive attitudes about learners with HFA / AS in mainstream schools but also that parents of neurotypical children at the school need to have an understanding about the condition in order to promote acceptance in their neurotypical children. The assumption is made that if the teachers understand the condition, they would then be able to convey this understanding to the neurotypical learners at the school.

Additionally, if the school is supportive of inclusion of learners with HFA / AS this could be promoted amongst parents of neurotypical children to familiarise them with HFA / AS and

the changes in government policy (South African Department of Education, 2001b). These are noted in the following quotes.

P: 2 *'that comes from the teachers doesn't it, so more of an education... then there's a more understanding amongst the children'*

P: 4 *'... Look we've got a child with autism in our school, we invite all the parents [of neurotypical learners], if you don't come you face the consequences, you know what I mean. I think it starts, ja... Other parents were the reason my daughter was expelled'*

Had the parents, mentioned in the above quote, been informed about the situation or been given a positive outlook on HFA / AS the situation could possibly have ended differently for the learner concerned. The focus group facilitator called for solutions and the participants agreed that the parents of neurotypical learners needed to be instructed about HFA / AS as noted in the below dialogue,

GF *'Let's think of solutions, what could we do? The other parents, what could be solutions?'*

P: 4 *'Educate them'*

P: 3 *'Education'*

P: 5 *'Yes educate them, yes'*

P: 4 *'Have a parents evening, I'd go, anyone...'*

P: 5 *'The other parents are definitely an issue'*

P: 2 *'I think the parents is where it starts'*

P: 5 *'Yes, thank you, you took the words right out of my mouth'*

Reichert et al., (1989) found that parents of neurotypical children were supportive of mainstream placements for children with special needs, although the study did not extend past grade R. The change in attitudes amongst school staff would also need to be in the form of taking action to make inclusion possible, action to arrange teaching on the topic to parents

of neurotypical children at the school as well as action to access resources from the government in order to implement educational policies (Education White Paper 6, South African Department of Education, 2001b). The action could take the form of involving the governing body of the school to raise awareness of ASD in the community. April is Autism awareness month and during April 2012 schools and institutions around South Africa dressed in blue and decorated their facilities in blue, the colour chosen to represent Autism, to show support of those with ASD and to raise awareness (Autism South Africa, 2012). This campaign initiated in South Africa by Autism South Africa followed the international campaign rallied by Autism Speaks which involved 48 countries worldwide, which were encouraged to “Light-It-Up-Blue” for Autism. Schools in the circuits of the Umlazi school districts could follow similar initiatives to involve the community and in particular parents of neurotypical learners at the schools. Guest speakers from support groups in the area, such as Action in Autism, could be invited by the schools’ governing bodies to present on the topic of HFA / AS to dispel myths about the condition and perhaps highlight famous individuals with HFA / AS to present the potential possible for learners with the condition.

P: 4 ‘So it all falls back on that’s the government’s problem, they’ve given us the White Paper 6 but that’s their problem, they must provide us with that support. We [the school] are not actually willing to go to the government and say, ‘we’ve got a child with Autism, what support can you give us?’

Changing attitudes is a difficult process as attitudes are intangible (Reber, 1995). Positive attitudes towards inclusion were noted to be linked to training in the field of special needs. Teachers who intended to pursue special needs teaching from the outset had favourable attitudes towards inclusion while those who had not had training expressed negative attitudes towards inclusion (Rix et al., 2013). It is noted that the attitudes of school staff are influenced by the attitudes of the senior staff members who set the attitudinal tone for the school

environment (Williams, 1983). With this in mind senior staff members could provide incentives for their teaching staff who attend training seminars on HFA / AS. Likewise from a governmental stance, educators could be required to continually update their teaching qualification by means of Continual Professional Development (CPD) as is required of other professionals such as occupational therapists and speech therapists (Health Professions Council of South Africa, 2013). Training in HFA / AS could be stipulated as mandatory on an annual basis. In the current absence of abundant training on HFA / AS in South Africa, these CPD points could be earned by the completion of on line classes on HFA / AS, for example those offered by the CARD organisation, which is based in the USA. In Australia professional development is offered for teachers by means of seminars, conferences and workshops, some held at irregular intervals, others annually or every second year (Government of South Australia, 2006).

4.3.5.5 Subtheme 4.4: Accommodations

The last solution offered by the focus group participants was that of accommodations in the classroom to accommodate learners with HFA / AS in a mainstream setting. This means small changes within the classroom or school setting to allow the learner with HFA / AS to manage more successfully in a mainstream environment. The first adaptation mentioned is in line with one of the options offered in the USA (United States Department of Education, 2004) and presented by Barratt (2005) where a learner with special needs is educated in a mainstream classroom with his / her peers as much as possible but has a safe place to retreat to for part of the day where other learning takes place. This was suggested in the focus group but practical means to bring the idea into reality were not mentioned. These would presumably be finances and training as a staff member would be needed in the additional safe room. Participant 4 makes her suggestion below.

P: 4 'Or the, the whole out of the box thinking of, for some classes our children work together and for those where they mainstream, they can mainstream so it means providing an extra room where they can go or a safe place you know in fact that's all my daughter needs is a safe place and I think a lot of them that's all they need'

The accommodations or adaptations the participants felt were needed for successful inclusion were noted to be small changes. These suggestions were not received openly by the schools and one could conclude that the suggested modifications for the classroom or school environment in themselves were not the issue but rather the inflexible attitudes of the teaching staff. This is illustrated by the following quotes.

P: 1 But you do really need to open your mind because, like you (P:4) were saying about everyone going outside, you know it's actually probably easy enough to accommodate...

P: 4 'It is. The school just needs to make a few adjustmentsnot big adjustments'

When a teacher has a willing attitude and views the needs of the child with HFA / AS as more than just academic, successful inclusion can occur. The implementation of classroom accommodations are therefore not solutions to barriers to admission to mainstream education for learners with HFA / AS in themselves but rather the solution would be a willing attitude to implement the modifications on the part of the teaching staff. Participant 1 described how one teacher had made allowances in the classroom and this had been successful for her child,

P: 1 'She [the teacher] said she loved having C: 1 [in her class] because, or she just sort of, she would do it, she said it was like anybody else, you know she just made allowances. She said he wasn't the only child she made allowances for, there were lots you know, that she'd have a box of papers under the desk, when they were wildly drawing they could sort of have some reasonably.. She didn't mind a little bit of noise, she didn't mind a little bit of mess because I think she'd had boys you know, and if you have boys you kind of know how to let things slide...'

The South African Schools Act (South African Department of Education, 1996b) requires ordinary public schools to admit learners with special education needs, where this is reasonably practical. It goes on to say that the schools are to promote change and make accommodations to assist special needs learners in their schools. Once again to achieve this goal, training of teachers on how to make adjustments in the learning environment is needed. Training then relates back to finances to provide the training.

4.3.6 Summary of Phase 2

The focus group yielded rich data on the barriers to admission to mainstream schooling for learners with HFA / AS. The participants' own experiences in admitting or attempting to admit their children into mainstream government schools in the two circuits of the Umlazi school district were presented in this section. The data were processed in reference to the Education White Paper 6 (South African Department of Education, 2001b), which is the governmental recommendation for inclusive education, which incorporates learners with HFA / AS. The data collected were classified into four themes which flowed from one to another illustrated in the flow chart below and mind map in Figures 4.12 and Figures 4.13 (The sub themes are not presented in the figures). The results from Phase 2 will be integrated with results from Phase 1 and data from the autoethnographic essay in section 4.7.

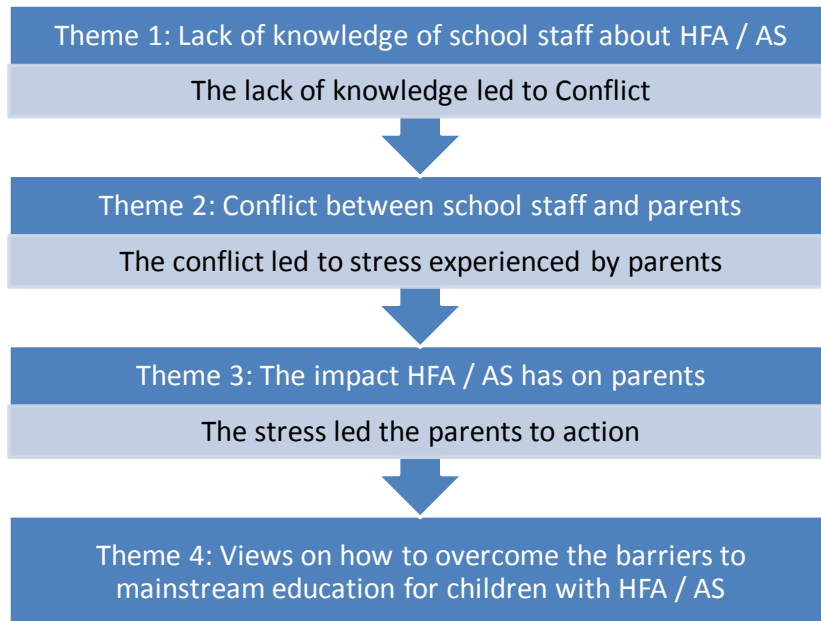


Figure 4.12: The progression of themes as determined by parental experiences of admission or attempted admission to mainstream schools for their children with HFA / AS

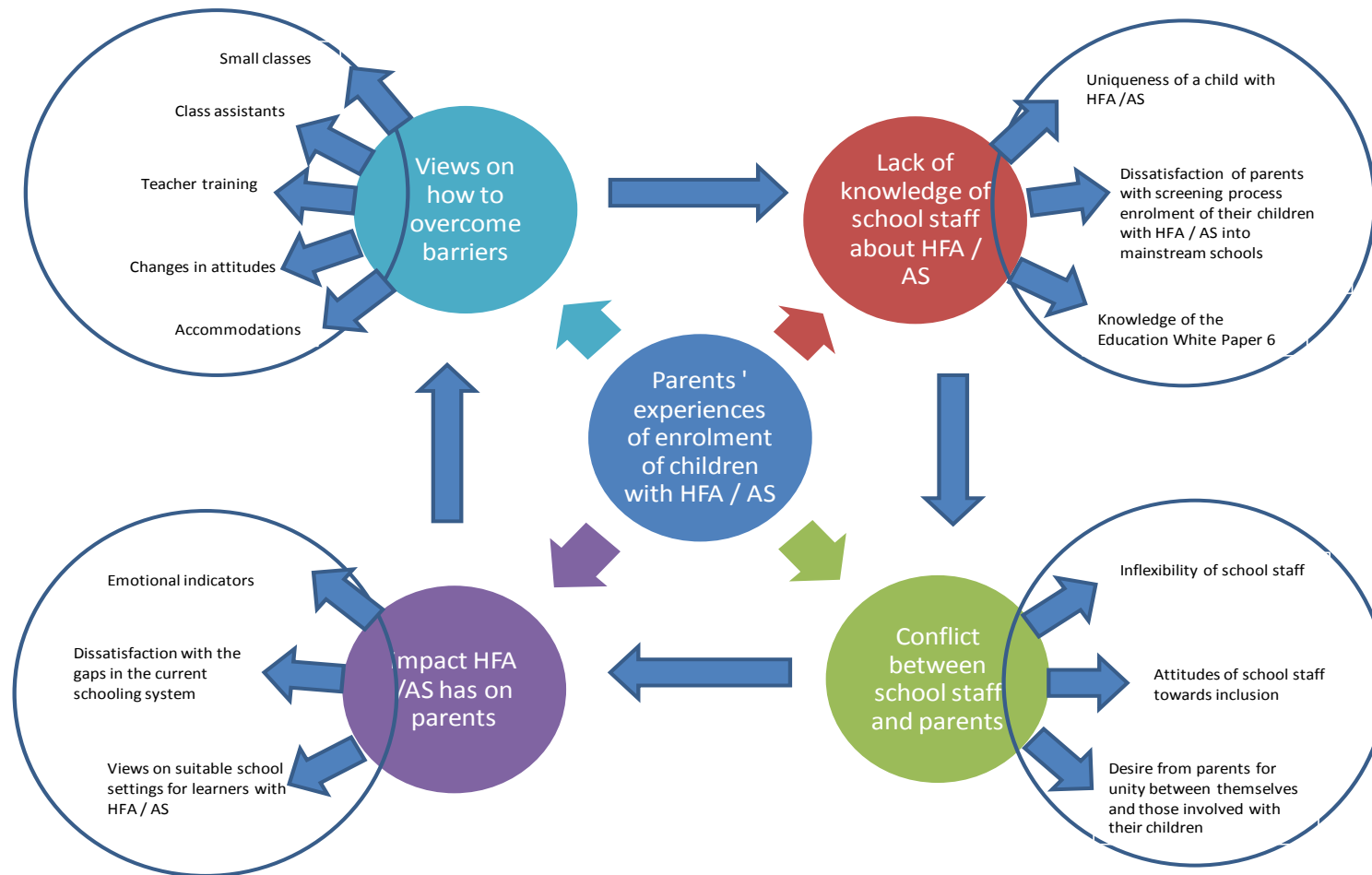


Figure 4.13: The relationship between Themes 1-4 from Phase 2 focus group: Parents' experiences of enrolment of children with HFA / AS

4.4 Results of Autoethnographic essay

The third source of data for this study is the autoethnographic essay. The essay was written in 2012 by the researcher about her experiences with enrolment to mainstream schools for her son with HFA / AS. As mentioned in the motivation of Chapter One, section 1.2., the researcher is a behavioural therapist who works with children on the Autism spectrum, including those with HFA / AS. The support she offers the schools her son attends is therefore not only as an involved parent but also as a professional. This input which one would assume would be appreciated by the schools, since it was offered free of charge, was experienced as a barrier to support. Difficulty was instead encountered in trying to form a partnership with the mainstream government school her son attended. The autoethnographic essay outlines these experiences and was analysed by the researcher as well as by an experienced academic. The themes identified by the senior academic are outlined below in Table 4.12 and the entire analysis along with the essay can be found in Appendix G. The themes emerging were grouped into four sections namely, 1: Experiences of access to education for HFA child is a road starting with hope / anticipation for inclusion, 2. Disillusionment / harsh realities: The road to inclusive education is steep, 3: Bouncing back strategies to face the challenges and 4: The author/researcher's conclusive reflections. Each theme has two to seven subthemes as illustrated below.

Table 4.11: Themes emerging from the autoethnographic essay as analysed by a senior academic

<p><u>Theme 1:</u> Experiences of access to education for HFA child is a road starting with hope/anticipation for inclusion. <u>Sub-theme 1.1</u> The road to access to education was steep and proceeded by incidents of social exclusion of the family from a community <u>Sub-theme 1.2</u> Policies implied/promised access to education</p>
<p><u>Theme 2</u> Disillusionment/ harsh realities: The road to inclusive education is steep <u>Sub-theme 2.1</u> Exclusion experiences - first world experience <u>Sub-theme 2.2</u> Exclusion from government and private education: South African experience</p>
<p><u>Theme 3:</u> Bouncing back strategies to face the challenges <u>Sub-theme 3.1</u> Offering and providing professional teacher support when access to Special Education in Public Schools was denied (compare sub-theme 2.2). <u>Sub-theme 3.2</u> Persevering efforts to convince a private school to accept the child -“the squeaky wheel gets the oil”. <u>Sub-theme 3.3</u> Providing professional behavioural support and the payoffs of the perseverance and breakthrough <u>Sub-theme 3.4</u> Calling on family for private school access in SA with rewarding payoffs <u>Sub-theme 3.5</u> Creative efforts and family support in dealing with financial challenges of private schooling for HFA child <u>Sub-theme 3.6</u> Continued, active involvement in her child progress at school as well as activist efforts of persevering to convince this government school to accept an offer for professional support to the teacher. <u>Sub-theme 3.7</u> The reward for active involvement and activism for utilizing professional support to empower teachers.</p>
<p><u>Theme 4:</u> The author/researcher’s conclusive reflections <u>Sub-theme 4.1</u> Ignorance of and lack of resources in mainstream schools are at the heart of struggling for access <u>Sub-theme 4.2</u> Parental involvement every step of the way is indispensable- as watchdogs and activist for the rights of their children <u>Sub-theme 4.3</u> We live with hope...and the future is uncertain for our children</p>

The essay as analysed by the researcher will be addressed in the following section. The researcher grouped the themes into three sections; Themes 1 and Theme 3 each have

subthemes. Theme 1: Ignorance of the school staff about HFA / AS, Subtheme 1.1: Rejection and acceptance experiences of applications to mainstream schools for a child with HFA / AS Subtheme 1.2: Inflexibility of school staff. Theme 2: Conflict between parents and school staff regarding admissions. Theme 3: The impact of HFA / AS on the parent. Subtheme 3.1: Emotional indicators Subtheme 3.2: The hopeful expectation of mainstream education for a child with HFA / AS and the accompanying rejection from schools, Subtheme 3.3: Encounters with persistence, resilience and strategy, Subtheme 3.4: Financial implications for a parent of a child with HFA / AS, Subtheme 3.5: Experiences involving teacher training and Subtheme 3.6: The need for parental involvement. These areas will be discussed following the presentation of Table 4.13.

Table 4.12: Themes arising from autoethnographic essay as analysed by the author of the essay

<p><u>1. Ignorance of school staff about HFA / AS</u> 1.1. Rejection and acceptance experiences of applications to mainstream schools for a child with HFA / AS 1.2. Inflexibility of school staff</p>
<p><u>2. Conflict between parent and school staff regarding admission</u></p>
<p><u>3. Impact of HFA / AS on the parent</u> 3.1. Emotional indicators 3.2. The hopeful expectation of mainstream education for a child with HFA / AS and the accompanying rejection from schools 3.3. Encounters with persistence, resilience and strategy 3.4. Financial implication for a parent of a child with HFA / AS 3.5. Experiences involving teacher training 3.6. The need for parental involvement</p>

4.5 Discussion of themes emerging from autoethnographic essay

The emerging themes are discussed sequentially from theme 1 to theme 3, using quotes from the essay to illustrate. The subthemes related to each main theme are discussed following the presentation of the main theme also using quotes from the essay to illustrate concepts. The author of the essay is identified as R/M in relation to the quotes signifying “researcher / mother”. The researcher referred to herself as “me” and “I” in discussing the essay in line with the method of analysis for autoethnographic essays (Ellis et al., 2011). Although the researcher made applications at mainstream schools in Denver USA and in a circuit of the Umlazi district for her son with HFA / AS, the majority of the discussion focuses on the experiences in the Umlazi district in fitting with the title of this study: Barriers to admission to mainstream primary schools for children with High Functioning Autism / Asperger’s Syndrome (Umlazi district). Data from certain themes will also be discussed in reference to the other themes in some cases. The data will be integrated with data from Phase 1 and Phase 2 in section 4.6.

4.5.1 Theme 1: Ignorance of school staff about HFA / AS

My experiences of schools’ preparedness for a learner with HFA was that there was little understanding and little training about the condition. This was the case both in private and government schools in the Umlazi school district and in a private school in Denver USA. School staff were not familiar with HFA / AS and thus were not welcoming of our enrolment applications. Since there are no tertiary institutions which offer formal training in the treatment of ASD and in particular HFA / AS in South Africa (University of KwaZulu-Natal, 2009), ignorance of teaching staff in the Umlazi school district is to be expected, both in government schools and in private schools. In the private school in Denver the lack of knowledge about HFA / AS was due to the inexperience the teaching staff had. In contrast the public schools in the area were all equipped with trained staff and special education units.

The private school did not have such facilities or personnel. In the Umlazi district the resistance from those in education which is mentioned in the below quote was due to the lack of knowledge the school staff had about HFA / AS. Lack of knowledge was a result of the minimal training given to the teachers. My quotes below illustrate my experiences of the lack of knowledge of school staff about HFA / AS.

R/M '...resistance encountered by those around me who did not and do not understand Autism, including those in education'.

R/M '...they [the private school in Denver] did not have Special Ed staff and the teachers did not have any experience with special needs. In addition they had never had a special needs learner of any kind at their school before'

R/M '...and low training available for the teachers'

The significance of the lack of knowledge of school staff in the Umlazi school district in the field of HFA / AS was that my son's education was at risk due to gaps in the education system. Since he is a South African citizen he is entitled to a basic education (Constitution of the Republic of South Africa, 1996) and the responsibility is therefore on the government to ensure that the teaching staff are sufficiently trained to provide him with that education.

Although there was a lack of knowledge about HFA / AS, fortunately not every school I approached to attempt to enrol my son rejected my application. These experiences are discussed in the following section.

4.5.1.1 Subtheme 1.1: Rejection and acceptance experiences of applications to mainstream schools for a child with HFA / AS

The experiences in mainstream school applications were varied depending on the school. The lack of familiarity with HFA / AS was experienced in a real way in the rejection of the enrolment application for my son in several schools. Those schools made no attempt to

contact previous teachers or get feedback from his previous schools and even with a good academic record my son's applications were denied as illustrated by the following quotes.

R/M 'Despite my son's good academic report, no government schools in our area were willing to accept him'

R/M 'We tried a private school [in the Umlazi school district] which rudely declined the application'

These rejections were indicative of fear of the unknown. Not feeling prepared in how to teach a child with HFA / AS would therefore lead to being fearful of it, as well as indicative of inflexible attitudes. Support was offered to the schools which one would hope would disarm the fear but this offer of support did not disarm inflexibility and the applications were still denied. Schools may have felt insecure about possibly losing authority should they partner with a parent, fearing the snowball effect on other parents at the school.

In Denver USA, the government schools were accepting of my son's applications at first but the quality of service offered was in question, which will be mentioned in Theme 2., which discusses the theme of conflict between parent and school staff regarding admission. The following quote shows that all the public schools which we applied at in Denver were favourable to the applications.

R/M 'We applied to approximately five public [government] schools in our area. None of the schools gave any resistance to accepting his application for kindergarten, despite his diagnosis of Autism which accompanied the applications'

The acceptance at all schools we approached shows a consistency in the education system in Denver. In the Umlazi district we experienced a variety of responses to the applications, responses such as parent interviews, phone calls, assessments and waiting periods. In Denver a policy towards inclusion was already established and so we knew the position of our

applications immediately and consistently. This consistency was not experienced in the Umlazi school district.

After my son had been in attendance at a private school in the Umlazi district for three years and due to financial restraints, we made applications at a government school in the area.

Acceptance to the mainstream government school was achieved although it was not expected as shown in the below quote.

R/M 'We applied to a local government school armed with a very good academic report and surprisingly were accepted'

The placement at the mainstream government school was not without difficulty and inflexibility and conflict with the school staff followed. This inflexibility had been experienced previously in Denver.

4.5.1.2 Subtheme 1.2: Inflexibility experienced from school staff

Inflexibility from the school staff was noted at the government school in Denver. Schools had policies and they did not seem to acknowledge the individual needs of each learner, in particular, my son. He was granted admission to the school but was denied access to support within that school system. In the absence of support being made available to him, I attempted to address the gap in the system by offering to provide support to my son at school at my own cost as illustrated below.

R/M 'I offered to send my son's behavioural therapist to accompany him at school at my own cost. This was declined ...'

The school was also inflexible in allowing their own support staff to assist my son. The school responded

R/M 'that their policy was not to give any additional support to children who were cognitively able'.

This inflexibility seemed unreasonable since children with HFA / AS have peer level cognitive skills (APA, 2000; WHO, 2012), and their deficits lie in other areas such as social, behavioural and emotional (Schopler & Mesibov, 1992; McAfee, 2002; Attwood, 2007). The inflexibility in providing my son with support in the classroom echoes Matthews and Matthews (2012) where enrolment of a child with HFA / AS should not be seen as a goal in itself but rather the quality of the learning experience should be considered. As a parent I could not support the schools' policies that a child should fail before support was given. This would not only make for increased work later as he would need to catch up on work not achieved but would also impact his self esteem and could cause nervousness, anxiety and depression (Attwood, 2007) Support offered on my part was also met with inflexibility from the government school in the Umlazi school district and my offer of a facilitator, meetings and training for my son's teacher were rejected as seen in the below quote.

R/M '...inflexibility in accommodating my son's special needs was obvious. I asked for time with his class teacher to equip her with strategies on HFA, to help problem solve and to give her support. This was denied. The support of a facilitator was also denied'

It does appear odd that teaching staff who were ill-equipped to work with children with HFA / AS would refuse help which would make their jobs easier. Unfortunately, this response from educators was repeated at more than one school. One may conclude that a possible reason for the refusal of help offered by me as a parent and as a professional could be that

school staff felt threatened. Perhaps they did not want to appear unskilled or perhaps risk the loss of authority if they partnered with a parent or took advice from a parent. The reality of working in the field of ASD and being a parent of a child with HFA / AS is that I knew the teachers were unskilled due to lack of available training. This does not come in the form of judgement but rather as a means of reality and an attempt to strive towards solution.

4.5.2 Theme 2: Conflict between parent and school staff regarding admission

Due to the inflexible attitudes of school staff towards the inclusion of my son with HFA / AS into their schools and the absence of suitable teaching input, conflict arose between myself and the schools with which we were in contact. I did not want to home school my son, and my other option was therefore to be persistent in achieving a successful mainstream placement, not just a placement (Matthews & Matthews, 2012) but a placement where my son would reach his potential. The disagreements between myself and the school staff concerned the best outcome options for my son. To achieve this I knew teachers needed support and training. As a parent I was also aware that if I was to realise the goal of helping my son reach his potential I needed to be on the teaching staff's good side, while balancing advocacy for my child. My quote below gives evidence to this.

R/M *'We try not to rock the boat too much and we pray'*

To me, as a parent and as a professional, it made no sense that schools would withhold support from a child with HFA / AS in a mainstream setting and would rather wait for the child to fail. Common sense echoes the old adages which say that a stitch in time saves nine or that prevention is better than cure. These schools chose rather to follow procedure rather than logic. Expecting a child to prove their skills first and then make adjustments is reflective

of the Medical model of education (Landsberg et al., 2005). The below quotes demonstrate the struggles and conflict I experienced with schools in order to give my son a chance at a mainstream education.

R/M '...the schools each assured me that should he fail with school work and fall behind his peers he would at that point be granted access to the support of the Special Ed staff. I found this unacceptable'.

R/M ' I contested the rejected application for six months. There were ongoing meetings, phone calls and correspondence with the professionals who worked with my son'

R/M 'After trying to respect the school policy for the six months we had been there I had to put my foot down and insist that the teacher accept support'

R/M 'My greatest resistance has been from those who I would have thought would have my son's progress at heart. The educators'

My continued struggle resulted in my son being placed in mainstream schools both in Denver and in the Umlazi school district. I was fortunate in that I was aware of the Education White Paper 6 (South African Department of Education, 2001b) and that I had experience and support to offer the schools where I was attempting to enrol my son. These options are not available to all parents, meaning learners with HFA / AS whose parents are not informed or knowledgeable could be at a disadvantage for enrolment at mainstream schools.

After the matter was resolved between myself and the teachers at the mainstream school my son attended in the Umlazi district, the strategies I recommended as a professional in the field of ASD were implemented by the teachers. My input was not only as a mother concerned about her child's education but also as a behavioural therapist with knowledge of support strategies needed for successful inclusion of learners with HFA / AS in mainstream schools. As the teacher accepted my help, the conflict was reduced as we pursued the common goal of my son's progress, as shown in this quote.

R/M *'The teacher's defences dropped as we formed a partnership in my son's education'*

The constant battle with the teaching staff and the need to be aware of gaps in the education system did have an impact on me as a person, as discussed in the following section.

4.5.3 Theme 3: Impact of HFA / AS on the parent

Being the advocate of a child with HFA / AS is a draining exercise emotionally for parents. Parents of neurotypical children do not face the same educational challenges that parents of children with HFA / AS face. Having two other children who are neurotypical, I have experienced the government school system from both perspectives. The exhaustion experienced as a parent of a child with HFA / AS can come in the form of admission difficulties as noted in section 4.5.1.1 above or in terms of the child's educational progress once at a mainstream school. My experience has been that the responsibility of my son's progress became my responsibility as his teachers were satisfied as long as he was passing and did not recognise his abilities in their fullness. My struggles are highlighted below.

R/M *'my experiences in accessing education for my son with High Functioning Autism (HFA) have been far from plain sailing'*

R/M *'By July the wheels had fallen off. My son's grades had dropped from 80's and 70's to 50's there were behavioural issues and he had no friends'*

R/M *'it is has not been an easy road and I am fearful of our potential experiences as we face high school'*

As a parent I have responsibilities to my family as a whole. Excessive energy used on one of my children leaves less for the rest of the family and this imbalance is not justified when teaching staff should be committed to every child in the class. The lack of knowledge of HFA / AS would contribute to low expectations a teacher may have towards a child with the condition (Anthony, 2009). This was the reality in my situation where the teacher was not at

all concerned that my son's grades had dropped and I was not notified of the difficulties he experienced until I saw his report card. Had his teacher been willing to receive my help as a professional my son's progress would not have been impacted. Contributing to the situation is that support and training is supposed to be provided to teachers by the district support teams (South African Department of Education, 2001b). In the absence of these support teams teachers are unprepared and children whose parents are not informed about HFA / AS are at a disadvantage educationally.

4.5.3.1 Subtheme 3.1: Emotional indicators

The up and down encounters of success and despair add to the emotional drain a parent of a child with HFA / AS experiences. The quotes below which are purposefully arranged alternating between positive and negative experiences relating to the education of my son with HFA / AS illustrate this concept.

R/M 'It all sounded perfect [the mainstream school], in fact it sounded too good to be true- it was'

R/M 'My son excelled at the school with the support of the behavioural therapist'

R/M 'I made contact with Autism South Africa to enquire about schooling options for my son. The response was bleak'

R/M 'The teaching staff accepted him openly. They embraced his challenges and gave support over and above what we expected'

R/M 'I was left feeling desperate'

The instability of what to expect from a school should not be present in the South African context where all children have the right to a basic education (Constitution of the Republic of South Africa, 1996). The difficulty arises due to the gap experienced between policy and implementation of policy, as seen in the policies outlined in the Constitution of the Republic of South Africa (1996), the Department of Women, Children and People with Disabilities

(2012), the Education White Paper 6 (South African Department of Education 2001b).

Regardless, hope is ever present for suitable education for our children with HFA / AS but what is hoped for is not always realised, as discussed below.

4.5.3.2 Subtheme 3.2: The hopeful expectation of mainstream education for a child with HFA / AS and the accompanying rejection from schools

'Hope and realism' is the title of the autoethnographic essay. This sums up the uncertainty a parent of a child with HFA / AS has when considering the child's education and future. Hope must not be discarded however, the reality of rejection and unmet educational needs are often experienced. It should be noted that what is hoped for, that is a suitable educational placement for my child, should not be a hope at all, it should be a reality. The provision of mainstream schooling is government policy for learners with mild disabilities (South African Department of Education, 2001b), so one should not have to hope for something one is already entitled to. In my essay hope is referred to several times in anticipation of my son's educational needs being met as presented below.

R/M 'Being a parent of a special needs child, this gives me hope' [in reference to policy changes for special needs education in South Africa]

R/M 'A breakthrough and the lure of hope'

R/M 'We spend many hours hoping our children will be allowed to stay at the school they are in'

This hope I would anticipate will become reality in the future for parents of learners with HFA / AS who are still to come. The Education White Paper 6 (South African Department of Education, 2001b) outlines that for inclusion to be successful finances are needed and the release of the finances will not be in the short term. This means for me and parents whose children with HFA / AS are currently in mainstream primary schools the responsibility for education of our children falls on us as parents and not on the South African Department of

Education. The hope is then transferred from hoping for the gap in policy and reality to narrow, to hoping that teachers will be willing to accept my help as an external source.

The experiences of rejection should not be present in the light of the Education White Paper 6 (South African Department of Education, 2001b) and the South African's Schools Act (South African Department of Education, 1996b) but they are. Since these policies are in place, hope for their implementation can remain intact but a time boundary on the implementation of the policies cannot be determined. The South African Department of Women, Children and People with Disabilities, (2012), outlines that the policy seeks to address inequality for persons with disabilities in opportunity and service delivery, including additional funding being allocated to this department. Additionally, mention is made that attention will be given to promoting the right attitudes towards disabilities. Schools would need to approach this department, by means of the district school offices, in an attempt to access some of these funds for the successful inclusion of learners with HFA / AS. The rejection experienced from schools is illustrated below. This not only has an emotional impact on me as a parent but also reflects the lack of interest of the school staff in my son.

R/M 'I was told repeatedly [at the government school] that I should take him back to the private school'

R/M 'I have been surprised at the responses of some of the schools who have turned down teacher training offered at my expense and have simply asked me not to be involved. I have had the unfortunate experience of being turned down by several schools because of my son's diagnosis; I have even had my neurotypical (without Autism) son refused entry into a school because of his brother's Autism'

Although rejection had an emotional impact on me as a parent, it also had benefits as it birthed persistence, resilience and strategy in me to overcome the barriers to admission to mainstream schooling for my child with HFA / AS, as discussed below.

4.5.3.3 Subtheme 3.3: Encounters with persistence, resilience and strategy

Since the above mentioned policies, The Education White Paper 6 (South African Department of Education, 2001b) and the South African's Schools Act (South African Department of Education, 1996b) are not yet fully realised in the present education system, coping mechanisms such as persistence and resilience are needed for a parent of a child with HFA / AS if the parent wishes the child to attend a mainstream school. I am such a parent and my experiences with rejection and inflexibility from schools moved me to action to overcome the barriers to admission to mainstream schooling for my child with HFA / AS. Resilience was important as conflict with school staff for enrolment was experienced. Likewise, without persistence a mainstream placement for my son would have been difficult. I needed to be proactive and not give up on my goal of my son's mainstream education. Strategy was similarly needed to achieve a mainstream placement, as schools in the area were not yet able to implement the policies of the Education White Paper 6 (South African Department of Education, 2001b) and admissions to the schools for learners with HFA / AS were therefore limited. These concepts are reflected in the below quotes from my essay.

Resilience

R/M '...resilience for the resistance encountered by those around me who did not and do not understand Autism, including those in education'

R/M 'As a parent of a child with Autism, I realised early on that I would need two things: resilience and money'

Persistence

R/M 'Feeling this school was the best placement for my son I would not give up and proved true the phrase "the squeaky wheel gets the oil"'

Strategy

R/M 'I phoned schools in our area and asked if they had vacancies for a child in grade two. This was suggested as the experience of other parents was that if one asked "do you take children with Autism?" the response would be that they were full'

R/M 'In desperation my father who had a business connection with a substitute principal at a private school pleaded on his grandson's behalf for his colleague to give him a chance'

4.5.3.4 Subtheme 3.4: Financial implication for a parent of a child with HFA / AS

Another reality experienced was that of the financial demands of a special needs child. This is in contravention of the Charter rights for persons with Autism as reflected on by Matthews and Matthews (2012) when related to education but it was unfortunately necessary. Since the government schools in the Umlazi district declined our applications in the formative years, we resorted to applying at private schools in order to avoid homeschooling. Should suitable schooling be provided by the government for learners with HFA / AS the costs of a parent choosing to send a child to a private school should rest on that parent. In the absence of suitable schooling provided by the government it is unfair for parents to be forced to seek alternative schooling which is excessive in cost. Other costs incurred involved my son's behavioural therapist and facilitators for my son, as indicated below.

R/M 'As a parent of a child with Autism, I realised early on that I would need two things: resilience and money'.

R/M 'I offered to send my son's behavioural therapist to accompany him at school at my own cost'

R/M 'We decided to apply to a private school in our area. This would mean we would need to pay expensive school fees in contrast with the public schools which were free [in the USA]'

R/M 'We rented out our basement to students in order to afford the school fees as well as made an application for a scholarship to the school and received a reduction on the fees'

4.5.3.5 Subtheme 3.5: Experiences involving teacher training

Although my experience was that educators had not been equipped to teach children with HFA / AS, and in particular my son, when they agreed to teaching my son with HFA / AS on a trial basis, they learned how to work with him, with positive results. I felt grateful for the schools' accommodations and acceptance of help, realising later that I was grateful for something which was already my right; suitable mainstream education for my son. These incidents are expressed in the following quotes.

R/M '...and the teacher now equipped with skills and strategy managed well and my son was promoted to grade one'

R/M 'They embraced his challenges and gave support over and above what we expected. They attended training seminars on Autism and promoted his strengths'

R/M 'I am grateful my son has a placement in a progressive mainstream government school considering the teachers have had no formal training and little experience with HFA'

Without suitable education children with HFA / AS would not be able to reach their full potential and contribute to society in later life (Attwood, 2007). My son being an active member in society in the future would have benefits to the community. The South African Department of Education (2001b) recognises this concept outlining how inclusion in the long term will positively affect the economy of South Africa. Schools looking at inclusion in the present as inconvenient are therefore short sighted in their approach.

4.5.3.6 Subtheme 3.6: The need for parental involvement

Since many of the teachers have not had the opportunity to undergo formal training in HFA / AS, it stands to reason that as a parent of a child with HFA / AS I would need to offer support to the teaching staff working with my son. I am in a position to do so as I am a professional in the field of ASD and work in mainstream schools in a private capacity to offer support to educators who teach children with ASD. Parents who have neither education nor

understanding on ASD would not have this option (Kujwana, 2008). Additionally, not all parents have the resources of time or money to offer the much needed support to educators. This means the basic right to education which all South African children have (Constitution of the Republic of South Africa, 1996) is not guaranteed to children with HFA / AS whose parents have limited resources. The basic educational rights of South African children should not be dependent on parents' abilities or willingness to provide support to the schools their children attend. This is nevertheless a reality due to the current gaps in service delivery of the Education White Paper 6 (South African Department of Education, 2001b).

The Education White Paper 6 (South African Department of Education, 2001b) refers to lack of parental involvement as a barrier to inclusive education. The specifics of what this entails are not provided. One would assume though that it would mean shared goals between parents and teachers of learners with special needs and not the provision of training or resources at the parents' expense. Training and support are noted in the document to be provided by means of the district support teams. The district support teams should be equipping the teachers on how to monitor learners with special needs in the mainstream classroom. In the absence of this provision as parents, including myself, wait for the roll out of the policies recommended in the Education White Paper 6 (South African Department of Education, 2001b) I took on this responsibility myself as shown in the below quote.

R/M 'We look for any gaps at school where our children may be falling behind and work on these at home. We lend the teachers books on Autism Spectrum Disorder'

I offered other areas of support to the schools my son attended, those being teacher training, parent meetings and the provision of professional staff (outside of the school staff) to work with my son at school. When the support was accepted and strategies implemented all proved to be successful in helping my son progress academically at mainstream schools. Although

the roll out of the policies for successful inclusion is delayed I remain hopeful for change and for barriers to admission for mainstream schooling for learners with HFA / AS to be lowered in the future. This was expressed in my essay and is reproduced below.

R/M 'Since it is considered that one in 88 children are affected by Autism I can only hope that South African schools will grow in awareness of the condition and will embrace these children who are different – no doubt – but not less'

4.5.4 Correspondence of themes identified by the researcher and the senior academic

The three themes identified by the researcher were linked to one another: The ignorance of the school staff caused conflict between the two parties and the conflict had various impacts on the parent. To overcome the conflict and pursue solutions, the personal finances of the researcher were impacted, as were her emotions.

The majority of the themes and subthemes identified by the researcher in this section correspond with the themes and subthemes identified by the senior academic. The correspondence between the two sets of themes is illustrated in Figure 4.14 below.

Themes identified by the researcher	Corresponding themes identified by the senior academic
Theme1: Ignorance of school staff about HFA / AS	Sub-theme 4.1 Ignorance of and lack of resources in mainstream schools are at the heart of struggling for access
Subtheme 1.1: Rejection and acceptance experiences of applications to mainstream schools for a child with HFA / AS Subtheme 1.2. Inflexibility of school staff	Sub-theme 2.1 Exclusion experiences - first world experience Sub-theme 2.2 Exclusion from government and private education: South African experience
Theme 2: Conflict between parent and school staff regarding admission	•Sub-theme 1.1 The road to access to education was steep and proceeded by incidents of social exclusion of the family from a community
Theme 3: Impact of HFA / AS on the parent Subtheme3.1. Emotional indicators Subtheme 3.2. The hopeful expectation of mainstream education for a child with HFA / AS and the accompanying rejection from schools	•Theme 2 Disillusionment/ harsh realities: The road to inclusive education is steep •Sub-theme 4.3 We live with hope...and the future is uncertain for our children
Subtheme 3.3. Encounters with persistence, resilience and strategy	•Theme 3: Bouncing back strategies to face the challenges
Subtheme 3.4. Financial implication for a parent of a child with HFA / AS	•Sub-theme 3.4 Calling on family for private school access in SA with rewarding payoffs •Sub-theme 3.5 Creative efforts and family support in dealing with financial challenges of private schooling for HFA child
Subtheme 3.5. Experiences involving teacher training	•Sub-theme 3.7 The reward for active involvement and activism for utilizing professional support to empower teachers.
Subtheme 3.6. The need for parental involvement	•Sub-theme 3.1 Offering and providing professional teacher support when access to Special Education in Public Schools was denied (compare sub-theme 2.2). •Sub-theme 3.3 Providing professional behavioural support and the payoffs of the perseverance and breakthrough •Sub-theme 3.6 Continued, active involvement in her child progress at school as well as activist efforts of persevering to convince this government school to accept an offer for professional support to the teacher. •Sub-theme 4.2 Parental involvement every step of the way is indispensable- as watchdogs and activist for the rights of their children

Figure 4.14: Correspondence of themes identified by the researcher and the senior academic

4.6 Integration of results

The saying goes that a problem well defined is half solved (Stewart, 2007). With this in mind the data from Phase 1, Phase 2 and the autoethnographic essay will now be integrated in reference to the aim and objectives of the study which define this research project. The results from Phase 1, Phase 2 and the autoethnographic essay will not be examined in depth in this section, as this was done in sections 4.2., 4.3. and 4.4. respectively. The results from the three data sources represent three different perspectives, those requiring services, as would a consumer, those who provide the services as would a producer / service provider and an individual within the system. Between the three perspectives trends in barriers to admission to mainstream schools for learners with HFA / AS emerge, as do differences in the view points. Several recommendations flow from the integrated results in the following section.

4.6.1 Objective 1: To explore reasons for refusal to admission into mainstream schools for children with HFA / AS

The data from senior school staff members, focus group participants and from the autoethnographic essay indicated that lack of staff training in the field of HFA / AS formed a barrier to admission to mainstream primary school education for children with HFA / AS in the selected circuits of the Umlazi school district. The literature confirms that the lack of teacher training was a barrier (Barnard et al., 2000; Roberts, 2007; Walton et al., 2009). The importance of this is that the issue of staff training is not specific to the two circuits of the Umlazi school district as the studies were conducted in other parts of South Africa. The increase in prevalence in ASD worldwide (Autism Society, 2011) would have a ripple effect on the increased numbers of children with ASD (including HFA / AS) needing to access education and in turn the need for teachers to be trained in how to teach children with this condition. This can be compared to the ripple effect caused by increase in child headed households due to HIV/AIDS where increased provision is needed for social services for

children who have lost their parents to the disease. In South Africa the significance of the increased numbers of learners with HFA / AS is that provision is made for learners with mild disabilities to be accommodated in mainstream schools and for training to be provided for teachers to work with the children within the Education White Paper 6 (South African Department of Education, 2001b). The training, unfortunately, has not yet been realised for parents and teachers in the selected circuits of the Umlazi school districts.

Other reasons given by schools for lack of enrolment of children with HFA / AS are mentioned below: Eighteen of the 28 schools which responded to the survey said no applications were made by children with HFA / AS to attend the schools. One parent in the focus group confirmed this, saying she had phoned mainstream schools and enquired about placement for her son but was put off by the schools and therefore did not pursue formal applications. One participant said she had considered concealing her child's diagnosis in order to increase her chances of enrolment at a mainstream school. This echoes the reported experience in Barratt's study (2005) where parents had implemented this method to ensure a mainstream placement for their children with HFA / AS. This method could assist parents in moving past the admission process however, would not avoid potential difficulties the teacher may experience in the classroom due to lack of training (Matthews & Matthews, 2012). The researcher had made applications at mainstream schools in the Umlazi school district and was initially denied access to mainstream schools, the reason given being that the schools did not accept special needs learners. After three years in a private school her son was accepted into a mainstream government primary school.

Issues such as class size, social deficits of learners with HFA / AS, learners with HFA / AS being bullied, curriculum adjustments, school staff being unaware of what HFA / AS is and parents of children with HFA / AS being too demanding, were also offered by schools as barriers to admission to learners with HFA / AS into their mainstream schools. Some of these

issues were also reported by the focus group participants who were all parents of children with HFA / AS. Class size was mentioned in the focus group as the participants felt with small classes the teachers would be able to give more individual attention to a learner with HFA / AS. This was a barrier for admission to mainstream schools for two of the participants who had decided to home school their children with HFA / AS. Other participants felt the big classes were problematic in keeping the learner with HFA / AS in the mainstream school but not necessarily a barrier to enrolment. Class size was not mentioned in the autoethnographic essay. Three members of the focus group mentioned finances as a barrier to admission as they were not able to provide a personal facilitator for the child.

Social issues and bullying as barriers to admission as mentioned by the schools were not mentioned by the parents or in the autoethnographic essay. It was mentioned as a difficulty experienced by the children of the participants once in mainstream schools but not as a barrier to admission to the school. For the schools which felt bullying is a barrier to mainstream education, this can be overcome by educating the neurotypical learners on HFA / AS by using books on the topic, talks from the Principal or even the child with HFA / AS addressing the class on the condition (Palmer, 2010) Since ignorance breeds fear, one would assume that knowledge and understanding would breed acceptance.

The majority of the parents in the focus group confirmed that teaching staff did not understand HFA / AS and this lack of training was a barrier to admission. This is also reflected in the literature (Barnard et al., 2000; Roberts, 2007; Walton et al., 2009). Parents felt in particular that schools did not understand or recognise the unique presentation of a child with HFA / AS and the individual needs of the child (Jordan 2001; McAfee, 2002). The autoethnographic essay, likewise, revealed that teaching staff were unaware of the condition or how to work with learners who presented with it. The data from Phase 1, Phase 2 and the autoethnographic essay were therefore in agreement that the lack of knowledge about

HFA / AS and lack of training in the field formed a barrier to the admission of learners with HFA / AS into mainstream government schools.

Poor past experiences with inclusion, as expressed by Fein and Dunn (2007) of learners with HFA / AS into mainstream schools was also put forward by schools as a reason why the schools did not currently have learners with HFA / AS enrolled. This barrier was also reported by Ainscow and Haile-Giorgis (1998) and the Education Review Office in New Zealand (2010). This will be discussed further under objective 4 below. One focus group participant reported that after her child was asked to leave one mainstream school no other mainstream school would give the child an interview for admission. Therefore one school's experience of the child became the barrier for mainstream education at other schools for that child with HFA / AS.

Lastly, schools mentioned the potentially demanding nature of parents of children with HFA / AS as a barrier to enrolling learners with HFA / AS. Focus group participants and the author of the autoethnographic essay however, did not mention themselves as parents of children with HFA / AS to be a barrier to admission for their children into mainstream government schools. They rather noted that they as parents needed to be persistent and outspoken in order to access education for their children with HFA / AS. It does seem improper that parents need to be assertive in order to access education for their children when education is the right of the children (Constitution of the Republic of South Africa, 1996; South African Department of Education, 2001b). It would be implied that the lack of assertiveness on the part of the parents could be viewed as a barrier to admitting their children with HFA / AS into mainstream primary schools. These two sources of data therefore saw themselves and their assertiveness as a necessary component if their children were to attend mainstream schools. Parents effectively need to be the child's school advocate (Harrington, 2011) and follow up on their child's needs being met at school. In the absence of district support teams the

approach parents use in “being the advocate” should be considered so as to form a partnership with the schools and not division. Areas parents need to follow up on at school can be simple things such as ensuring the child returns to class after break, not seating him / her next to the bell or a distracting student, talking to the neurotypical class members about HFA / AS and how they can assist their classmate with HFA / AS (Harrington, 2011). The need for parents to follow up and show initiative in the education setting can easily be perceived by schools as a potential difficulty and schools may want to avoid the possible conflict with parents which could result. In the case of the autoethnographic essay the researcher’s outspokenness related not only to her commitment as a parent but also to her knowledge of HFA / AS as a professional. The presence of this knowledge could evoke feelings of insecurity amongst the school staff who could possibly feel threatened by the researcher due to their own lack of knowledge on the topic.

The significance of the reasons given as barriers to admission to mainstream education for children with HFA / AS as discussed above is that schools, parents and the researcher all experienced the barriers as realities. This means there are children with HFA / AS who are not receiving mainstream education in the selected circuits of the Umlazi school district, even though provision is made for them in the Education White Paper 6 (South African Department of Education, 2001b). The importance of the data collected on the reasons why barriers to mainstream education for learners with HFA / AS is to find ways to overcome these barriers. This is the purpose of objective 6 below.

4.6.2 Objective 2: To explore schools’ perceived barriers to mainstream education for children with HFA / AS

Misunderstanding about HFA / AS amongst senior management staff of schools was noted to form barriers to admission to mainstream schools for learners with HFA / AS. This misunderstanding of HFA / AS, which will be discussed below, formed perceived barriers on

the part of the senior management staff. The misunderstood characteristics as indicated by the senior management staff from the list provided in the questionnaire; are not by definition part of HFA / AS. The misunderstanding included that children with HFA / AS were not able to learn (four schools) (APA, 2000; WHO, 2012); being not able to communicate (14 schools) (APA, 2000; WHO, 2012); being not able to follow instructions (13 schools) (APA, 2000; WHO, 2012) and being violent (eight schools) (Autism Society, 2013d). It can be deduced that the senior staff members had mistaken HFA / AS for Classic Autism where the presentation of characteristics are more severe (Kanner, 1943; Autism Society, 2013c). Twenty-two schools did not recognise the individual presentation and therefore needs of learners with HFA / AS (Jordan 2001; McAfee, 2002). By omission, the perception could be that all learners with HFA / AS are the same and a perceived barrier to admission for future children with HFA / AS could be formed. Four of the five focus group participants felt that schools did not recognise the individual needs of their children, confirming the data from the 22 schools. The perceived barrier to admission on the part of the senior management staff was that how the child presented on the day on screening at the school was how the child would present on a regular basis (Fein & Dunn, 2007).

This perceived barrier is further discussed in objective 4 below where the past experiences could be seen to influence future admission of learners with HFA / AS. Should a person be unfamiliar with HFA / AS, they may be unaware of the individual presentation of a child with the condition, within the triad of impairments. Therefore, stereotyping could be a barrier to admission to mainstream schooling for learners with HFA / AS. The perceived barrier that all children with HFA / AS present in the same way could exclude future learners with the condition based on the (poor) experience of the educators due to the presentation of learners with the condition in the schools in the past (Ainscow & Haile-Giorgis, 1998; Education Review Office, 2010). Stereotyping is recognised as a barrier to inclusion in the Education

White Paper 6 (South African Department of Education, 2001b) and misunderstanding about the individual presentation of each child with HFA / AS could result in stereotyping of the condition and thus become a barrier to admission for learners with HFA / AS.

The perceived barrier implied in the autoethnographic essay (experienced at one school) was that teachers would not be able to cope with her child with HFA / AS even in the presence of a professional person provided to assist the teacher. This barrier was overcome with persuasion and the barrier which was perceived to be a problem was not experienced.

Similarly the results from focus group revealed that teachers overcame the perceived barrier that the child with HFA / AS would be challenging as they gained experience in teaching the child with HFA / AS (Carrington, 1999).

The importance of recognising barriers which are perceived; is that they are real in preventing admission to mainstream primary schools or learners with HFA / AS when believed to be real by senior school staff. This means a senior staff member who has a misunderstanding about HFA / AS could reject admission applications from children with the condition based on that staff member's perception of the condition which is unfounded. Additionally, discovering what the perceived barriers are to mainstream education for learners with HFA / AS gives opportunity to explore ways to overcome them. The difficulty remains that the applications are subjectively viewed and a standard measure for applications of learners with HFA / AS into mainstream schools is needed. This is discussed by means of screening methods in the following section.

4.6.3 Objective 3: To explore the experiences of admission or attempted admission to mainstream education for parents of children with HFA / AS

The discussion of the results from Phase 2 of this study, the focus group comprising of parents of children with HFA / AS, was dealt with under Objective 3 in detail. The data from the autoethnographic essay revealed some commonalities with the experiences reported in the focus group. The data collected from schools did not contribute to this objective of parents' experiences but information on screening methods for schools can be found in section 4.2.9.6.

Both relevant data sources revealed the admission or attempted admission of the children with HFA / AS was met with conflict between parents and school staff. The source of the conflict was inflexibility on the part of the school staff to accommodate the needs of the learner with HFA / AS and the lack of understanding about the condition from the school staff. Both sources outlined the emotional difficulty experienced by the parents as a result of the admission or attempted admission process for their children. The parents' emotional experience came in the form of insecurity about the correct educational placement for their children as well as future educational placements. Parents did not have the confidence that their children would have a school placement from year to year. Both sources mentioned dissatisfaction with the schooling options available for their children with HFA / AS and both revealed that personal finances were impacted indirectly in the admission process as personal facilitators were provided by two of the parents in order to ensure the child's placement at the schools. Although additional finances for the education of learners on the Autism spectrum provided by the parents of the learners goes against the charter rights of persons with Autism as reflected upon by Matthews and Matthews (2012) it is the unfortunate reality for parents of learners on the Autism Spectrum in South Africa (Yssel et al., 2007). Additionally both sources revealed that the senior management staff of the schools which the parents

approached for enrolment did not have an open attitude towards inclusion (this was with the exception of one focus group participant). This finding was consistent with research done in various first world countries as outlined in Carrington's study (1999) and in New Zealand (Education Review Office, 2010). Despite this experience both sets of data revealed that the parents desired unity with the schools. It is recommended that for parents to manage the stress experienced as a result of the schooling difficulties with their children with HFA / AS to attend support groups. This is the practice in other parts of the world, for example India (Action for Autism, centre for Autism, n.d.), Australia (Harrington, 2011), in South Africa (Swart et al., 2004) and in the greater Durban area (Action in Autism, n.d.). Meeting regularly with teachers has also been noted to reduce the stress experienced by parents (de Nysschen, 2008; Kujwana, 2008).

One area where the two data sources relevant to Objective 3 did not overlap was in regards to the screening process experiences for the admission of children with HFA / AS into mainstream schools. The autoethnographic essay made no mention of the screening process for admission. However, the data from the focus group revealed that the schools did not have effective screening methods in place. (See results on Phase 2 for more details on the screening process experiences of focus group participants). Since not all learners with ASD are suitable candidates for mainstream schooling (Schopler & Mesibov, 1992), schools would need direction in knowing which learners would benefit from mainstream placements and those which would not. The district support teams (South African Department of Education, 2001b), being professionals employed to give educators support in the inclusion of learners with special needs, including HFA / AS, could assist in screening and with accessing appropriate resources. These professionals who we would assume to be knowledgeable about HFA / AS could be a point of contact for parents of learners with ASD and their teachers. The district support teams could make the distinction between learners with HFA / AS and

learners with Classic Autism based on the fundamental characteristics of HFA / AS, those being peer level cognitive skills, peer level language skills and peer level self help skills (APA, 2000; WHO, 2012). As clinicians become familiar with the DSM-5 (APA, 2013) and research emerges on effective screening tools to be used under the new categories of diagnosis, these new tools should be evaluated for use by district support teams. Screening tools such as the High-Functioning Autism Spectrum Screening Questionnaire (ASSQ) (Ehlers et al., 1999) mentioned in Phase 2, a 10 minute screening questionnaire developed for use by parents and teachers for the screening of learners who may have HFA / AS can be used. The significance of the use of such a screening tool would be that consistency would be established in the acceptance of learners with HFA / AS into mainstream government schools and should be administered by the district support teams. Learners with HFA / AS would then be able to enrol at their local mainstream schools by means of an objective screening tool and not subjective opinions. The Inclusion International Global Report (2009) mentions the importance of correct identification tools and systems to recognise children with special needs in order for the children to access appropriate education. The need expressed in the report relates to special needs in general from a global perspective but fits with the specific need for identification tools (screening tools) in relation to HFA / AS and accessing appropriate education by means of mainstream schooling.

In their reflection on The charter rights for persons with Autism, Matthews and Matthews (2012) explains how access to mainstream schools for learners with HFA / AS should not be a goal in itself. The educational quality and experience for the learners must be meaningful in terms of educational value. Likewise Swart et al. (2004) and Yssel et al. (2007) discuss how enrolment should not be the only focus in inclusion but the implications for the school community must also be considered. This concept was a reality for two of the focus group members whose children were admitted into mainstream schools initially but were later as

asked to leave as the schools realised that their staff did not have the necessary skills to effectively deal with the needs of the learners. The importance of collecting data on the enrolment experiences of parents of children with HFA / AS was to explore if barriers to admission to mainstream emerged. The data revealed the need for senior staff members to be informed about HFA / AS and the need for district support teams to be involved in directing learners with HFA / AS to the schools most suited to their needs.

Since parents felt that there was no structure to the admissions process for their children with HFA / AS, it would be beneficial for schools to develop a plan on how to review applications and how to practically implement inclusion. In doing so a fair method of inclusion would be established and access would not only be for those whose families are financially able or who have the resource of time to offer schools. The change for a school from mainstream to inclusive mainstream is a process which takes planning and time (Walton, 2002). Ideally parents should be included in the development of the change as they know well the needs of their children with HFA / AS.

4.6.4 Objective 4: To explore the encounters of schools who admit children with HFA / AS

This objective was discussed in detail in the results of Phase 1. Data from the focus group and autoethnographic essay will contribute to this objective below however, the majority of the data were collected from the schools.

Eleven of the 28 schools reported that teachers found teaching learners with HFA / AS to be a difficult experience. Data from the focus group revealed that the parents understood the difficult position teaching staff were placed in regarding teaching learners with HFA / AS and the parents suggested being encouraging towards the teachers considering the teachers had not had training. Teachers reported to the parents that they were not able to cope with the

learners with HFA / AS and schools reported similar experiences. The autoethnographic essay supported this finding with the author reporting that teachers expressed,

R/M 'that was hard work'

referring to teaching her child with HFA / AS. Seven schools expressed that the difficulty experienced was due to untrained staff and class sizes. Lack of staff training was also identified in the data from the focus group and autoethnographic essay. The need for small classes was expressed in the focus group but not in the autoethnographic essay. Twelve of the 28 schools reported that having a learner with HFA / AS in the class was a drain on the teachers' time. Focus group participants expressed a similar sentiment but conveyed it by means of saying that learners with HFA / AS do well with one on one attention. Data from the focus group, autoethnographic essay and survey revealed that educators gained teaching experience and increased their knowledge about HFA / AS as a result of having children with HFA / AS in their classes.

All schools in the study which currently had learners with HFA / AS enrolled or had done so in the past five years, reported that having a learner with HFA / AS also affected the neurotypical learners at the school. There were mixed reports about the positive and negative impact on the neurotypical learners (See results from Phase 1). Data from the focus group also offered mixed results ranging from bullying of the child with HFA / AS by neurotypical learners to increased social skills of the child with HFA / AS and friendships built with neurotypical learners (Attwood, 2007; Autism Independent, UK, 2010). It would appear that the impact on the neurotypical learners differs case by case. In contrast research shows inclusion to be beneficial for both neurotypical and special needs learners (including HFA / AS) (Simpson et al., 2003; Fein & Dunn, 2007; Yssel et al., 2007). The significance of the mainstream placement in regards to social skills for learners with HFA / AS is that this is

a life skill needed to support the person in adulthood in maintaining employment and contributing to society (Attwood, 2007). Peer level cognitive skills without suitable interactional skills could limit the employment opportunities for the person in later life.

The importance of exploring the experiences of schools which admit learners with HFA / AS was to establish the effect the experiences may have on future admissions of learners with HFA / AS into the schools. Considering the numbers of learners with ASD and specific to this study, learners with HFA / AS are increasing, how schools view inclusion and accepting these learners is important.

4.6.5 Objective 5: To determine the current numbers of children with HFA / AS admitted into mainstream primary schools in a specific population

This objective was not achieved in this study due to the low response rate from Phase 1, the descriptive survey questionnaire. The numbers of children with HFA / AS in the two circuits of the Umlazi school district remain undetermined. This could be determined in the future by means of a census or by the South African Department of Education requesting the numbers of children HFA / AS enrolled in mainstream schools in the selected circuits of the Umlazi school district.

4.6.6 Objective 6: To explore possible ways barriers to admission to mainstream schools for children with HFA / AS may be overcome

The data from the schools, the focus group and the autoethnographic essay revealed ways to attempt to overcome the barriers to admission to mainstream schooling for children with HFA / AS. Of the seven categories emerging, to overcome the barriers, four were common to all three data sources. These are changes in attitudes, educator support, finances and training. The proposed ways to overcome the barriers to admission will be discussed below with reference to the Education White Paper 6 (South African Department of Education, 2001b)

and the recommendations made in the document for successful inclusion. Twenty five of the 28 schools in the study had had some level of understanding about the Education White Paper 6 (South African Department of Education, 2001b). The author of the autoethnographic essay and one focus group participant were informed about the document. Four of the five focus group participants were unaware of the document.

4.6.6.1 Attitudinal changes

All three sources of data revealed that attitudes of school staff were problematic in accessing mainstream education for learners with HFA / AS. Overcoming this barrier to admission to mainstream education for learners with HFA / AS is challenging as attitudes are intangible entities (Reber, 1995). The theme of flexibility in education is present in the Education White Paper 6 (South African Department of Education, 2001b). The data from the focus group and the autoethnographic essay in contrast to this revealed that inflexible attitudes towards inclusion of learners with HFA / AS were experienced from educators by parents regarding enrolment and continued placement. Since only eight of the 28 schools in the study felt that mainstream education was the learning environment best suited to learners with HFA / AS, a change in educator attitudes is needed to make inclusion successful in the Umlazi school district. The Education White Paper 6 (South African Department of Education, 2001b) says “we are about changing attitudes” (p. 55). To overcome attitudes as a barrier to mainstream education for learners with HFA / AS educators would need practical assistance in the schools (Carrington, 1999). Changing attitudes is not only about feeling good about inclusive education but also feeling prepared for it and feeling successful in implementing it. Attitudes are only likely to change if educators are given hands on practical help with the learners with HFA / AS (Carrington, 1999). In Palestinian Authority, positive attitudes towards inclusion resulted from the use of support teams giving teachers hands on support in educating learners with special needs. The success of the strategy led to the involvement of donors outside of the

educational system to providing learning materials and resources for learners with special needs (Mittler, 2003). Unfortunately in Jordan, negative attitudes towards inclusion remained despite the assistance of teachers by means of support teams and training on special needs. Teachers felt doubtful of the successful future of inclusion and their attitudes (Mittler, 2003) towards inclusion were therefore not embracing.

The attitudes as a barrier to admission to mainstream schooling for learners with HFA / AS could further be addressed by means of a standardised screening process for school admissions, as mentioned in Objective 3. In the United States of America the education system is responsible for the identification and assessment of special needs learners as well as the correct educational placement of the learners (Kozleski et al., 2008). This creates a uniform system for admissions. In South Africa disabilities are identified by means of the medical system which does not overlap with the educational system, making admissions subject to the views of school Principals. Screening tools such as the ASSQ (Ehlers et al., 1999) as mentioned in Phase 2, a 10 minute screening questionnaire developed for use by parents and teachers for the screening of learners who may have HFA / AS would be useful in this regard. Additionally, a basis should be formed for the number of learners with HFA / AS which could be included per mainstream class. In this way teachers would know what is expected of them and schools can grow proportionally with inclusion and have definite measures for admission (Walton, 2002). By using a standardised measure, the subjective attitudes for admission of senior staff members would be removed.

The focus group participants felt the attitudes of parents of neurotypical children could be altered at a school level if schools provided parent evenings on the topic and if schools had positive attitudes towards HFA / AS. Senior staff members could present their future plans

for inclusive education at annual parent meetings along with other news presented at the time. This would give parents of neurotypical learners confidence that the school has a structure to work towards and is aware of the steps needed to make inclusion in the school successful. Concerns from the neurotypical parents such as if their children will be negatively affected by inclusion, would be addressed at such meetings. The attitudes of the neurotypical learners can also be influenced by senior staff members views on inclusion (Walton, 2002). A way to overcome the barrier amongst parents of neurotypical parents could be for a senior staff member to address the learners who learn alongside the child with HFA / AS on the topic and establish a positive outlook amongst the learners which one would hope would be reported to their parents (Walton, 2002). Partnerships with special needs schools resulting in shared “fun days” or outings could also result in the development of positive attitudes towards inclusion. Community awareness can also influence attitudes and this can be addressed by means of projects such as the *Light it Up Blue* campaign promoted by Autism South Africa (2012). Community awareness for inclusion was seen as important in Uruguay (Inclusion International, 2009) and in Lesotho (Mittler, 2003). In Peru thousands of families and teachers have taken part in the *Inclusion Celebration* held at a local stadium. This event has been repeated over several years and has drawn attention to special needs learners. Focus was on developing inclusive practices and developing resource centres from existing special needs schools (Inclusion International, 2009).

The views of the senior staff members impacts the attitudes for the other staff members (Williams, 1983; Coleman et al., 2003) therefore for inclusion to be successful senior staff members would need positive approaches to inclusion (South African Department of Education, 2010). In Egypt an attempt at inclusion involved teacher training, support teams, practical guidance and awareness about inclusion given through the media. The endeavour

failed for several reasons including teachers having negative attitudes towards inclusion and some senior staff members preventing their staff from attending training (Mittler, 2003). This emphasises the importance for senior staff members being favourable towards inclusion for inclusion to be successful.

To foster positive attitudes towards inclusion in senior staff members and if finances allow, senior staff members would benefit from practical exposure to successful inclusion in other countries. Examples of these could include the USA (United States Department of Education, 2004) and Australia (Government of South Australia, 2006). The method of international exposure to inclusion was utilised in Morocco (Mittler, 2003) where a study visit to France was taken to assist educators in better understanding inclusion. Similarly, educational representatives from Zanzibar visited Lesotho and drew from changes observed in Lesotho to make changes to the educational policy in Zanzibar. The legislative changes to adopt inclusion of special needs learners into mainstream schools in Zanzibar were made in 2006 (Inclusion International, 2009).

Schools which felt they were not able to accommodate learners with HFA / AS due to poor past experiences with learners with HFA / AS in their schools, could possibly express this as a barrier as they felt ill-equipped to teach the children. Should they have the aid of the district support teams they may be more willing to accommodate the learners with HFA / AS. The barrier, therefore, would not be attitudes of unwillingness to enrol the learners but rather the realistic attitude of not being able to provide the best educational support for learners with HFA / AS. To overcome this barrier therefore related back to the need for finances, support and resources.

Organisations such as Action in Autism and Autism South Africa have raised awareness of ASD by advertising and offering training on ASD to schools and communities. These types of initiatives increase knowledge on ASD (including HFA / AS) which can in turn influence attitudes about ASD, including HFA / AS. In Malaysia, attitudes were seen as a barrier to

mainstream education (Yoke, 2010). To overcome this barrier and to change teachers' perspectives on inclusion it was suggested that all teaching qualifications include a practical placement in a special needs setting or inclusive education environment. If teachers view their role only as to teach neurotypical learners, inclusion will continue to be viewed as problematic. If from the outset teachers are aware that teaching includes learners with HFA / AS in a mainstream setting there would not be a need for a change in attitudes- the correct attitude would already be in place.

Lastly recognition from the South African Department of Education or KZN Department of Education could be given to schools who embrace inclusion as well as to educators who are on the front lines of working with learners with HFA / AS in mainstream settings. These recognitions could be in the form of mention in government newsletters which are distributed to all schools as well as mention made on the websites for the South African Department of Education as well as the KZN Department of Education. In doing so not only would attitudes be positively affected but also teacher support would be achieved.

4.6.6.2 Educator support

All three sources of data agreed that the lack of teacher support was a barrier to mainstream education for learners with HFA / AS. The Education White Paper 6 (South African Department of Education, 2001b) acknowledges that inadequate support for educators is a barrier to inclusion and proposes district support teams to meet this need. The role of the support teams would be to support teachers by means of input on adaptations and flexibility with teaching methods as well as with assessment methods and materials for special needs learners. For district support teams to be effective in overcoming the barrier of educator support at mainstream schools, one would assume the support team members would be sufficiently knowledgeable about HFA / AS (Koegel et al., 2011). Mittler in his paper

prepared for UNESCO (2003) outlines how in Jordan, the concept of support teams was utilised in 40 primary schools. The support teams were made up of trainers from government and from NGO's. Initially the program was piloted in two schools and training with hands on assistance was given to teachers.

Support teams had not yet been made available to the schools when this study was conducted and schools did not make mention of the existence of such district support teams. From a governmental level, an alternate way to give teachers support would be by assigning student teachers to teachers of learners with HFA / AS in mainstream settings as part of the student teachers' practical experience towards his / her teaching qualification (Barratt, 2005; Yoke, 2010). This method would address both barriers of attitudes as mentioned above as well as teacher support. The focus group participants and the author of the autoethnographic essay had attempted to overcome this barrier by offering themselves as support to the teachers. Two parents offered professionals or paraprofessionals to assist the teacher in the classroom, one involved a psychologist as well as an individual who trained school facilitators, and the researcher offered herself as a behavioural therapist to schools her son attended. Schools attempted to overcome this barrier by employing class assistants or support staff which were funded by the parents of the special needs learners or by fund raising initiatives done by the schools. Class assistants would be valuable as a support to teachers not only in practical help in the classroom but also to brainstorm and problem solve any issues arising related to the learners with HFA / AS (de Nysschen, 2008). Collaboratively the teacher and class assistant could develop strategies and specific methods to best support the learner with HFA / AS. To overcome the barrier of educator support in the short term in the selected circuits of the Umlazi district, it would appear the responsibility rests on the parents of the children with HFA / AS or on the schools themselves. This would have financial implications for both the

schools and the parents (Yssel et al., 2007). The responsibility of teacher support and the finances to provide it should not rest on parents or on schools (South African Department of Education, 2001b; Matthew & Matthews, 2012) but unfortunately due to the gap between recommending policies and implementing policies, this is the reality for parents and schools currently in the two circuits of the Umlazi school district. The gap could be addressed by means of student teachers as mentioned above or by volunteers from the community. Parents or family members of neurotypical children who wish to volunteer as class assistants could be offered small incentives such as giving out prizes on sports days or end of year functions or priority seating during school events such as school plays.

Untrained teachers working with learners with ASD who have a large work load are noted to experience emotional stress (de Nysschen, 2008). The emotional support needed by teachers could be provided by means of support groups, wellness meetings with other staff from other schools practicing inclusion and brainstorming groups consisting of parents, teachers and staff from schools in the area which are also practicing inclusion. Additionally senior staff members could monitor stress experienced by teachers working with learners with HFA / AS and recommend the establishment of the above mentioned support groups and the attendance of them. The lack of teacher support, while problematic in the selected circuits of the Umlazi district; is not a unique problem as revealed by Inclusion International (2009) in their global report. The report involved over 75 countries and inclusion was found to be unsuccessful in countries where there was a lack of teacher training, experience, support within the classroom, inclusive curriculum and overlap / practical training between teachers who had an understanding of special needs and those who were new to special needs. These concepts would also apply to HFA / AS. The Guidelines for Full-service/Inclusive Schools 2010 (South African Department of Education, 2010) states that the total percent of special needs learners per mainstream school should not exceed 3%. Having a boundary on the numbers of

special needs learners will also give support to teachers in that their teaching output would not be exhausted on an overwhelming number of special needs learners.

4.6.6.3 Finances

All data sources agreed that additional finances would reduce barriers to admission to mainstream schools for children with HFA / AS. This barrier could be likened to the need for finances to remove barriers to admission for learners with physical disabilities. For example a learner who is cognitively able but is in a wheelchair may experience this as a barrier to admission if the school did not have ramps to access buildings. The additional resources for learners with HFA / AS are needed to supply teacher support by means of district support teams, independent support staff or class assistants mentioned above. Staff training would also require finances as would adjustments to the curriculum and the implementation of small classes, meaning more teaching staff would need to be employed. Ideally, these costs would be covered by the government as is the case in other countries such as the USA (United States Department of Education, 2004) where there is no extra charge at public schools for a child with special needs. However, as seen in the autoethnographic essay, views may differ on the definition of suitable education for learners with HFA / AS. For the learners who qualify, classroom aides are available, and learners can attend some classes with their neurotypical peers and other lessons separately depending on the needs of the learner with HFA / AS. This is at no extra cost to the parents of the child. The Government of South Australia (2013) provides support and individualised education programs for learners with ASD and in particular HFA / AS and the schools are able to apply for funding grants from the government for any particular adjustments needed to successfully accommodate learners with special needs, including those with HFAS / AS (Department for Education, UK, 2011). This is important as the educational needs of the learners will change as changes are made in educational policy within schools.

The Education White Paper 6 (South African Department of Education, 2001b) mentions the financial challenge associated with the roll out of the strategies outlined in the document and acknowledges that additional funding will be needed for improved special needs education. Caution is given that this may not be a reality in the short term due to the other demands on the government budget outside of education. In order to start the process of inclusion the South African Department of Education could start with one school in a ward or circuit and develop it to be prepared for inclusion, as suggested by Barratt (2005) for Singapore. After one inclusive school is established and functioning well with the proper supports in place, attention could be given to developing a second school for efficient inclusion. In this way the budget can be staggered and from a perspective of support, the first school could mentor the second and in this way training would also be from the experiences of the teachers currently teaching learners with HFA / AS in a mainstream setting. Vietnam used this method starting with one preschool and one primary school which were prepared for inclusion of learners with special needs. This number grew to over 1000 inclusive preschools and primary schools by the year 2000. A similar method was implemented in Lesotho on a bigger scale starting with 10 schools being identified for inclusion and the teachers involved given training. These teachers then worked through local neighbourhoods informing community members that the schools were open to inclusion (Mittler, 2003). Until methods such as starting small with inclusion are adopted in KZN, the financial responsibility once again falls on the parents of the children with HFA / AS and the schools which are willing to enrol them. When inclusion is successfully implemented and as a result learners with HFA / AS have access to appropriate education, the long term effect is that the learners become educated adults who are effectively able to contribute to society. Available finances is a barrier to this long term end.

Many developing countries included in the Inclusion International global report (2009) had accessed financial help from developed countries and international NGO's to assist with the implementation of inclusion. The option of international financial support for inclusion would have similar results and would bring about the expedited implementation of the Education White Paper 6 (South African Department of Education, 2001b). The International recognition of Nelson Mandela and the prestigious Nelson Mandela Children's Fund, could be utilised to draw donors and sponsors for inclusive education as the fund represents the rights of children (Nelson Mandela Children's Fund, 2013).

4.6.6.4 Training

As with the above solutions, all three data sources named staff training as a means to overcome barriers to mainstream education for learners with HFA / AS. This option has already been mentioned regarding finances. The importance of correctly trained staff is great as indicated by the data of this study as discussed in the results of Phase 1 and Phase 2. The school staff felt unprepared and the parents felt their children with HFA / AS were not receiving a suitable education. Training for educators and school management staff is also mentioned in the Education White Paper 6 (South African Department of Education, 2001b) as necessary for successful inclusion. To overcome this barrier in practical terms in the current educational system in the Umlazi district, time is needed for the roll out of the policies represented in the Education White Paper 6 (South African Department of Education, 2001b). In the short term schools would need to rely on external sources to train their staff or schools would need to form stronger partnerships with the parents of children with HFA / AS in order to learn from the experience the parents have gained from handling their children with the condition. The inclusion International global report (2009) refers to the support of those who know, such as special needs schools or agencies, given to those who do not, such

as mainstream schools, as knowledge network for inclusive education. In the report it is mentioned that there is an abundance of knowledge on special needs (which would include HFA / AS) but accessing the knowledge is the challenge, especially in rural areas which do not have digital access. Sources for training contributing to the knowledge network for inclusive education (Inclusion International, 2009) could be local Autism support agencies such as Action in Autism, Autism South Africa or through internet searches. Special needs schools in the target areas which accommodate learners with ASD could be approached and asked to assist with training of staff who work in mainstream schools which have embraced inclusion. De Nysschen (2008) makes a similar recommendation but related to special needs schools networking with each other. Similarly private schools which have learners with HFA / AS could be invited to share their experiences and teaching techniques with teachers at government schools who have less experience in the field. Assistance from the support agencies, special needs schools and private schools could be given in the form of instruction on conversation skills, academic work and behaviour management. How to implement concrete learning methods with visual supports would also be beneficial (Anthony, 2009), as would be how to use charts, models and diagrams to maximise learning for children with HFA / AS (Palmer, 2010). Teachers in mainstream schools could be assigned mentors from special needs schools which have experience with HFA / AS (Barratt, 2005). In this way teachers in mainstream schools who are new to the condition would have a point person to contact for advice and direction for specific areas in working with the learners with HFA / AS. Alternately, should professionals not be available to present on the topics, training could be done by means of DVDs to be viewed by the teachers or by means of on line training course such as those offered by the CARD organisation. As a minimum option, the South African Department of Education could issue books on HFA / AS to schools as was done in Singapore (Barratt, 2005).

Regular scheduled training meetings would be important not just a once off workshop (Engelbrecht et al., 2001). In Southern Australia the government provides training on Asperger's Syndrome twice a year. Following the training course the materials are available on line on the Autism Southern Australia website (Government of South Australia, 2006). Additionally conferences, workshops and seminars on the topic are held at irregular intervals and a national conference on ASD is hosted every second year. The importance of ongoing training is that HFA / AS presents differently in each child, therefore strategies which are effective for one learner may not be effective for another. Regular meetings have been noted to assist teachers of learners with special needs, not only with educational strategy but also confidence and energy to teach effectively, especially when conducted in conjunction with teachers from other schools, where a network of support and shared experiences can be formed (Engelbrecht et al., 2001).

4.6.6.5 Curriculum adjustment / accommodations

Data from schools and from the focus group revealed that small adjustments to the curriculum as well as accommodations were needed to give learners with HFA / AS better access to mainstream schools. The Education White Paper 6 (South African Department of Education, 2001b) emphasises the importance of a flexible curriculum in order to meet the individual needs of learners with special needs, stating, "Central to the accommodation of diversity in our schools, colleges, and adult and early childhood learning centres and higher education institutions, is a flexible curriculum and assessment policy that is accessible to all learners, irrespective of the nature of their learning needs. This is so since curriculum create the most significant barrier to learning and exclusion for many learners, whether they are in special schools or settings, or 'ordinary' schools and settings" (p. 31). A flexible curriculum for learners with HFA / AS may include social skills teaching (Attwood, 2007) as learners

with HFA / AS can achieve well academically but may still experience isolation from their peers without social skills training (Barratt, 2005). In Hungary the curriculum was adjusted for learners with special needs at the Children's House Alternative Program in Budapest. The inclusion policy follows the Social Ecological model where teaching methods are diversified and the teaching is based on the learners' needs (Inclusion international, 2009). In the case of different learning needs as mentioned in the Education White Paper 6 (South African Department of Education, 2001b), changes may include sensory breaks or reduction in homework as suggested in the focus group. Specific accommodations were not mentioned in the autoethnographic essay. In order for educators to know what accommodations to make or which changes need to be made to the curriculum, training would be needed on the topic of HFA / AS, as well as the need for the input from district support teams, which again relates back to need for additional funding.

In the absence of active district support teams, mainstream schools could approach special needs schools which have experience in ASD in general as well as in HFA / AS for assistance with changes in the curriculum. Changes to the curriculum and classroom accommodations special needs schools have found successful include using visual materials, a structured approach to learning, teaching on life skills, support with group work or class discussion and the development of Individualised Education Programs (I.E.P.s). I.E.P.s identify the specific areas each special needs learner has with the goal of those areas being addressed during the year. I.E.P.s. I.E.P.s are effectively ongoing assessments of the child's individual learning needs. These would apply to special needs learners in mainstream schools, including those with HFA / AS as outlined in the Guidelines for Full-service/Inclusive Schools 2010 (South African Department of Education, 2010). This concept is in practice in the USA (United States Department of Education, 2004) and encourages collaboration between parents, teachers and professionals who work with children with special needs. For this to become active in mainstream schools in the target area, parents of learners with HFA / AS would

need to approach the school management team as well as parent governing body to pursue the implementation of government policy. This may need to be done with the assistance of an independent Autism resource group.

4.6.6.6 Class sizes

Small classes were suggested as a means to overcoming barriers to admission for learners with HFA / AS by schools in the study and by focus group participants. Class size is not mentioned in the Education White Paper 6 (South African Department of Education, 2001b) or the autoethnographic essay however, it is raised in the literature (Simpson, et al., 2003 Roberts, 2007; Walton et al., 2009). Small classes would allow for more individual attention for learners with HFA / AS, it would also allow for the practice of social skills for children with the condition, in a non threatening environment (de Nysschen, 2008). Large classes can be overwhelming socially for a child on the Autism spectrum and the added noise a large class brings can also impact the sensory challenges a learner with HFA / AS can have (Dunn et al., 2002; Schetter & Lighthall, 2009; Autism Speaks, 2012). The practice of small classes would seem beneficial but once again to overcome this barrier finances are needed as additional teaching staff would be needed and possibly additional classrooms. One mainstream school in the study overcame this difficulty by having a support unit which operated alongside each grade. Learners with various mild disabilities, including HFA / AS, made up these classes which had a maximum of 14 learners per class. The funding for the operation of the academic support units was provided by the school and not by the government.

4.6.6.7 Unity between parents of children with HFA / AS and school staff.

Data from the focus group and autoethnographic essay revealed one more recommendation for overcoming barriers to admission to mainstream schools for learners with HFA / AS. This was unity between schools and parents. Although this theme did not emerge from the data collected from schools, it is mentioned in the Education White Paper 6 (South African Department of Education, 2001b), where the non involvement of parents with the education of their special needs children is mentioned as a barrier to inclusion. In Lao People's Democratic Republic, the need of unity between parents of learners with special needs and their teachers was noted as important (Mittler, 2003). In the paper Mittler prepared for UNESCO (2003) he noted that attention was given in Lao People's Democratic Republic to improving communication between parents and schools and improving attitudes of the two parties for the benefit of the special needs learners. Data from the focus group revealed that parents desired to have increased communication with the school staff and were willing meet with their children's teachers. Data from the autoethnographic essay showed that the author's child with HFA / AS progressed educationally when his teacher and mother were able to form a partnership regarding his education. Should educators feel that they have the support of the parents of the child with HFA / AS schools may be more willing to enrol learners with the condition realising unity is desired. Research shows that the success of mainstream placements for learners with special needs is dependent on parental involvement (Yssel et al., 2007; Harrington, 2011; Koegal et al., 2011) and that lack of parental involvement can result in miscommunication and stress between the educators and the parents (de Nysschen, 2008; Kujwana, 2008). A partnership is therefore needed between parents and educators, each giving the other support in the educational progress of the child. Since poor past experiences concerning learners with HFA / AS were seen to influence the possibility of the educators repeating the process (Barnard et al., 2000), the removal of stress for educators by means of

unity with the parents of children with HFA / AS could be seen as a means to remove one of the barriers to admission to mainstream schools for learners with HFA / AS. Regular scheduled meetings between parents and teachers to discuss the success or failure of implemented classroom strategies and evaluation of the child's progress would benefit all parties concerned and in particular promote the successful inclusion of the child with HFA / AS (Harrington, 2011). It is also recommended that parents attend training on HFA / AS in the mainstream classroom to enable them to have realistic expectations about the demands on a mainstream teacher working with learners with HFA / AS within the limitations of the current education system (de Nysschen, 2008).

One of the barriers to the unity desired by the parents between themselves and the schools appeared to be the different approaches towards inclusion. Schools' views of inclusion reflected the Medical model of education where the learner with special needs has to "earn" the right to fit into a mainstream school. Any challenges the learner may experience within that school are viewed as being the responsibility of the learner (Landsberg et al.2005; Jordan, 2008). Parents held the view of the Social Ecological model (South African Department of Education, 2001b; Landsberg et al.2005) where the individual needs of the learner are considered and the responsibility of addressing the child's learning style and subsequent educational progress rests on the educators at the school that child attends. South African schools have traditionally followed the Medical model of education. Change in outlook regarding special needs education is needed to move towards the Social Ecological model of education. The policies outlined in the Education White Paper 6 (South African Department of Education, 2001b) direct educators to this end. Unfortunately the practical roll out of the policies outlined in the Education White Paper 6 (South African Department of Education, 2001b) have not yet been achieved in the target area of this study, it therefore stands to reason that the teaching staff still follow the Medical model of education. Unity

between parents of children with HFA / AS and staff of mainstream schools may only be realised when the full implementation of the Education White Paper 6 (South African Department of Education, 2001b) is achieved. De Nysschen (2008) recommends support meetings for parents and teachers of learners with HFA / AS as does Harrington (2011). In this way common difficulties can be discussed and solutions sought. By mutual discussion the challenges each party faces can be raised in order for the parties to appreciate the others' perspective and in this way be supportive of one another.

4.7 Summary of Chapter Four

This chapter focused on the results of the three sections of the study: Phase 1 the descriptive survey questionnaire conducted in schools in the selected circuits districts of the Umlazi district; Phase 2 the focus group comprising parents of learners with HFA / AS in the selected circuits of the Umlazi district, lastly, results from the autoethnographic essay, written by the researcher on her experiences of mainstream schooling with her son with HFA / AS. The data from the three sources was presented and then discussed in reference to the barriers to admission to mainstream primary schools for children with HFA / AS. Following the results and discussion for each of the three sections, the results were integrated. This revealed that all three data sources saw the lack of teacher training and lack of knowledge about HFA / AS amongst school staff were barriers to mainstream placements for learners with HFA / AS. In some schools it was revealed that there was misunderstanding about HFA / AS and that Classic Autism was confused with HFA / AS, which would also serve as a barrier to admission to mainstream education for learners with HFA / AS.

Results from the focus group and autoethnographic essay agreed that large class sizes were a barrier. Schools alone reported that bullying, poor past experiences and potentially demanding parents of learners with HFA / AS were barriers to admission. Parents reported

that their own assertiveness was essential in gaining a mainstream placement for their children and that the inflexibility of school staff was a barrier to admission for learners with HFA / AS in mainstream schools. Using a mixed methods research design gave a broad base of evidence of data. The aim and objectives of the study would have been answered by qualitative or quantitative research alone (Vaughn, Schumn & Sinagub, 1996; Delpont & Fouche', 2011)

Solutions to overcoming the barriers to admission to mainstream schools for children with HFA / AS emerged as the need for attitudinal changes amongst school staff, educator support, increased finances, staff training, curriculum adjustments, small class sizes and unity between parents and school staff.

“If you are out to describe the truth, leave elegance to the tailor”

*Albert Einstein, commonly considered to be on
the Autism Spectrum US (German born)
physicist (1879-1955)*

CHAPTER FIVE: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1 Conclusion

All children in South Africa have a right to education (Constitution of the Republic of South Africa, 1996). Learners with mild disabilities such as HFA / AS have the right to attend mainstream schools alongside their peers in their communities (South African Department of Education, 2001b). The growing numbers of learners with HFA / AS (Whitby, Travers & Harnik, 2009; Autism Society, 2011) necessitates increased provision for appropriate education for these learners in order for them to exercise their right to education. The mixed methods research design used in this study revealed that there were significant barriers to admission to mainstream primary schools for children with HFA / AS. The barriers were not unlike the barriers found in other countries.

The overriding barrier to mainstream education for learners with HFA / AS in the selected circuits of the Umlazi school district was found to be the gap between educational inclusion policies and the implementation of those policies. Other barriers can be categorised into five main groups:

1. Lack of knowledge and misconceptions about HFA / AS
2. Lack of training of school staff
3. Lack of support resources and funding
4. Lack of unity between parents and school staff
5. Negative attitudes towards inclusion from school staff.

Main results highlighted the under preparedness of mainstream schools to admit learners with HFA / AS. The results showed that 100% of the schools had received no training in the form of continued professional development on HFA / AS from the local and national Departments of Education. All senior staff members indicated they would like their staff to attend training on HFA / AS if it were offered. The general lack of training and experience amongst teachers in HFA / AS and lack of support for teachers provided by the South African Department of Education impacted open admissions to mainstream schools for learners with the condition. Inclusion International (2009) in their global report found that lack of teacher support contributed to ineffective inclusion policies. The policies in the Education White Paper 6 (South African Department of Education, 2001b) highlight many essential factors to make inclusion successful but the means to implement such strategies have not yet been realised.

Few schools had learners with HFA / AS enrolled, and in this study only one parent had a positive mainstream school experience. The dissatisfaction with the school system expressed by focus group participants should not be present in the light of the policies in the Education White Paper 6 (South African Department of Education, 2001b). Mainstream education should be available to learners with HFA / AS regardless of their parents' financial status or time resources. Currently mainstream education for learners with HFA / AS is mainly available to children whose parents have financial resources. Finances are needed to provide personal facilitators for the children at school and to pay for professionals such as occupational, behavioural and speech therapists to work to the child. In addition parents need

to be available to partner with teachers to aid in the child's education. This immediately places many children at a disadvantage. In most cases parents need to act as the child's advocate to ensure suitable education is provided and not all parents are equipped or knowledgeable enough for this task. The majority of the parents in the study were unaware of their children's educational rights.

The negative attitudes of senior school staff towards inclusion is understandable due to the lack of support schools received to teach learners with HFA / AS. Ironically, the Education White Paper 6 (South African Department of Education, 2001b) which set out to change attitudes towards disabilities has in fact created negative attitudes towards inclusion due to the lack of support offered to schools.

The results revealed that ways to overcome the barriers to admission to mainstream schools for learners with HFA / AS, included small classes, attitudinal changes of school staff, educator training, increased funding, teacher training, curriculum adjustments and classroom accommodations and unity between parents and school staff. It was noted that overcoming the barriers would be a slow process. This means current learners with HFA / AS will be disadvantaged for their future.

The support of the government in terms of the district support teams described in the Education White Paper 6 (South African Department of Education, 2001b) was noted to be absent in helping overcome the barriers. A time frame on the implementation of the document objectives was not established. In general the schools were not yet ready for inclusion of learners with HFA / AS.

Although it is the constitutional right of all children in South Africa to receive an education (Constitution of the Republic of South Africa, 1996) it will take more than documented policy to achieve this. For children with HFA / AS in the selected circuits of the Umlazi

schools district, their educational needs are not being met. This is a violation of their and their families' rights. There are several practical barriers to their admission to mainstream government schools, but if the Department of Education, schools, organisations, staff, educators and families join forces, the education of children with HFA / AS can be achieved.

5.2 Limitations

5.2.1 Phase1

The low response rate of 18% (Babbie & Mouton, 2007) for the questionnaires for mainstream government primary schools in two circuits of the Umlazi school district is a limitation to the study. This impacts the study in that the results cannot be generalised to a greater population (Gravetter & Forzano, 2010). The results are therefore interpreted within the context presented. This limitation could be addressed in future studies by using a research team of people who could personally collect questionnaires from schools as this method yielded the greatest return of questionnaires.

Likewise, since this is a descriptive study, it is limited in that it will not have external validity, meaning the results cannot be generalised to a greater population (Gravetter & Forzano, 2010). Due to the financial and time restrictions of this study conducting an equivalence study to test reliability or to use the test- retest method to establish reliability was not possible. The extent to which this study could be replicated over time (Cohen et al., 2007) is therefore limited. However, since inclusion of students with HFA / AS in mainstream government schools is not widely practiced and the teaching experience of mainstream educators in the field of ASD is narrow, it would not be impossible that a similar study may reveal results similar to those in this study. The pilot study was limited in that only two people were used to pilot the questionnaire.

Convenience sampling was used for Phase 1, the quantitative component of the study. This holds the potential for researcher bias as the researcher was familiar with some of the schools and was aware of some of the challenges some of the schools in the target areas experienced regarding inclusion. Additionally convenience sampling and can be considered a weak sampling method (Gravetter & Forzano 2010). These potential limitations were addressed by utilising a cross section of schools in the target population i.e. schools ranged in resources from affluent areas to rural areas, schools were single sex schools; boys only and girls only as well as mixed gender schools and schools ranged in grades offered such as grades 1-3 other grades 4-7 and others grades R-7. Therefore, the sample was reasonably representative and not strongly biased.

5.2.2 Phase 2

Using only one focus group could be regarded as a limitation to a study, as typically research studies consist of three to six focus groups from which data are collected (Onwuegbuzie & Collins, 2007; Stewart, 2007). This study, however, followed a mixed methods design (Vaughn et al., 1996; Delpont & Fouche' 2011) and therefore only one focus group was conducted (Stewart, 2007). The interview schedule was piloted by one person: this could be a limitation of the study.

A second potential limitation for Phase 2 could be seen as the number of participants in the focus group. The focus group consisted of five participants and not the recommended number of six (Vaughn, et al., 1996; Stewart, 2007; Tashakkori & Teddlie, 2010). Vaughn, et al. (1996) and Stewart (2007) present this as a limitation as it holds the potential for one or two participants to dominate the discussion or for long pauses and poor dialogue to occur during the focus group. The discussion in this study was stimulating and no one participant dominated the conversation (Vaughn et al., 1996; Stewart, 2007), thus making the limitation of one less participant insignificant. With one participant less than the typical number of six,

there was in a benefit experienced as each participant had greater opportunity to contribute to the discussion and in greater depth. Focus groups have been successfully conducted with as few as two participants (Peek & Fothergill, 2007) or three participants (Pugsley, 1996).

The focus group consisted of only female participants, which in some studies is a limitation. A mixed gender representation in a focus group has been known to provide a different dynamic than a single gender meeting and often different outcomes of the discussion result in mixed gender focus groups (Stewart, 2007). However, if the outcomes of the focus group are consistent with the aims and objectives of the study, a homogenous group is not problematic (Stewart, 2007). Participants do not need to be representative of the population in all respects. They need only be representative in issues which are relevant and substantial to the study (Babbie & Mouton, 2007). In this case the gender of the participants i.e. of parents of children with HFA / AS would not affect whether a child would be admitted into mainstream schools. That would be dependent on the school policy and educational policy of the country (Jordan & Jones, 1999; Jordan, 2012; Siewe, 2012). Phase 2 may also have been limited in that all participants who responded to the invitation were English speaking. The Autism support groups from which the participants were sourced comprised a wide cross section of people of different races, financial standings, ages and languages and not all aspects were represented in those who responded to participate in the study.

A potential limitation of using the focus group facilitator could be a lack of training in the field of HFA / AS, however administering the interview schedule was done successfully.

The potential limitation of researcher bias for the autoethnographic essay was discussed in Chapter Three, section 3.8.1., Personal considerations.

5.3 Recommendations

High Functioning persons being diagnosed under the recently released DSM-5 (APA, 2013) will no longer receive the diagnosis of Asperger's Syndrome. They may now receive the diagnosis of Autism Spectrum Disorder. This may cause further confusion for mainstream school admissions, especially in the presence of Asperger's Syndrome still being an active diagnosis according to the ICD-10 (WHO, 2000). The recommendations in this study emerged in response to the results for learners with HFA / AS but will still apply to learners with Autism Spectrum Disorder in the future. In order for mainstream schools to become better prepared for the inclusion of learners with HFA / AS and for the barriers to admission to those mainstream schools to be reduced, the following recommendations are made.

- The implementation of a specific screening tool, for example but not limited to, the ASSQ (Ehlers,1999) to be used by district support teams or in their current absence, by schools, as a standard measure to distinguish between learners with Classic Autism and those with HFA / AS. Learners with HFA / AS would not be admitted or rejected into mainstream schools by subjective views. For those diagnosed with Autism Spectrum Disorder (APA, 2013) in the future, appropriate screening tools should be used.
- Attention should be given to addressing the attitudes of senior staff members towards inclusion of learners with HFA / AS. This could be done by means of mainstream schools partnering with special needs schools (in the absence of district support teams). Similarly attitudes towards Autism Spectrum Disorder will need to be addressed.
- In order for positive attitudes towards inclusion to be adopted from a governmental level, recognition in departmental newsletters and on governmental websites is

recommended for schools and teachers embracing mainstream education for learners with HFA / AS. In the future this would also apply to schools and teachers working with learners with Autism Spectrum Disorder.

- Addressing community attitudes is achievable by schools participating in initiatives promoted by ASD resource organisations, such as *the Light it Up Blue* campaign publicised by Autism South Africa. Participating persons and organisations around South Africa dressed in blue and decorated their facilities in blue, the colour chosen to represent Autism, to show support of those with ASD and to raise awareness (Autism South Africa, 2012). Attitudes may also be addressed by schools highlighting famous adults with HFA / AS who have contributed to society. It is recommended that this is done during April, which is Autism awareness month.
- Partnerships need to be established between parents of learners with HFA / AS and educators for the common goal of the learners' educational progress. This is achievable by means of regular scheduled meetings between the parties as well as attendance for both parties at support group meetings (de Nysschen, 2008; Inclusion International 2009). Likewise for learners diagnosed with Autism Spectrum Disorder in the future, partnerships between parents and educators would be necessary.
- Networking and collaborative meetings between mainstream schools which are attempting inclusion of learners with HFA / AS but are ill-prepared to do so, would assist with brainstorming solutions and sharing of successful teaching methods. In the future this would include learners with Autism Spectrum Disorder (Inclusion International 2009).
- It is recommended that the South African Department of Education start with implementing the Education White Paper 6 (South African Department of Education, 2001b) with a single school and grow the programme school by school (UNESCO

2003). This will make for manageable budget adjustments, rather than delaying the implementation of the program due to huge financial outlay to implement it as a whole, resulting in the delay of the start of the program altogether.

- The development and implementation of district support teams is an urgent recommendation for the success of inclusion of learners with HFA / AS in the selected circuits of the Umlazi school district and in South Africa as a whole.
- Classroom adjustments including social skills, visual materials, a structured approach to learning, teaching on life skills, support with group work or class discussion and the implementation of Individualised Education Programs (I.E.P.s) is recommended.
- In the absence of training provided by district support teams, teacher training in the following forms is recommended: Attendance at support group meetings run by local Autism resource groups, on line learning, training DVDs on HFA / AS, mentoring by experienced teachers at special needs schools who work with learners with HFA / AS.
- To address the need for teacher training, the requirement of continued professional development (CPD) for educators on the topic of HFA / AS is recommended to be instituted by the South African Department of Education. This may follow the guidelines of the HPCSA (2013) where professionals are required to obtain a specified number of CPD points for training attended on an annual basis (Government of South Australia, 2006).
- Teacher support in the form of class assistants or facilitators for the child with HFA / AS is recommended (de Nysschen, 2008). In the absence of government funding, volunteers from the community could be requested. Alternately teacher training policy could be altered to include a practical component for student teachers in an inclusive classroom as a class assistant. Parent funded facilitators could be

utilised in classrooms following models used in other countries (United States Department of Education, 2004; Inclusion International, 2009)

5.3.1 Recommendations for further research

This study may form a platform from which further research in the field may be pursued.

Recommendations for further research are given below.

- Objective 5, to determine the current numbers of learners with HFA / AS admitted into mainstream primary schools in a specific population was not achieved in this study. This means the current numbers of learners with HFA / AS in the selected circuits of the Umlazi school district are still unknown. Further research to establish these numbers is recommended in all areas of KZN and South Africa.
- This study focused on government primary schools in the target area and the related difficulties of inclusion of learners with HFA / AS. Data collected therefore did not include the needs of high school learners with HFA / AS. Research into the educational needs and provisions for high school learners is therefore recommended.
- Further in depth study is recommended in private schools in South Africa where inclusion of learners with HFA / AS is currently successfully implemented. A possible practical model for inclusion could be developed to give district support teams an outline of the practical needs of inclusion of learners with HFA / AS into mainstream government schools.
- A tracer study is recommended to determine what occurs to learners with HFA / AS after leaving school in terms of future education, employment and independent living.
- Since the establishment of district support teams needed to assist teachers working with learners with HFA / AS is not yet realised in the target area, research into the

possibility of existing special needs school staff mentoring mainstream school staff in teaching learners with HFA / AS is recommended.

- In the absence of a specific curriculum for learners with HFA / AS in mainstream schools in the target area, it is recommended that future studies are used to develop such a curriculum, which would also include learners with Autism Spectrum Disorder in the future.
- Study into developing standard admission methods and therefore admission policies for mainstream government schools is recommended.

5.4 Summary of Chapter Five

In Chapter Five the main research results concerning barriers to admission to mainstream primary schools for learners with HFA / AS were presented. The limitations of the study were discussed and recommendations as a result of the study were raised. Specific recommendations for schools and the South African Department of Education to employ in order to successfully implement inclusion of learners with HFA / AS were made. Lastly, recommendations for further study were given. It is hoped that parents experiencing difficulties in enrolling their children with HFA / AS into mainstream schools may have a basis for stimulating re-consideration of entry criteria outlined by the management of the schools concerned as a result of this study.

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APPENDICES
APPENDIX A: Descriptive Questionnaire



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**INYUVESI
YAKWAZULU-NATALI**

Phindile Nene, Postgraduate Officer, School of Health Sciences, Westville Campus, 031 2608280

Questionnaire regarding barriers to mainstream primary school education for children with High Functioning Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) and Asperger's Syndrome (Collectively here referred to as High Functioning Autism/Asperger's Syndrome HFA / AS).

This questionnaire is for completion by the school Principal, Deputy Principal or Head of Department only.

Dear School Principal, Deputy Principal or Head of Department

Thank you for taking time to complete this questionnaire. Please answer by marking with an X or by filling in your answer as applicable.

Would your school like feedback about this study when it is completed?

Yes	
No	

If yes, please give school address and email

Section A

1. Position held at the school

Principal	
Deputy Principal	
Head of Department	

2. Age

3. Number of years of teaching experience

4. Describe what was included in your teacher training curriculum with reference to High Functioning Autism / Asperger's Syndrome

Section B

5. Type of school

Public	
Private	

6. Is this a mainstream primary school?

Yes	
No	

7. Which grades does your school offer? Mark all which apply

R	1	2	3	4	5	6	7

8. How many children do you have in your school?

9. How many children do you have on average per class?

10. Structure of school

All boys	
All girls	
Boys and girls	

11. a) Does your school have class assistants?

No	Yes	Number

b) Does your school have support staff? (Remedial teachers and / or therapists)

No	Yes	Number

c) If yes, please specify who pays the support staff

	Government funded	School funded	Parent funded
Occupational therapist			
Speech therapist			
Remedial teacher			
Psychologist			
Class assistants			
Other _____ Please state what type of support staff			
Other _____ Please state what type of support staff			

Section C

12. Do you currently have children with any of the following conditions in your school?

If yes, please specify numbers

	No	Yes	Number
High Functioning Autism			
PDD-NOS			
Asperger's Syndrome			
Don't know- some suspected but undiagnosed			

13. Have you had children with the below mentioned conditions in your school in the past 5 years? If yes, please specify how many and when

	No	Yes	Number	Year
High Functioning Autism				
PDD-NOS				
Asperger's Syndrome				
Don't know- some suspected but undiagnosed				

14. If you currently have or have had in the past, children with Autism, PDD-NOS or Asperger's Syndrome in your school, please answer the following questions a)-e). If not, continue from question 15.

a) My teaching staff report that having children with HFA / AS in the school was/ is ...

	Yes	No	Don't know
Difficult for the teachers			

b) My teaching staff report that having children with HFA / AS in the school was/ is ...

	Yes	No	Don't know
A growing experience for teachers			

c) My teaching staff report that having children with HFA / AS in the school was/ is ...

	Yes	No	Don't know
A drain on the teachers' time			

d) My teaching staff report that having children with HFA / AS in the school was/ is ...

	Yes	No	Don't know
A opportunity for other learners to understand those who are different			

e) My teaching staff report that having children with HFA / AS in the school was/ is ...

	Yes	No	Don't know
Problematic for other learners			

Please give reasons for your answers

a)

b)

c)

d)

e)

f) Please add any additional information about your experience of children with HFA / AS in your school

15. Have you ever discouraged or declined an application to your school to a child with HFA / AS?

No	Yes	Number

If yes, please specify why. Mark all which apply

Our staff not trained to teach children with HFA / AS	
Our staff do not know what HFA / AS is	
Class size too big to accommodate learning styles of children with HFA / AS	
We hold a high educational standard therefore cannot risk enrolling learners who may not meet our standard	
The children with HFA / AS do not cope socially	
We are concerned about bullying	
We have had poor experiences with children with HFA / AS in our school in the past	
Parents of children with HFA / AS are potentially too demanding	
Other, please specify	

Section D

16. If you do not currently have children in your school with HFA / AS please specify why, mark all which apply

No applications made for children with HFA / AS	
We do not know what HFA / AS is	
Our staff not trained to teach children with HFA / AS	
Class size too big to accommodate learning styles of children with HFA / AS	
We hold a high educational standard therefore cannot risk enrolling learners who may not meet our standard	
The children with HFA / AS do not cope socially	
We are concerned about bullying	
We have had poor experiences with children with HFA / AS in our school in the past	
Parents of children with HFA / AS are potentially too demanding	
Other, please specify	

17. Have you had a learner/s with HFA / AS in your school in the past who you asked to leave the school?

Yes	
No	

If yes, please specify why

18. Have you had a learner/s with HFA / AS in your school in the past who have chosen to leave your school of their own accord?

Yes	
No	

If yes, please specify why

19. We would accept children with HFA / AS into our school if... Please mark all which apply

we had class assistants	
the parents provided a personal facilitator for the child	
we had more government funding	
there were training courses our teachers could attend	
the children did not have behavioural issues	
we had therapists employed at the school to give support	
we assessed the child to be suitable for our school	
Other, please specify _____	

20. What screening method do you use to determine suitability of admission of a child with HFA / AS to your school? Please mark all which apply

a) None	
b) Interview with parents	
c) Interview with child	
d) Performance test	
e) Report from previous school	
f) Observation of behaviour	
g) Other, please specify _____	

21. a) For each method marked above, indicate what criteria you apply to the screening methods

b) Interview with parents (for example are there specific questions asked, if so please list)

c) Interview with child (for example are there specific questions asked, if so please list)

d) Performance test

e) Report from previous school

f) Observation of behaviour (for example which behaviours would deem a child suitable or unsuitable for your school. If so please list)

g) Other

Section E

22. I feel the learning environment most suited to a child with HFA / AS is...

a special needs school	
a remedial school	
a mainstream school	
home school	
private school	
Children with HFA / AS cannot learn	

23. Indicate which of the following you understand to describe High Functioning Autism/ Asperger's syndrome. Please mark all that apply

Poor social skills	
Poor concentration	
Behavioural issues	
Self injury	
Inability to follow instructions	
Inability to communicate	
High intelligence	
Sensory issues	
Inability to make friends	
Inability to make eye contact	
Poor imaginative skills	
Flapping of hands, spinning in circles, rocking their bodies	
Have obsessive interests	
Low Intelligence	
Poor reading comprehension	
Violence	
Learning problems	
Peer appropriate cognitive skills	
Good maths skills	
Emotional outbursts for minor incidents	
Honesty	
Have attention to detail	
Unable to learn	

Other, please specify

Section F

24. What do you understand inclusion to mean according to the Government White Paper 6?

25. Has the Department of Education provided your staff with continuing professional development training on High Functioning Autism/ Asperger's Syndrome?

Yes	
No	

If yes, what type of training and when?

26. Have your staff attended training on High Functioning Autism/ Asperger's Syndrome provided by parties other than the Department of Education?

Yes	
No	

If yes, what type of training and when?

27. Would you like your staff to attending training on High Functioning Autism/ Asperger's Syndrome if it were offered?

Yes	
No	

28. Any other comments you would like to add?

Thank you for participating in this study

APPENDIX B: Letter of Approval, Ethics Committee of the School of Health Sciences at the University of Kwazulu-Natal (Westville)



25 January 2013

Mrs Carryn Wendy Collins 911337591
School of Health Sciences
Westville Campus

Dear Mrs Collins

Protocol reference number: HSS/0008/013M
Project title: Barriers to admission to mainstream primary schools for children with High Functioning Autism / Asperger's Syndrome (Umlazi district)

Provisional approval - Expedited

This letter serves to notify you that your application in connection with the above has been approved, subject to necessary gatekeeper permissions being obtained.

This approval is granted provisionally and the final approval for this project will be given once the above condition has been met. Please quote the above reference number for all queries/correspondence relating to this study.

Kindly submit your response to the Chair: Prof. S Collings % Ms. P Ximba, Research Office as soon as possible

Yours faithfully

Professor Steven Collings (Chair)
Humanities & Social Sciences Research Ethics Committee

/px

cc Supervisor Jenny Pahl
Dr Carolyn Turnbull-Jackson
cc Academic leader Professor J van Heerden
cc School Admin. Ms P Nene

Professor S Collings (Chair)
Humanities & Social Sc Research Ethics Committee
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban, 4000, South Africa
Telephone: +27 (0)31 260 3587/8350 Facsimile: +27 (0)31 260 4609 Email: ximbap@ukzn.ac.za / snymanm@ukzn.ac.za
Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

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APPENDIX C: Letters of Permission and Approval, KZN Department of Education



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Phindile Nene, Postgraduate Officer, School of Health Sciences, Westville Campus, 031 2608280

1 Rhodes Ave
Glenwood
Durban
4001

15 February 2013
KZN Department of Education
247 Burger Street
Pietermaritzburg
3200

Umlazi District Head: Mr. Sibusiso Alwar
Dear Mr. Alwar

Permission to conduct a Masters research study in mainstream primary schools in the Chatsworth and Durban Central circuits of the Umlazi school district.

Barriers to admission to mainstream primary schools for children with High Functioning
Autism / Asperger's Syndrome

I am a Postgraduate student currently undertaking a Master of Medical Sciences degree in
Autism Spectrum Disorders at the University of KwaZulu-Natal (Westville Campus). This study
has received ethical clearance from the Humanities and Social Sciences research ethics
committee. Clearance number: HSS/0008/013M Please see attached copy of the letter.

My dissertation concerns the barriers to admission to mainstream primary schools for children
with High Functioning Autism, Asperger's syndrome and Pervasive Developmental Disorder -
Not Otherwise Specified, in the above mentioned school

circuits. These conditions will be collectively referenced as HFA / AS. HFA / AS refers to
children who experience social, communicative and behavioural difficulties, but have average or
above average IQs, who may attend mainstream schools. Many parents of children with HFA /
AS desire their children to attend mainstream schools, but experience difficulty in being granted
access to the mainstream schools which are appropriate to their children's education.

The research aims to explore what the barriers to acceptance into mainstream schooling are for
children with HFA / AS as well as to gain information from the schools which will assist in
understanding how the barriers can be overcome. The results of the study will be of value to the

Department of Education in reinforcement of the White Paper 6, to allow access to mainstream schooling for children with peer level cognitive skills. Exploring these barriers could assist the Department of Education with school and teacher planning for future enrolment of children with HFA / AS into mainstream schools. In addition information on the type of support or school preparation needed to include children with HFA / AS into mainstream schools will be obtained through this study.

I would greatly appreciate your permission to conduct this study by means of administering questionnaires to schools in the Chatsworth and Durban Central circuits of the Umlazi school district. The questionnaires will be either posted, hand delivered or sent electronically to the schools depending on the location of the schools and the access to the internet. The questionnaire will be completed by either the Principal, Deputy Principal or a Head of Department at each primary school in the Chatsworth and Durban central circuits. The questionnaire will take 10-20 minutes to complete and will not cause any disruption to the school schedule.

All contact information obtained from the questionnaires will be kept confidential and no names of schools, Principals or other individuals will be made public. Schools and staff members will be represented by code numbers only. Electronic data collected will be stored on a password protected computer and data collected in hard copy will be stored in a locked storage device and all will be destroyed after five years by deletion or shredding respectively.

I would be most grateful for your assistance in this matter. Should you require further information regarding this study, please contact me or the supervisors listed below:

Yours sincerely



Carryn Collins

B. SocSci (Psy)
Email: 911337591@stu.ukzn.ac.za
Telephone: 0761918332
1 Rhodes Ave,
Glenwood
Durban
4001

Ms. J.A. Pahl
Research Supervisor
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Email: pahlj@ukzn.ac.za
Fax: 031 2608984
Telephone: (031) 260 7624

Dr C.J.A. Turnbull-Jackson
Research Co-Supervisor
B.A(UN).; B.Ed(Hons)(UN).; U.E.D(UN).; M.Tech(Education)(DIT);
D.Tech(Education)(DIT);Assessment Competency Certificate(SAQA Unit ASSMT01)(BSU,DIT);
T.V.Arts Certificate(TN)

Email: carolyntj@telkomsa.net;
Telephone: cell 0836989557

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Postgraduate Officer
School of Health Sciences
Westville Campus
031 2608280
Nenep1@ukzn.ac.za



education

Department:
Education
PROVINCE OF KWAZULU-NATAL

Enquiries: Sibusiso Alwar

Tel: 033 341 8610

Ref:2/4/8/346

Mrs C Collins
1 Rhodes Avenue
Glenwood
DURBAN
4001

Dear Mrs Collins

PERMISSION TO CONDUCT RESEARCH IN THE KZN DoE INSTITUTIONS

Your application to conduct research entitled: **BARRIERS TO ADMISSION TO MAINSTREAM PRIMARY SCHOOLS FOR CHILDREN WITH HIGH FUNCTIONING AUTISM/ASPERGER'S SYNDROME (UMLAZI DISTRICT)**, in the KwaZulu-Natal Department of Education Institutions has been approved. The conditions of the approval are as follows:

1. The researcher will make all the arrangements concerning the research and interviews.
2. The researcher must ensure that Educator and learning programmes are not interrupted.
3. Interviews are not conducted during the time of writing examinations in schools.
4. Learners, Educators, Schools and Institutions are not identifiable in any way from the results of the research.
5. A copy of this letter is submitted to District Managers, Principals and Heads of Institutions where the intended research and interviews are to be conducted.
6. The period of investigation is limited to the period from 01 March to 30 September 2013.
7. Your research and interviews will be limited to the schools you have proposed and approved by the Head of Department. Please note that Principals, Educators, Departmental Officials and Learners are under no obligation to participate or assist you in your investigation.
8. Should you wish to extend the period of your survey at the school(s), please contact Mr. Alwar at the contact numbers below.
9. Upon completion of the research, a brief summary of the findings, recommendations or a full report / dissertation / thesis must be submitted to the research office of the Department. Please address it to The Director-Resources Planning, Private Bag X9137, Pietermaritzburg, 3200.
10. Please note that your research and interviews will be limited to schools and institutions in KwaZulu-Natal Department of Education (Umlazi District).

Nkosinathi S.P. Sishi, PhD
Head of Department: Education
Date: 11 June 2013

KWAZULU-NATAL DEPARTMENT OF EDUCATION

POSTAL: Private Bag X 9137, Pietermaritzburg, 3200, KwaZulu-Natal, Republic of South Africa

PHYSICAL: 247 Burger Street, Anton Lembede House, Pietermaritzburg, 3201. Tel. 033 392 1004 Fax: 033 392 4203
EMAIL ADDRESS: Kehlogile.connie@kzndoe.gov.za; CALL CENTRE: 0860 596 363; beyond the call of duty

WEBSITE: www.kzndoe.gov.za

APPENDIX D: Letter of Information and Informed Consent for School Staff



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Phindile Nene, Postgraduate Officer, School of Health Sciences, Westville Campus, 031
2608280

1Rhodes Ave
Glenwood
Durban
4001

18 February 2013

Dear Principal/ Deputy Principal / Head of Department

Postgraduate research study on High Functioning Autism and mainstream Inclusion

I am a Postgraduate student currently undertaking a Masters of Medical Sciences degree in Autism Spectrum Disorders at the University of KwaZulu-Natal (Westville Campus). My dissertation concerns the barriers to mainstreaming children with High Functioning Autism, Asperger's Syndrome and Pervasive Developmental Disorder - Not Otherwise Specified in the Chatsworth and Durban Central circuits of the Umlazi school district. These conditions will be collectively referenced as HFA / AS. HFA / AS refers to children who experience social, communicative and behavioural difficulties, but have average or above average IQ who may attend mainstream schools. This study has received ethical clearance from the Humanities and Social Sciences research ethics committee. Clearance number: HSS/0008/013M. Please see attached copy of the letter.

The research aims to explore what the barriers to acceptance into mainstream schooling are for children with HFA / AS as well as to gain information from the schools, such as experiences the schools have had with children with HFA / AS and what type of support or training the schools feel they need to educate children with HFA / AS. The study also seeks to explore possible ways to overcome these barriers.

Involvement in this study is voluntary, and all information will be treated in a confidential manner. The study will in no way negatively affect your school or you as a person, since the identification of the school and participants will be kept confidential. Schools and staff members will be represented by code numbers only. Should you

decide to participate in this study, you may withdraw from it at any time without consequence.

Your participation would be greatly appreciated. Should you wish to receive feedback about the study after its completion please indicate so on the questionnaire in the space provided.

Please find a questionnaire attached as well as a consent form. Should you wish to participate in this study, please complete both attachments. The questionnaire will take 10-20 minutes to complete. They may be returned via the self addressed envelope or via electronic mail to 911337591@stu.ukzn.ac.za. Questionnaires may also be collected by me in some cases. Please return them by 21 July 2013. Electronic returns will be kept in a password protected computer and hard copies will be stored in a locked filing unit. Both will be destroyed after five years. Should you choose to participate in this study, kindly retain this letter for your own reference.

Thank you for considering participating in this study. Your involvement will be greatly appreciated. For further information, please contact me, my supervisors or the school of Health Sciences UKZN research office listed below:

Yours sincerely



Carryn Collins
B. SocSci (Psy)
Email: 911337591@stu.ukzn.ac.za
Telephone: 0761918332
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Phindile Nene, Postgraduate Officer, School of Health Sciences, Westville Campus, 031
2608280

1Rhodes Ave
Glenwood
Durban
4001

Title of Research study: Barriers to admission to mainstream primary schools for
children with High Functioning Autism / Asperger's Syndrome (Umlazi district)

DECLARATION OF INFORMED CONSENT

Questionnaire

I consent to participate in this study voluntarily and understand my rights as a participant.

I understand the purpose of this study and I commit to complete the questionnaire with
accurate information. I understand that I can withdraw from participating in the study at any
time without penalty.

Signature of participant

Date

Signature of Witness

Date

APPENDIX E: Biographical Questionnaire for Focus Group,
Invitation, Interview Schedule and List of Discussion Questions
Sent to Participants



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YAKWAZULU-NATALI

1Rhodes Ave
Glenwood
Durban
4001

16 September 2013

Dear Parent / Guardian,

I am a Postgraduate student currently doing a Masters of Medical Sciences degree in Autism Spectrum Disorders at the University of KwaZulu-Natal (Westville Campus). This letter explains my research and requests your participation in it. This study has received ethical clearance from the Humanities and Social Sciences research ethics committee (Clearance number: HSS/0008/013M) as well as approval from the Department of Education.

Research Title: Barriers to admission to mainstream primary schools for children with High Functioning Autism / Asperger's Syndrome

What is this study about?

My study concerns the barriers to admission to mainstream government primary schools for children with High Functioning Autism / High Functioning PDD-NOS / Asperger's Syndrome (referred to here as HFA / AS) in the Chatsworth and Durban Central circuits of the Umlazi school district. As parent or caregiver of a child with HFA / AS your experiences of enrolling or attempting to enrol your child into a mainstream government primary school would assist me in exploring what the barriers are and give insight into attempting to overcome these barriers.

Who can participate in this study?

Parents / caregivers of children diagnosed with Asperger's Syndrome, Autism or PDD-NOS who present as high functioning are invited to participate in this research study. If you have enrolled your child with HFA /AS into a mainstream government primary

school or have attempted to do so and been unsuccessful in the past 5 years you are eligible to participate in this study. Additionally the child must have been between the ages of 4.5 years and 12 years at the time of enrolment or attempted enrolment.

What will I be asked to do if I agree to participate?

There will be a group interview with other parents or caregivers of children with HFA / AS, where you will be asked to talk about your experiences with mainstream schooling for your child with HFA / AS. The questions/topics will be forwarded to you before the group meets in order to help you prepare for the discussion. The group interview will be recorded using a digital video recorder as well as an audio recorder in order to process the data later. The group will be facilitated by Dr. Kathleen Collins.

Would my participation in this study be kept confidential?

All personal information will be treated in a confidential manner. The study will in no way negatively affect you as a person, since your identification, that of your child and the names of the schools will be kept confidential. Participants and schools will be represented by code numbers only. All data will be kept in a password protected computer and hard copies will be stored in a locked filing unit. Both will be destroyed after five years by deletion and shredding respectively. The recording of the group interview will not be made available to anyone outside of the research process. This too will be deleted after five years.

What are the benefits of this research?

It is hoped that by exploring the barriers to admission to mainstream education for children with HFA / AS means to overcoming these barriers may become possible in the future for other children with HFA /AS. A copy of this study has also been requested by the Department of Education once it is completed.

Do I have to be in this research and may I stop participating at any time?

Involvement in this study is voluntary. Should you decide to participate in this study, you may withdraw from it at any time without consequence.

What if I have questions?

If you have questions you can contact myself, my supervisors or the research department at the UKZN, for whom all the details are listed below.

Should you wish to participate in this study, please reply to this email or contact me via the contact information give below. Your involvement will be greatly appreciated.

Yours sincerely



Carryn Collins

B. SocSci (Psy)

Email: tothefull@gmail.com

Telephone: 0761918332

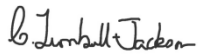
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ASSMT01)(BSU,DIT); T.V.Arts Certificate(TN)
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INYUVESI
YAKWAZULU-NATALI

Invitation: Discussion group

Parents / Guardians of children with High Functioning Autism, High Functioning PDD-NOS and Asperger's Syndrome, you are invited to share your experiences in admitting or attempting to admit your children with High Functioning Autism, High Functioning PDD-NOS or Asperger's Syndrome into mainstream government primary schools. This discussion group forms part of a research study, please see the attached letter for more information.

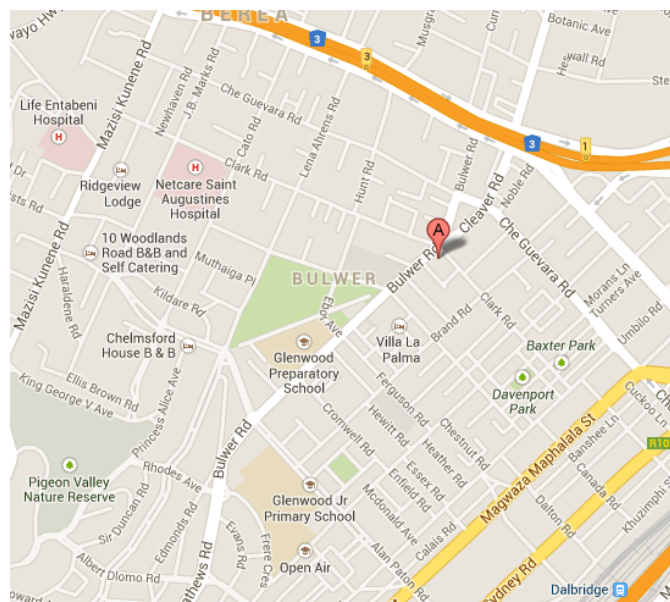
Date: 5 October 2013

Time: 10am to approximately 11am- 11:30am

Place: Glenwood Community Church, corner of Clark and Bulwer roads, Glenwood (entrance in Clark Rd)- see map below

RSVP to Carryn Collins on 0761918332 or email tothefull@gmail.com

Participants will receive a free DVD on Autism Spectrum Disorders in South Africa and transport costs will be reimbursed. Refreshments will be provided.





Thank you for participating in this focus group. Please complete this short questionnaire before we start the discussion.

Please mark with an X where applicable

1. Regarding a child with High Functioning Autism, Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) or Asperger's Syndrome I am a:

Parent	
Guardian	
Other Please specify	

2. Age of child: _____

3. Child's diagnosis _____

4. Diagnosed by: Please mark all which apply

Paediatrician	
Psychologist	
Doctor, GP	
Neurologist	
Other, please specify	

5. Current school grade of child: _____

6. My child is currently:

homeschooled	
In a government school	
In a private school	
Other, please specify	

7. In which year/s did you apply to a mainstream school /s for your child with High Functioning Autism / Asperger's Syndrome or High Functioning PDD-NOS?

8. At how many schools were applications made? _____

9. Was your application successful?

yes	
no	

10. Which circuit and school district was the school in? _____

11. Would you like feedback about the study on its completion?

yes	
no	

If yes please provide your email address or postal address below



Interview schedule

1. Introduction

Introduce yourself (focus group facilitator), invite participants to help themselves to refreshments and point out where the bathrooms are.

Thank you for agreeing to participate. I am very interested to hear about your experiences in enrolling or attempting to enrol your children with HFA / AS into mainstream government primary schools. This discussion will provide invaluable information about what the barriers to admission to mainstream education for children with HFA / AS are, as well as explore possible ways these barriers to admission may be overcome.

In focus groups, there are no incorrect answers. I want to hear from all present, so please don't hesitate to add your view to the discussion. I will be facilitating the session and keeping the discussion active so that we touch on all key points. If I feel we are getting bogged down on topics that don't support the main issue which is barriers to admission to mainstream education for children with HFA / AS, I will move the discussion on. My role today is to facilitate the group's experiences and to see that we have a fruitful discussion.

- The purpose of this study is to determine and explore barriers to admission to mainstream primary schools for children with High Functioning Autism / Asperger's Syndrome in the Durban central and Chatsworth circuits of the Umlazi school district.
- We will not disclose your name, the name of your child or the names of any schools or school staff mentioned during the focus group. That will be kept confidential. We would also ask that you in turn will respect the confidentiality of the other participants present.
- We will be recording the discussion so that we can accurately capture the experiences and opinions presented. No names will be attached to the recording of the focus groups and the recordings will be destroyed after 5 years.
- You may refuse to answer any question or withdraw from the study at anytime without penalty.
- If you have any questions following this focus group you may contact Mrs. Carryn Collins who is conducting this study. Alternately you can contact one of her

research supervisors Ms. J.A. Pahl or Dr. Carolyn Turnbull-Jackson whose contact details appear on your copy of the consent form.

- Please complete the brief biographical questionnaire provided and sign the consent form to show you agree to participate in this focus group and to be recorded before we get started.

2.Interview

1. As parents of children with HFA / AS you will be very familiar with the condition, let's start off our discussion by talking about the characteristics of HFA / AS as you understand them.

Probe questions: Describe how your child presents at home. What can you describe as benefits and challenges of HFA / AS?

2. All parents deal with the issue of education for their children. As parents of children with HFA / AS I am interested in your experiences in getting your children admitted into primary schools. For some of you that will be mainstream government schools, for others the reasons why mainstream government schools were not selected are also valuable. Tell me about those experiences.

Probe question: Tell us about why your application for admission to a government mainstream school was declined.

3. Describe the screening process used to determine your child's suitability or lack of suitability for the mainstream primary school?

Probe question- Tell us about any special requirements requested by the mainstream school in order to consider your child's application.

4. Tell us about the reported experiences from the teachers working with your children with HFA / AS in mainstream government schools.

Probe question- How would you describe the teachers' experiences and please give examples.

Please describe any action which was necessary following the teachers' reports of teaching your child with HFA / AS

5. Tell us about the learning environment you feel is best suited to a child with HFA / AS and why.

Probe question- There are various schooling options in South Africa such as private schools, remedial schools, home school etc. Explain why you feel one setting would be better than another for children with HFA / AS.

How do you feel about special needs schools for children with HFA / AS?

6. What do you feel would make for suitable education at a mainstream government primary school for children with HFA / AS?
Probe question- What suggestions do you have to make schooling for children with HFA more appropriate in these mainstream schools?

7. What do you feel is important for parents of children with HFA / AS to offer the teachers and schools who work with children with HFA / AS?
Probe question- What suggestions do you have for offering support to teachers and schools who admit children with HFA / AS?

8. How do you understand your child with HFA / AS's educational rights in terms of the government White Paper 6?

9. Let's talk about any additional barriers to mainstream primary school education for children with HFA / AS.

10. What else would you like to add to the discussion?

3. Conclusion

That concludes our focus group. Thank you so much for giving up your time to come and share your experiences with us. If you have anything else you would like to add which we did not have time for, please contact Mrs. Collins or to one of her supervisors, either Mrs. Jenny Pahl or Dr. Carolyn Turnbull-Jackson. You will find all contact information on your copy of the consent form.

Thank you for your participation.



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The areas below will be discussed with reference to Asperger's Syndrome, High Functioning Autism and High Functioning PDD-NOS, collectively referred to as High Functioning Autism/ Asperger's Syndrome (HFA / AS). The group will be facilitated by Dr. Kathleen Collins BA(SW) BA(Hons)(SW) MA(SW) (Stell) PhD(Wits).

Areas for discussion:

- Characteristics of HFA / AS
- Experiences in admitting your child to a mainstream Government primary school or attempting to do so
- Screening used by mainstream government primary schools for admission of your child
- Educator's experiences of teaching your child with HFA / AS
- Best educational environments for children with HFA / AS
- What is needed to accommodate children with HFA / AS in mainstream government primary schools?
- Parental involvement at mainstream government primary schools admitting with HFA / AS
- The White Paper 6 and HFA / AS

APPENDIX F: Informed Consent Form for Focus Group Participants



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Title of Research study: Barriers to admission to mainstream primary schools for children with High Functioning Autism / Asperger's Syndrome (Umlazi district)

DECLARATION OF INFORMED CONSENT

Focus group

This study has been explained to me and I have had an opportunity to ask questions. I understand the purpose of this study and understand my rights as a participant. I understand that I can withdraw from participating in the study at any time without penalty. I commit to complete the questionnaire and participate in the group discussion with accurate information.

I consent to participate in this study

yes	<input type="checkbox"/>
no	<input type="checkbox"/>

voluntarily.

I give my consent for the discussion to be recorded using a digital video recorder and audio recorder.

yes	<input type="checkbox"/>
no	<input type="checkbox"/>

Signature of participant

Date

Signature of Witness

Date

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ASSMT01)(BSU,DIT); T.V.Arts Certificate(TN)
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APPENDIX G: Autoethnographic Essay and Analysis by a Senior Academic

Thematic analysis of an auto-ethnographical essay.

The essay, for the purpose of the research, is focused on the researcher's experiences of challenges/hurdles of access to education for a child with HFA. In the description of these experiences, explicit and clear themes emerged. Background /contextual info mentioned in the text, however, also implicitly convey a noteworthy theme because of its interrelatedness to the process and outcome of the researcher's experience.

The themes are presented in a "story-line" format, starting with the contextual experience.

Theme 1: Experiences of access to education for HFA child is a road starting with hope/anticipation for inclusion.

The hope for inclusive education inevitably links to previous experiences of exclusion and policy directives.

The following sub-theme related to previous experience is noteworthy:

Sub-theme 1.1 The **road to access** to education was steep **and proceeded by incidents of social exclusion of the family from a community**

The following quotes are presented to verify this theme:

"We had encounters at a sports club where we were not welcome due to my son's Autism"...

"I have even had my neurotypical (without Autism) son refused entry into a school because of his brother's Autism.

Hope was also related to policy directives as indicated in the following sub-theme

Sub-theme 1.2 Policies **implied/promised access to education**

The first words in the title of the essay "from hope..." reflect the researcher's anticipation of inclusion in the field of education. This hope was not based on just a wish (considering sub-theme 1.1) but on rational expectations as stated in guidelines for inclusive education in South Africa and elsewhere

The following quote illustrates:

"Inclusive education is currently a "hot topic" in South Africa. Moves are being made

to downsize special needs schools and include as many children as is possible in mainstream schools (The South Africa Department of Education, July 2001). Being **a parent of a special needs child, this gives me hopes** for my son”.

Theme 2 **Disillusionment/ harsh realities: The road to inclusive education is steep**

Sub-theme 2.1 **Exclusion experiences - first world experience**

- Open access to public schools but exclusion from Special Education in public schools.
- Denied access in private schools – no staff resources, as rationale.

The following quotes from the essay substantiate these sub-theme categories:

“None of the schools gave any resistance to accepting his application for kindergarten, despite his diagnosis of Autism which accompanied the applications. The public schools in our area in Denver each had a Special Education (Special Ed) unit for children who needed additional support. All sounded perfect, in fact it sounded too good to be true- it was. We were told by each school in turn that since our son had no cognitive delays he did not qualify for any Special Ed support... the policy was not to give any additional support to children who were cognitively able”

“The private school declined our application on the grounds that they did not have Special Ed staff and the teachers did not have experience...”

Sub-theme 2.2 **Exclusion from government and private education: South African experience**

Despite admirable policy directives application for access to mainstream government South African schools and selected private schools were denied.

Compare the following excerpts from the essay

“Before we returned to South Africa I made contact with Autism South Africa to enquire about schooling options for my son. The response was bleak. I was referred to local Autism schools and therapy centres in the greater Durban area, where I was told mainstream government schools would not be accepting of a child with Autism, even High Functioning Autism”.

““Despite my son’s good academic report, no government schools in our area were willing to accept him.

““We tried a private school, which rudely declined the application

Whenever hope was slashed and exclusion/ rejecting was experienced the parent-researcher chose to stand up to it and persevere in her efforts for access

Theme 3: Bouncing back strategies to face the challenges

The essay reflects some of the “bouncing back “strategies (developing resilience) in the researcher’s perseverance for her child’s right to inclusive education.

In the following section, these efforts are best portrayed chronologically and by including longer, explanatory/illuminating narratives from the essay, in italics.

Sub-theme 3.1 Offering and providing professional teacher support when access to Special Education in Public Schools was denied (compare sub-theme 2.2).

“I offered to send my son’s behavioural therapist to accompany him at school at my own cost. This was declined with the response that the schools already had Special Ed staff employed at the school. When I pointed out that my son was denied access to the Special Ed staff due to his cognitive abilities, the schools each assured me that should he fail with school work and fall behind his peers he would at that point be granted access to the support of the Special Ed staff. I found this unacceptable.”

The narrative reflects that the researcher’s offer was not accepted but so also did she not accept the school’s offer that could set up her child for possible experiences of failure/rejection.

The next strategy was to approach a private school

Sub-theme 3.2 Persevering efforts to convince a private school to accept the child - “*the squeaky wheel gets the oil*”.

We were referred back to the public schools, which were “better equipped”. I contested the rejected application for six months. There were ongoing meetings many phone calls and correspondence with the professionals who worked with my son. Feeling this school was the best placement for my son I would not give up and proved true the phrase “the squeaky wheel gets the oil”.”

These efforts of perseverance, resulted in conditional acceptance by the school

Sub-theme 3.3 Providing professional behavioural support and the payoffs of the perseverance and breakthrough

In what I felt was an attempt to keep me quiet the school agreed to accept my son on a trial basis for one term, with the provision of support of his behavioural therapist in the classroom. A breakthrough and the lure of hope placement...

My son excelled at the school with the support of the behavioural therapist who was essential, especially in the first few weeks at the school. As the term progressed her presence and support was faded and the teacher now equipped with skills and strategy managed well and my son was promoted to grade one at the end of the school year. By the end of grade one he was receiving only half an hour of behavioural support and this was at break to assist with interacting with the other children outside of the classroom

Continued resilient behaviour and perseverance strategies for access to SA mainstream schools

Sub-theme 3.4 Calling on family for private school access in SA with rewarding payoffs

Following rejection by both government and private schools in the neighbourhood

the researcher reverted to family contacts for private school access:

In desperation my father who had a business connection with a substitute principal at a private school pleaded on his grandson's behalf for his colleague to give him a chance. My son breezed through the entrance assessment and started at the school and gave support over and above what we expected. They attended training seminars on Autism and promoted his strengths

This “success” story came at a cost that became unbearable for parents

Sub-theme 3.5 Creative efforts and family support in dealing with financial challenges of private schooling for HFA child

We rented out our basement to students in order to afford the school fees as well as made an application for a scholarship to the school and received a reduction on the fees.

All the while granny was assisting with the expensive school fees. After 3 years at the school, Granny retired and we could no longer afford the school fees. We were forced to seek alternate schooling. (Durban)

The financial resources no longer available, the struggle and efforts for access to a government school started again and *armed with a very good academic report* the application was accepted

Sub-theme 3.6 **Continued, active involvement in her child progress at school as well as offering assertive efforts of persevering** to convince this government school to accept an offer for professional support to the teacher.

Inflexibility in accommodating my son's special needs was obvious. I asked for time with his class teacher to equip her with strategies on HFA, to help problem solve and to give her support. This was denied. The support of a facilitator was also denied...

After trying to respect the school policy for the six months we had been there, **I had to put my foot down and insist that the teacher accept support.**

Sub-theme 3.6 **The reward for active involvement and activism for utilizing professional support to empower teachers.**

By this stage she too was feeling overwhelmed and she agreed to my help. Thankfully, the second half of the year saw change and my son's grades began to climb. *The teacher's defences dropped as we formed a partnership in my son's education, just in time for the year to end and for me to have to start the whole process over with teachers for grade.*

Theme 4: The author/researcher's conclusive reflections

4.1 Ignorance of and lack of resources in mainstream schools are at the heart of struggling for access

My greatest resistance has been from those who I would have thought would have my son's progress at heart. The educators... I found great misunderstanding about the condition and low training available for the teachers. However how a school responds to that can make a world of difference to the education of the child with HFA as evidenced by the contrast between my experiences at the private schools and government schools, both in the USA and in South Africa. The principals and teachers, understandably, feared backlash from the parents of the neurotypical children.

I honour those teachers, some of whom have taught my son, some of whom have taught my clients, who go the extra mile because they see the child, and not the limitations of Autism.

4.2 Parental involvement every step of the way is indispensable- as watchdogs and activist for the rights of their children

- believing in the constitutional rights of their children and enforcing policy directives
- believing in and advocating the strengths of this child with special needs.
- Leading the way for empowering educators with attitude change and competence.

Parents, who believe that children have potential, are capable of learning and who believe the South African Constitution that says every child has a right to an education...

We look for any gaps at school where our children may be falling behind and work on these at home

4.3 We live with hope...and the future is uncertain for our children

It is has not been an easy road and I am fearful of our potential experiences as we face high school

We...spend many hours hoping our children will be allowed to stay at the school they are in.

“Will they allow us back next year?” we wonder...

Carryn Collins

911337591

Master of Medical Sciences- Autism Spectrum Disorders (research)

Autoethnographic essay: Hope and realism- accessing education for a learner with High Functioning Autism

Inclusive education is currently a “hot topic” in South Africa. Moves are being made to downsize special needs schools and include as many children as is possible in mainstream schools (The South Africa Department of Education, July 2001). Being a parent of a special needs child, this gives me hope, however my experiences in accessing education for my son with High Functioning Autism (HFA) have been far from plain sailing. My son’s education started in [REDACTED] where we were living and even there in a country which is further long the inclusion road than South Africa is, we faced many challenges. This essay relays my experiences as a mother of a child on the Autism Spectrum to access education for my son.

As a parent of a child with Autism, I realised early on that I would need two things: resilience and money. Money of course, for the necessary assessments and treatments for my son. The many visits to psychologists, paediatricians, occupational therapists, speech therapists and behavioural therapists all take their toll on one’s budget. Resilience for the resistance encountered by those around me who did not and do not understand Autism, including those in education.

I had encounters at a sports club where we were not welcome due to my son’s Autism, I have been surprised at the responses of some of the schools who have turned down teacher training offered at my expense and have simply asked me not to be involved. I have had the unfortunate experience of being turned down by several schools because of my son’s diagnosis; I have even had my neurotypical (without Autism) son refused entry into a school because of his brother’s Autism.

My family and I were living in [REDACTED] when my son started Kindergarten (equivalent to the South African Reception/ grade R year). He had already received his diagnosis of Autism and was considered High Functioning at that stage. We applied to approximately five public [REDACTED] schools in our area. None of the schools gave any resistance to accepting his application for kindergarten, despite his diagnosis of Autism which accompanied the applications. The public schools in our area in [REDACTED] each had a Special Education (Special Ed) unit for children who needed additional support. The units consisted of remedial teachers, psychologists, class assistants and teachers who had training and experience with special needs, including Autism. Children with special needs were placed in the mainstream classroom as much as possible and only given Special Ed support as needed. This could also include one of the Special Ed staff accompanying the child in the mainstream classroom. It all sounded perfect, in fact it sounded too good to be true- it was. We were told by each school in turn that since our son had no cognitive delays he did not qualify for any Special Ed support. He would need to struggle in the mainstream class alone despite the deficits he had within the triad of impairments associated with Autism (behaviour, social and communication challenges) all of which affect learning.

The social and communication impairments were of particular concern to me in the context of group learning. He could struggle with expressing himself if he did not understand work and could easily have trouble participating in class. This had already been evidenced at preschool. These concerns were expressed to the schools, which responded that their policy was not to give any additional support to children who were cognitively able. I offered to send my son’s behavioural therapist to accompany him at school at my own cost. This was declined with the response that the schools already had Special Ed staff employed at the school. When I pointed out that my son was denied access to the Special Ed staff due to his cognitive abilities, the schools each assured me that should he fail with school work and fall behind his peers he would at that point be granted access to the support of the Special Ed staff. I found this unacceptable.

We decided to apply to a private school in our area. This would mean we would need to pay expensive school fees in contrast with the public schools which were free. The private school declined our application

on the grounds that they did not have Special Ed staff and the teachers did not have any experience with special needs. In addition they had never had a special needs learner of any kind at their school before. We were referred back to the public schools which were “better equipped”. I contested the rejected application for six months. There were ongoing meetings, phone calls and correspondence with the professionals who worked with my son. Feeling this school was the best placement for my son I would not give up and proved true the phrase “the squeaky wheel gets the oil”. In what I felt was an attempt to keep me quiet the school agreed to accept my son on a trial basis for one term, with the provision of support of his behavioural therapist in the classroom. A breakthrough and the lure of hope.

We rented out our basement to students in order to afford the school fees as well as made an application for a scholarship to the school and received a reduction on the fees. My son excelled at the school with the support of the behavioural therapist who was essential, especially in the first few weeks at the school. As the term progressed her presence and support was faded and the teacher now equipped with skills and strategy managed well and my son was promoted to grade one at the end of the school year. By the end of grade one he was receiving only half an hour of behavioural support and this was at break to assist with interacting with the other children outside of the classroom. In addition he represented the school at an interschool Spelling Bee competition of twenty schools, which he won. It was at this point that our family relocated back to South Africa.

Before we returned to South Africa I made contact with Autism South Africa to enquire about schooling options for my son. The response was bleak. I was referred to local Autism schools and therapy centres in the greater [REDACTED] area, where I was told mainstream government schools would not be accepting of a child with Autism, even high Functioning Autism and our best hope was private schools. Following the advice from other parents of children with High Functioning Autism, I phoned schools in our area and asked if they had vacancies for a child in grade [REDACTED]. This was suggested as the experience of other parents was that if one asked “do you take children with Autism?” the response would be that they were full.

Despite my son’s good academic report, no [REDACTED] schools in our area were willing to accept him. We tried a [REDACTED] school which rudely declined the application. In desperation my father who had a business connection with a substitute principal at a [REDACTED] school pleaded on his grandson’s behalf for his colleague to give him a chance. My son breezed through the entrance assessment and started at the school shortly after. The teaching staff accepted him openly. They embraced his challenges and gave support over and above what we expected. They attended training seminars on Autism and promoted his strengths. All the while granny was assisting with the expensive school fees. After 3 years at the school Granny retired and we could no longer afford the school fees. We were forced to seek alternate schooling. We applied to a [REDACTED] school armed with a very good academic report and surprisingly were accepted.

From the first meeting with the principal it was obvious that our experience at the [REDACTED] school was going to be very different from that of the [REDACTED] school. While we were grateful for a placement, inflexibility in accommodating my son’s special needs was obvious. I asked for time with his class teacher to equip her with strategies on HFA, to help problem solve and to give her support. This was denied. The support of a facilitator was also denied however we had to try and move forward knowing our only other educational option was homeschooling, which we did not want to pursue.

By [REDACTED] the wheels had fallen off. My son’s grades had dropped from 80’s and 70s to 50’s there were behavioural issues and he had no friends. His teacher still refused assistance and I was told repeatedly that I should take him back to the [REDACTED] school. I was left feeling desperate. After trying to respect the school policy for the six months we had been there I had to put my foot down and insist that the teacher accept support. By this stage she too was feeling overwhelmed and she agreed to my help. Thankfully the second half of the year saw change and my son’s grades began to climb. The teacher’s defences dropped as we formed a partnership in my son’s education, just in time for the year to end and for me to have to start the whole process over with teachers for grade [REDACTED].

As a behavioural therapist, I work with children on the Autism spectrum. I encounter two kinds of parents: group one has been told by doctors and other professionals not to expect too much from their children. They find some sort of care facility for their kids and are happy as long as the kids are happy.

Group 2 hasn’t believed the misinformation from the professionals and who know their children have potential, are capable of learning and who believe the South African Constitution which says every child has a right to an education.

Group 2 parents, of which I am one, having a ■-year-old son with High Functioning Autism, spend many hours hoping our children will be allowed to stay at the school they are in.

“Will they allow us back next year?” we wonder.

We look for any gaps at school where our children may be falling behind and work on these at home. We lend the teachers books on Autism Spectrum Disorder (ASD), if they will take them, we try not to rock the boat too much and we pray. Our kids are under the microscope. If a neurotypical child shouts out in class the child gets a verbal reprimand and the day goes on. When our children do the same thing we are told at pick-up that day there was “an incident” and that other parents would not be happy with what our child has done (disrupting the class). This is a mainstream school after all. Good thing for that resilience.

Some of my clients are in mainstream schools. There are some schools where principals continually upgrade the staff by means of training in the field of ASD, then there are others where teachers have been left exhausted, principals frustrated and parents, of course, are left feeling desperate at the thought of where to send their children if things don't work out at the current school.

Although children with HFA are not always model students, some having sensory issues and behavioural difficulties, they are after all South African and deserve an education.

In our case there was much misunderstanding about the condition and low training available for the teachers. However how a school responds to that can make a world of difference to the education of the child with HFA as evidenced by the contrast between my experiences at the ■ schools and ■ schools, both in the USA and in South Africa. The principals and teachers, understandably, feared backlash from the parents of the neurotypical children. They have to answer to the school board and they feel the neurotypical children may not understand a child who is different. However I found great understanding and support from the parents of the neurotypical learners at all schools my son attended. There have been those who encouraged their children to help my son make friends, and I found children who were kind and helpful to my son. My greatest resistance has been from those who I would have thought would have my son's progress at heart. The educators.

I am grateful my son has a placement in a progressive mainstream ■ school considering the teachers have had no formal training and little experience with HFA. But it is has not been an easy road and I am fearful of our potential experiences as we face ■ school.

I honour those teachers, some of whom have taught my son, some of whom have taught my clients, who go the extra mile because they see the child, and not the limitations of Autism. The ones who emphasise the strengths of the child with autism to build the child's confidence and raise respect among the child's classmates. The teachers who try harder, go the extra mile, who never give up, who say at the end of the school year, “That was hard work” followed by “I have learned so much from this child and I am so glad he was in my class.”

Since it is considered that 1:88 children are affected by Autism I can only hope that South African schools will grow in awareness of the condition and will embrace these children who are different – no doubt – but not less.