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THE PREVALENCE OF AUTISM SPECTRUM DISORDERS AT TARA HOSPITAL CHILD AND ADOLESCENT CLINIC

Dr Philemon M Pitjeng

A research report submitted to the Faculty of Health Sciences, University of Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Medicine in the branch of Psychiatry in September 2020

DECLARATION

I, Dr Philemon Pitjeng, declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in branch of Psychiatry in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

_____

Dr Philemon M Pitjeng

September 2020

ACKNOWLEDGEMENTS

I would like to acknowledge my indebtedness and render my warmest thanks to my supervisor, Dr. Danie Hoffman, who made this work possible. His friendly guidance and expert advice have been invaluable throughout all stages of the work.

I would also like to express my gratitude to Dr.Thebe Madigoe for extended discussions and valuable suggestions which have contributed greatly to the improvement of the thesis.

Special thanks to my wife, Thembi Pitjeng, and my four children, Njabulo, Tebogo, Thato and Thorisho, for their continuous support and understanding. To my niece, Kholofelo Pitjeng, thank you sincerely for your selfless sacrifices and passion you have shown during the process of this work, your logistical support was truly amazing. To my extended family and friends, thank you for your prayers and willingness to lend a helping hand throughout this journey.

To the University of Witwatersrand, Department of Psychiatry and Tara hospital, I wish to express my appreciation for granting me the opportunity to conduct my work. I acknowledge the contribution from all non-teaching staff members of Tara Hospital for their kind help and co-operation.

Above all, from my very soul I thank God, The Almighty, for bestowing me with the knowledge and strength to complete my work successfully.

PLAGIARISM DECLARATION FOR WRITTEN WORK

I, Dr Philemon Pitjeng, as a postgraduate student registered for a MMed degree at the University of the Witwatersrand declare the following:

- I am aware that plagiarism is the use of someone else's work without their permission or without acknowledging the original source.
- I am aware plagiarism is wrong.
- I confirm that this written work is my own work except where I have stated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or if I have failed to acknowledge the ideas or writing of others.

_____

Dr Philemon M Pitjeng

September 2020

PRESENTATIONS ARISING FROM THIS STUDY

This work was presented at the Annual Department of Psychiatry Research Day in 2019.

PUBLICATIONS ARISING FROM THIS STUDY

This work has never been published.

ABSTRACT

Introduction: There are limited studies on the prevalence of Autism Spectrum Disorders (ASD) in Africa as a continent, and in South Africa in particular. This study is aimed at determining the prevalence of Autism Spectrum Disorders at a specialised psychiatric hospital in Johannesburg.

Method: This is a retrospective study based on a sample of 1370 patients aged between 1-17 years of age who were evaluated over a period of 6 years at the Tara Hospital Child and Adolescent Clinic. 76 received a clinical diagnosis of ASD as per the DSM-IV-TR or the DSM-5. All patients that were not diagnosed with ASD and those that were diagnosed with ASD but were above the age of 18, were excluded.

Results: The prevalence of ASD was 5.5% with a 95% confidence interval of 4.4% to 6.9%. These children also presented with co-morbid psychiatric illnesses, the most common being ADHD at 72% followed by GAD at 34%. Patients that received OT made up 21%, while 17% were at remedial school as per the recommendation made by the multi-disciplinary team.

Conclusion: The findings of this study correlate with other studies that have been conducted. There was also an incidental finding that indicated a higher paternal than maternal heritable contribution of ASD. Further research is recommended to measure the outcomes of the cases that were diagnosed.

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LIST OF ABBREVIATIONS

ADDM	Autism and Developmental Disabilities Monitoring
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CI	Confidence Intervals
DD	Developmental Delay
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders – 4th Edition (Text Revision)
DSM-5	Diagnostic and Statistical Manual of Mental Disorders – 5th Edition
GAD	Generalised Anxiety Disorder
HREC	Human Research Ethics Committee
ID	Intellectual Disability
IQ	Intelligence Quotient
LD	Learning Disability
MDT	Multidisciplinary Team
MS	Microsoft
NDD	Neuro-developmental Disorder
PDD-NOS	Pervasive Developmental Disorder, Not Otherwise Specified
OT	Occupational Therapy
SAS	Statistical Analysis System
SPECIAL ED	Special education
USA	United States of America

CHAPTER ONE: INTRODUCTION

1.1 Background

Tara Hospital is a quaternary (Level Four) hospital located in Hurlingham which is an elite surburb, in Sandton, north of Johannesburg. It is a public sector specialised psychiatric hospital. The hospital renders specialised inpatient and outpatient services to adults and children with severe mental illness.

The service package for Tara Hospital constitutes that of a quaternary level hospital. A quaternary level hospital renders highly specialised services and receives referrals from tertiary, secondary and primary facilities. The hospital is both a provincial and national asset and provides some services that are not available in other provinces.

Tara Hospital manages numerous psychiatric illnesses, and its children's clinic treats numerous psychiatric illnesses including that of ASD and its numerous co-morbid psychiatric conditions, making it an appropriate and noteworthy facility to evaluate when investigating prevalence of the condition. This enables a greater understanding of the patterns of the condition in order to assist with the effective management of the condition.

Autism Spectrum Disorders (ASDs), previously referred to as pervasive developmental disorders, are a group of developmental disabilities characterised by atypical development in socialisation, communication, and behaviour (1). ASD comprises of autistic disorder, Asperger disorder, and pervasive developmental disorder not otherwise specified, a part of its diagnostic continuum (2).

Impaired communication, impaired social interaction, and restricted or repetitive behavioural patterns are the pillars of the triangle that characterises ASDs. Epilepsy, sleep problems, motor impairments, intellectual disability (very common in Africa), attention problems, externalising behaviours, and impaired sensory perception are some of the comorbidities for ASDs. This clinical expression varies greatly depending on the severity of the autistic symptoms and on the developmental level (3).

Individuals with ASDs experience several co-occurring cognitive, medical and behavioural difficulties in addition to their core ASD symptoms. Coupled with medical and psychiatric disorders, they also exhibit a high prevalence of gastrointestinal

disorders, immune dysregulation, depression, obsessive-compulsive disorder, aggressive and self-injurious behaviours. Reports have also shown that children with autism spectrum disorders exhibit developmental regression where their cognitive and social maturation is followed by the loss of a mastered skill. They have also been found to exhibit colitis and duodenitis (4).

There is a wide range of symptom intensity in ASD, and within each diagnostic category multiple domains of function influence the impact of the disorder**.** According to studies, 25 to 50 percent of children with ASDs lose acquired language and social skills before the age of two (regression). It is estimated that 60 to 75 percent of individuals with autism progressing into adulthood experience poor or very poor outcomes (5).

The question on the lips of researchers about ASDs, which are considered to be universal disorder, is whether behavioural differences occur across cultures. This concern is based on the fact that certain studies have identified disparities between ethnic groups, which some have attributed to the lack of standardised assessment tools and instruments (6).

In 90 to 95 percent of ASD cases, the cause of it is uncertain. Five to ten percent of the characteristics of the ASD are believed to be secondary to a child's primary impairment. Some of the common secondary causes may include early exposure to rubella, chromosomal abnormalities and genetic disorders (7).

ASDs can be genetically acquired, although the structure of inheritance is very complex, probably including multiple susceptibility genes, one of which can probably be found on chromosome 7q**,** which is yet to be identified (5).

The 'subgroup model' and 'severity model' have been propagated to address the variability in the phenotypic characteristics of the 'spectrum'. In terms of the subgroup model, the differences might be explained as a discrete phenotype within the disorder with unique gene attribution to the different aspects of the phenotype such as social interaction, language and interests. In terms of the severity model, the various presentations of the major symptoms observed in autism are assigned to a continuous severity gradient with addition to a genetic effect in terms of susceptibility. In simpler terms, the higher susceptibility genes a person has, the higher the severity of the phenotype will be. However, a clear cause for ASD has not yet been demonstrated (8).

ASDs are considered to be chronic disorders that have a significant functional and financial impact on individuals and their families. Families of individuals with autism put a substantial demand on social, medical and educational services (1).

It is estimated that children with autism have nine times more healthcare expenditure than of other children in need of medical interventions. They often require regular support services throughout their lifespan which are usually very expensive. Annual costs for care of a child with ASD is estimated to be 85 to 550 percent more compared to the cost of care of a typically developing child. Approximately $4.7 million is estimated to be the average lifetime public expenditure for a person with ASD (5).

Accurate prevalence estimates are needed for the planning of support services for children with ASDs and comorbid conditions. These should be considered by public health providers during the planning of intervention strategies, prior to implementation (9).

1.2 Purpose of study

The purpose of this research study is to determine the prevalence of autism spectrum disorders at Tara Hospital Child and Adolescent Clinic, Gauteng Province, South Africa.

1.3 Study Objectives

- To determine the prevalence of autism spectrum disorders at Tara Hospital Child and Adolescent Clinic.
- To describe the demographic profile of ASD patients attending the Clinic.
- To determine the comorbid medical and psychiatric conditions identified in ASD patients at the clinic.
- To investigate how ASD diagnoses are made in terms of DSM-IV-TR and DSM-5 criteria.

1.4 Hypothesis

There is a high prevalence of children with Autistic Spectrum Disorders attending Tara Hospital Child and Adolescent Clinic. These children also present with comorbid psychiatric illnesses, which are also expected to be high in this population.

CHAPTER TWO: LITERATURE REVIEW

2.1 Diagnostic Criteria

2.1.1 Classification from DSM-IV-TR to DSM-5

According to the DSM-5, Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder not otherwise specified (PDD-NOS) from DSM-IV-TR should be given the diagnosis of Autism Spectrum Disorder. Individuals who have identified deficits in social communication, but whose symptoms do not otherwise meet the criteria of ASD, must be assessed for social communication disorder (10). According to Wing (11), significant issues have been overlooked during the classification, such as social imagination, diagnosis in infancy and adulthood, and the possibility that women and girls with autism may continuously be unrecognised or misdiagnosed under DSM-5. Mandy (12) highlighted that among high functioning individuals ASD is a dyad, not a triad, with distinct social communication and repetitive behaviour dimensions. As suggested in the DSM-5 criteria, sensory abnormalities are part of the restricted, repetitive behaviour symptom cluster. The full diagnostic criteria of DSM-IV-TR and DSM-5 may be seen in Appendices Five and Six respectively (13).

2.1.2 Clinical features

The age and pattern of onset should be noted for ASD. Symptoms of ASD are typically recognised as early as during the second year of life. A significant proportion of children are not diagnosed until school age.

There are three kinds of sensory abnormalities that are common among children with ASD: (14)

1. Sensory over-responsivity: This is categorized by negative responses to particular sensory stimuli which entail but are not limited to light, sound and particular tactile experiences. Responses to these stimuli may include distress, avoidance, or hypervigilance.

2. Sensory under-responsivity: The main trait is a tendency to be unaware of or non-responsive to various sensory stimuli; and

3. Sensory seeking: This is witnessed when one engages in actions or movements that provide improved sensation.

The pattern of onset description might include information about early developmental delays or any losses of social or language skills. The behavioural features of ASD first become evident in early childhood, with some cases presenting as a lack of interest in social interaction in the first year of life. For example, there might be delays or disorders in social smiling, facial recognition and being responsive to one's names are some of the pre-morbid social behaviours. There may also be pre-morbid communication behaviours, such as unusual pronunciation, using different types of gestures, and difficulty in synchronising verbal and nonverbal behaviours, like pairing eye contact with vocalisations (7).

During the second year of life, odd and repetitive behaviours and the absence of typical play become more apparent. Repetitive or limited use of toys or objects in manipulative play, engagement in high rates of stereotypic motor behaviours, or an intense focus on narrow interests become more evident in the second year of ASD (7).

ASD is not a degenerative disorder, and it is typical for learning and compensation to continue throughout life. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naïve and vulnerable, and prone to anxiety and depression (15).

2.2 Prevalence

The reported prevalence of ASDs has increased markedly during the past three decades. Some researchers have attributed the increase of autism spectrum disorders to some non-etiological factors. These factors include changes in diagnosis reporting practices, greater public awareness and recognition, better case ascertainment, lower age at diagnosis, diagnostic substitution, changes in the diagnostic constructs and corresponding diagnostic criteria, as well as service availability, even though these factors have not been fully substantiated. This is because these underlying reasons for the apparent prevalence changes are difficult to study empirically (9).

Others have also attributed factors like varying urban, rural, and country location and population of study, younger age, and inclusion of individuals with average intelligent quotient (IQ) and those with other neuropsychiatric and medical disorders as alternative explanations for the increased prevalence (9).

Some studies have shown that the estimated prevalence of ASD in children currently is estimated to be around one percent, although it has been conveyed to be 2.6 percent high (16). The frequency of ASD across the United States of America (USA) and other countries has been reported to have come up to one percent of the population, with evaluations in child and adult samples being parallel (15). The change in prenatal, perinatal, and neonatal factors as potential risk factors for ASD have contributed to the increased incidence. ASD prevalence estimates and increases have shown significant growth over shorter time frames and over decades globally. Different studies have shown diverse estimated prevalence of ASDs (17).

During the 20th century, four to five cases of autism per 10 000 people was the norm, though it was reported that 20 per 10 000 children met the criteria for ASD. Recent reports have demonstrated increased prevalence estimates for all ASDs of 30 to 90 cases per 10 000, which is substantially higher than previously recognised (9).

Although the identified increased prevalence of ASDs has been more pronounced for those with average or above-average IQ, studies have also shown it to be present at all levels of intellectual ability. In the population aged up to 17 years, teenagers have had the highest estimated proportion with diagnosis of ASDs. Sex, age, race, ethnicity, country of origin, family income, level of child impairment, and education are factors that have varied in the proportion of children diagnosed with ASDs. Due to a sharp increase of ASDs without intellectual disability, the prevalence of children aged up to17 years diagnosed with ASDs escalated 3.5-fold between the years 2001 and 2011. It was widely speculated that a large number of the observed increases in the prevalence of ASDs might probably be due to increased awareness and ascertainment rates (18).

Irrespective of whether the recent ASD prevalence increase is attributable to increased awareness, changes in diagnostic practices, a true change in prevalence, or all of these factors, a true increase in incidence cannot be ruled out (18).

Generally, the prevalence of ASDs is substantially greater than previously recognised (9). However, little is known of the prevalence of autism spectrum disorders in Africa as details of clinical presentation of ASD remain elusive (19).

The Prevalence of ASDs in Tunisia and Egypt among children with developmental disabilities have been shown to be 11.5% and 33.6% respectively. Studies carried out in Nigeria have found the prevalence of ASD to be 0.08% which is probably highly

influenced by low help-seeking behaviours for childhood neurodevelopmental disorders in the African population (20).

Published evidence addressing the prevalence of ASDs in South Africa is limited. No known epidemiological studies have been conducted to date in South Africa and the impact of ASD on the South African population is not accurately known. Between 1996 and 2005, there was an increase of 8.2 percent in the number of cases presenting with ASD in Johannesburg. This could translate to 270 000 South Africans having ASD (19).

The increase in familial levels of income was found to be associated with a decrease in the prevalence, particularly in children with a comorbid intellectual disability. Along the same vein, an increased level of parental education has been associated with a decrease the prevalence of ASD, despite the presence of intellectual disability (18).

2.3 Demographics

2.3.1 Age at Index Presentation to psychiatry

Previous studies have shown that the reasonable index age at which to monitor peak prevalence is eight years of age (1).

It has been noted that race and ethnicity combined with socioeconomic factors affect the age at which the children are diagnosed. The study observed that children from minority groups and lower income or rural areas are often diagnosed at later ages (6).

In a population-based surveillance study, it was found that experienced clinicians can generally diagnose ASD at the ages between two to three years. It was also found that there is a gap between potential and actual age of identification ranges between 2.7 to 3.7 years. This gap indicates remarkable weaknesses in the overall system of community screening and identification for ASD (21).

2.3.2 Gender

ASD prevalence is significantly higher among males than among females (1). This may be likely due to girls being able to disguise their behavioural difficulties more easily than males. Also, parents may be unwilling to report certain behaviour exhibited by a girl or families may be more attentive to the development of a boy compared to a girl (22).

Male behaviour such as hyperactivity and aggression may trigger clinical evaluation. Females with ASD may portray less repetitive behaviours compared to males. This may further increase the gender bias during research and clinical evaluation which ultimately influences the credibility of the reported findings. Females with a higher IQ tend to mask the language and communication problems that are noticed in patients with ASD. This makes it challenging for clinicians to make a diagnosis in these patients (6).

2.3.3 Geographical area of origin

A community-based study conducted in India indicated a significantly higher prevalence of ASD among children up ten years of age from rural areas compared to those in urban areas. Contrary to this, a study conducted in Saudi Arabia reported a higher prevalence in urban areas than in rural areas (22).

It is postulated that the prevalence of autism spectrum disorders is generally somewhat lower in countries outside of North America and Europe. In the USA for example, white children tend to have the highest prevalence of ASD while children of Hispanic descendants have the lowest prevalence. However, the influence of culture-specific patterns of social cognitive processing upon ASD prevalence is yet to be fully explored (23).

2.3.4 Socioeconomic Status

Research carried out in India at an urban tertiary centre stated that most autistic children are from the middle class. This may be because the upper class do not usually use government facilities to source medical interventions. Contrary to the results found in India, studies done in Saudi Arabia indicated that the majority of the children diagnosed with autism belonged to lower socioeconomic standards characterised by lower income (22).

In the USA, one of the reasons for ASD diagnosis disproportions may be cultural dissimilarities. It was found that a diagnosis may be received up to a year or a year and a half later by a child in lower income, minority and rural families as compared to their wealthier, white and urban counterparts (6).

2.4 Psychiatric Comorbidities

Individuals with ASD have been found to have one or more comorbid mental disorders, with 70 percent of the population having one comorbid mental disorder and 30 percent having two or more comorbid mental disorders. The common comorbidities include attention deficit hyperactivity disorder (ADHD), generalised anxiety disorder (GAD), depressive disorder and specific learning difficulties (LD) (15). Mood disorders and injurious behaviour, which involves unprovoked kicking, biting, pinching, hitting or head-banging towards self or others, are the other comorbid disorders (4).

A study was conducted where individuals presenting with severe intellectual disability, with or without ASD, were compared. It reported that individuals with ASD had four times more psychiatric comorbidities than those without ASD. Intellectual disability (ID) prevalence in ASD ranged from 16.7 to 84 percent. It also found that mood disorders, anxiety, sleep disorders and organic syndromes were more prevalent in individuals with ASD than those without ASD. The causes of psychiatric comorbidities are often not well understood even though psychiatric comorbidities are common in ASD (24).

The reason for the infrequent identification of comorbid psychiatric disorders in ASD has also been shown during screening for ID in which symptoms have been attributed to the intellectual disability. Personal interviewing was challenging due to the wide IQ range and communication challenges. Caregivers habitually found it problematic to make suggestions regarding mental state (25).

Sensory over-responsivity has higher prevalence in children with ASD than normally developing children, and those with other developmental delays. It has been shown that there is an association between sensory over-responsivity and anxiety symptoms in children with ASD. For example, in a study where 170 toddlers with ASD were sampled, it was shown that toddlers with elevated levels of sensory processing problems demonstrated significantly increased levels of anxiety than toddlers with low levels of sensory problems (14).

2.5 Medical comorbidities

Medical conditions that are significantly associated with autism spectrum disorders include epilepsy, sleep problems, constipation and avoidant or restrictive food intake disorder among others (15). Developmental regression seen in ASDs is not linked with

epilepsy or epileptic-form activity. The risk of medical co-occurrence is not influenced by the regression.

The existence of medical comorbidity was despite the severity of developmental disability. Children with autism spectrum disorders are said to exhibit an increased prevalence of epilepsy. The prevalence of epilepsy was found to be associated with intellectual disability, which is in children with ASDs is estimated at 30 percent (4).

However, children with autism but without additional neurological disorders have been reported to show a much lower rate of epilepsy of about 6 percent (26). Females with ASD were more likely to develop epilepsy than their male counterparts. Factors such as age, sex, comorbidity, subtype of pervasive developmental disorder (PDD) or intellectual disability (ID) with regards to heterogeneity of samples has been attributed to the variability in prevalence rates of epilepsy (26).

Prevalence of gastrointestinal problems in children with ASD is reported to have ranged from nine to 91 percent. However, only about nine percent of children with autism had gastrointestinal symptoms prior to diagnosis. 42 percent of children with ASD had more gastrointestinal symptoms than the 12 percent of their typically developing siblings. Constipation and chronic diarrhoea have also been found to be the two most common gastrointestinal problems in children with ASD. 68 percent of children with ASD were reported to have one or more lifetime gastrointestinal symptoms and language regression. ASD children with gastrointestinal problems displayed severe symptoms on measures of irritability, anxiety and social withdrawal (26).

Sleeping problems included sleep anxiety, parasomnias and daytime sleepiness. It was noted that severity of autism symptoms aggravated sleep problems in ASD individuals (27).

Children with ASD were found to exhibit more food refusal and had a more limited food repertoire than typically developing children with regards to food selectivity. It was also discovered from studies that a significant association existed between visual and auditory sensitivity and the number of eating problems in children with ASD (27).

2.6 Aim of the present study

Given the changes in diagnostic processes between DSM-IV-TR and DSM-5 and the varying prevalence reported, together with demographic factors, psychiatric and medical comorbidities in ASD, this study aims to establish the prevalence of ASD at Tara Hospital Child and Adolescent Clinic. It also aims to throw further light on demographic factors, psychiatric and medical comorbidities in ASD.

CHAPTER THREE: METHODOLOGY

3.1 Study Design and Population

A retrospective record review of all children and adolescents with autism spectrum disorders, attending the Tara Hospital Child and Adolescent Clinic over a period of six years from 2012 to 2017, was performed.

Patient data were extracted from the files by the MMed student and loaded onto a MS Excel sheet anonymously. The data collection sheet may be found in Appendix One.

3.2 Inclusion Criteria

All children from age 1 to17 years attending the Tara Hospital Child and Adolescent Clinic from January 2012 to December 2017 and diagnosed with autism spectrum disorders (DSM-5) or a pervasive developmental disorder (DSM-IV-TR) at Tara Hospital Child and Adolescent Clinic were included in this study.

3.3 Exclusion Criteria

All patients aged 18 and above were excluded. Those within the required age range and who were not diagnosed with autism spectrum disorders or pervasive developmental disorder were also excluded.

3.4 Data Collection

The data were collected on all patients with ASD aged 1 to 17 years who presented to Tara Clinic from 2012 to 2017. The following data collected included demographic variables, criteria used to make the diagnosis, and medical and psychiatric comorbidities.

3.5 Statistical Analysis

Descriptive analysis of the data was carried out as follows:

- Categorical variables were summarised by frequency and percentage tabulation and illustrated using bar charts.

- Continuous variables were summarised by the mean, standard deviation, median and interquartile range, and their distribution was illustrated graphically.

- Data analysis was carried out using SAS version 9.4 for Windows.

3.6 Postgraduate Committee and Ethics Committee Approval

The study was submitted to the University of the Witwatersrand's Human Research Ethics Committee (HREC), and approval was granted unconditionally. Due to the retrospective nature of the study, direct informed consent was not necessary. The names and personal identifying details of all the patients in the study remain anonymous and were not recorded on the data sheets. The Ethical Clearance Certificate may be found in Appendix Three.

Permission from the Chief Executive Officer at Tara Hospital was obtained to conduct research and access to the records at Tara Hospital Child and Adolescent Clinic. (appendix Two.) Postgraduate research committee approval of the initial research protocol was obtained and all corrections to the initial research proposal were reviewed by the research supervisor and approved by the Postgraduate research committee (Appendix Four).

CHAPTER FOUR: RESULTS

4.1 Descriptive analysis of the study group

1370 patients in total were seen in the Child and Adolescent Unit during the study period. Of these, 76 were diagnosed with ASD according to DSM IV-TR and DSM-5 (post its inception in 2014). The prevalence was 5.5% at a 95% confidence interval.

4.2 Age at presentation to Tara Child and Adolescent Clinic

The median age at index was 8 years (IQR 6 to 12 years; range 2 to 17 years). The distribution of the data is shown below in Figure 4.1.

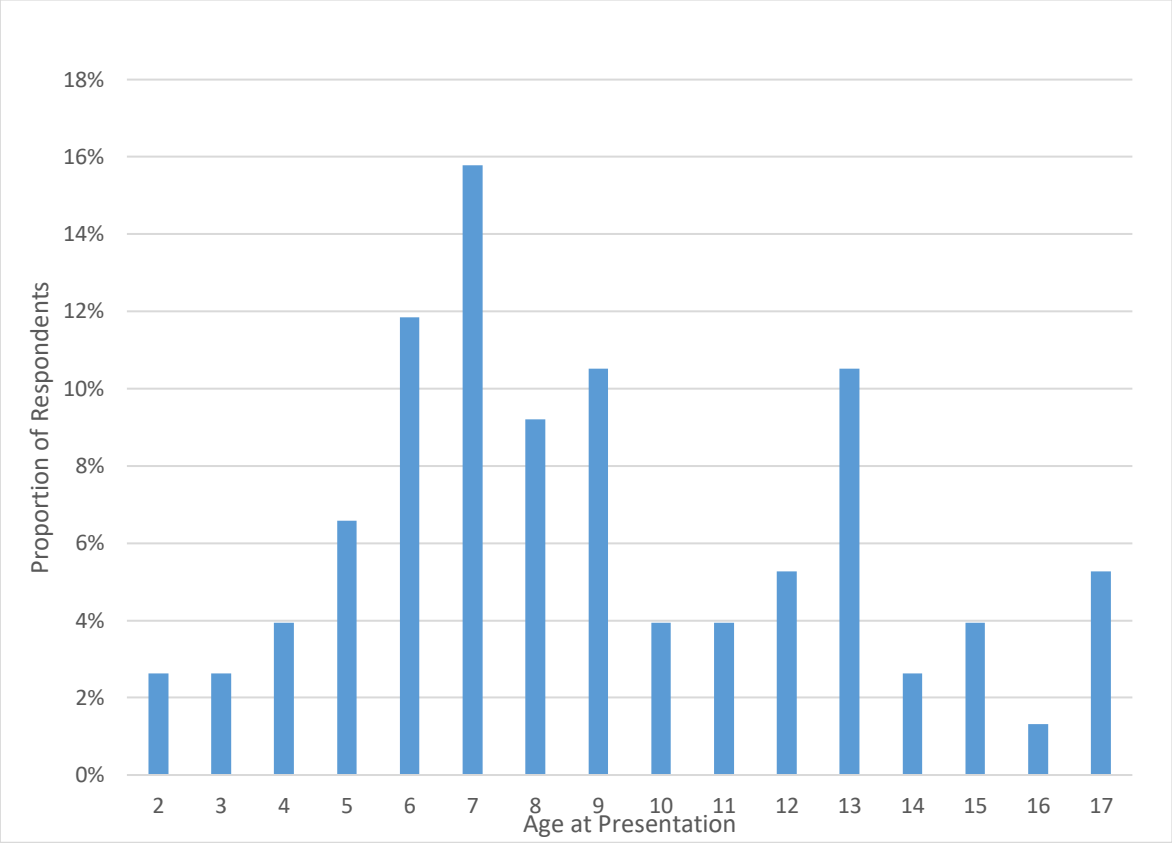

Figure 4. 1: Age at presentation to Tara Child and Adolescent Clinic

4.3 Gender and geographical area of origin:

Table 4.1 shows that of the 76 patients, 84% of the patients were male which indicates that the majority of patients with ASD are male. The majority of patients originated from urban areas (86%) while the rest came from semi-urban areas.

Table 4. 1: Gender and area of origin.

Variable	Category	Percentage
Gender	Male	84
	Female	16
Area of origin	Urban	86
	Semi-urban	14

4.4 Race:

The patients were predominantly White (53%) and African (39%). Coloured and Indian patients were at 3% each, as can be seen in Figure 4.2.

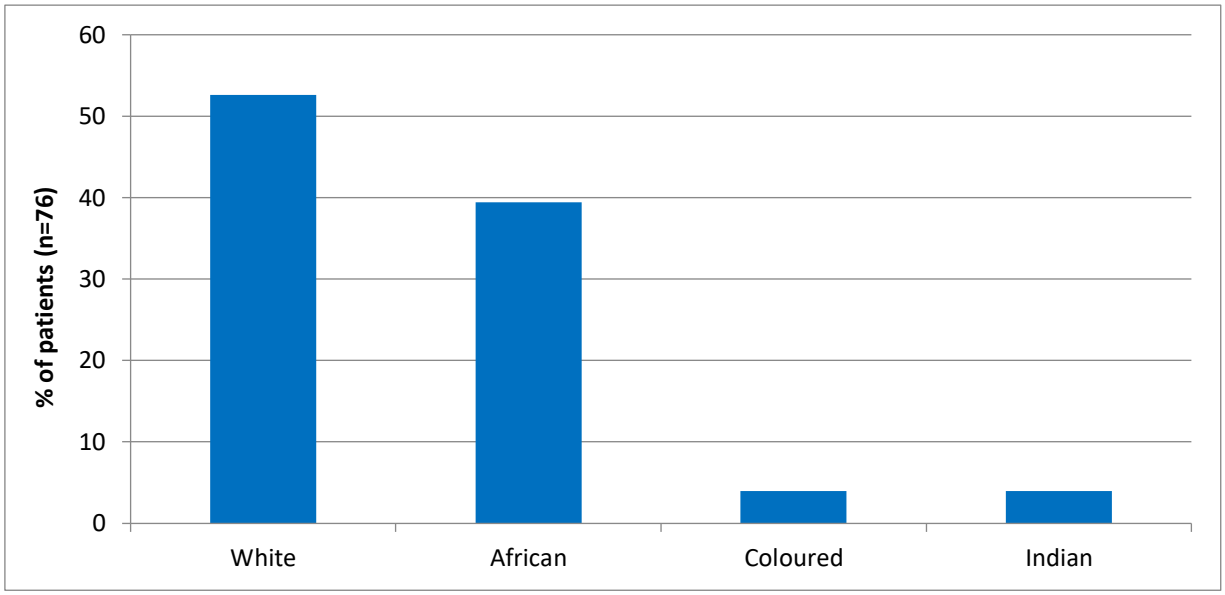

Figure 4. 2: Race

4.5 Home Language:

The predominant home language was English (51%). This can be seen in Figure 4.3, which also shows that 8% of patients were Zulu and Afrikaans speaking, while 6% were Northern and Southern Sotho speakers and Tswana and Xhosa speakers were both 3%.

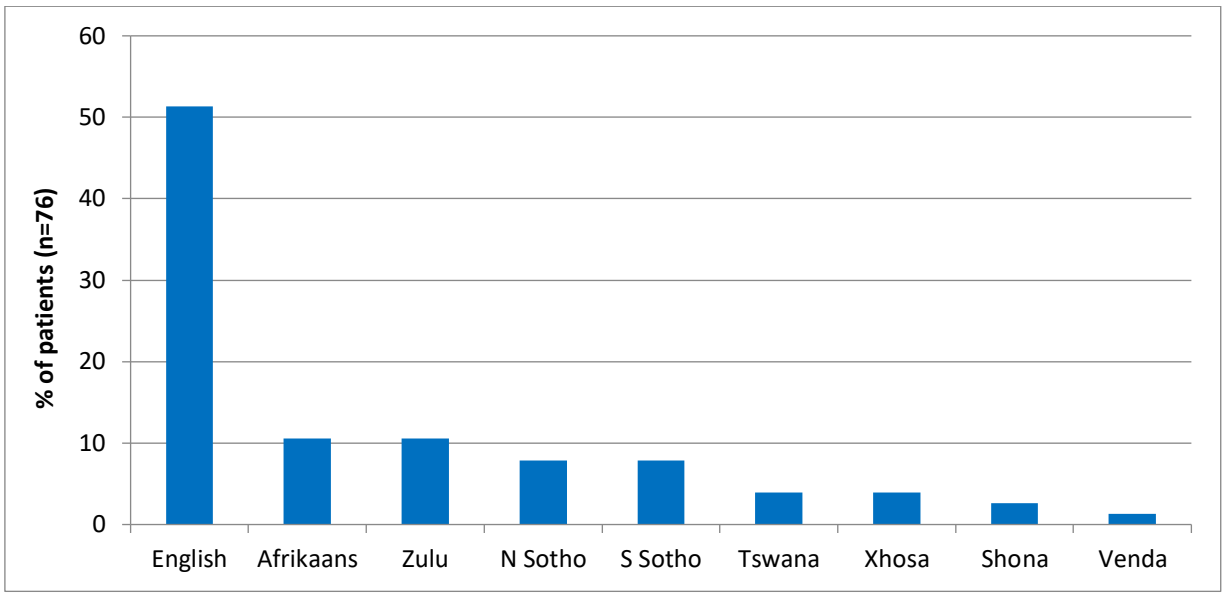

Figure 4. 3: Home languages

4.6 Schooling history of the patients:

55% of the patients attended mainstream schools, while 12% were not at school. The grade achieved within each school type is described in Figure 4.4. Grades RR to 12 were included and it was found that grade 1 was 14%, followed by grade RR with 8% and grade 0 and 2 with 7% respectively, totaling 29% for the lower grades. The remaining higher grades totaled 64%.

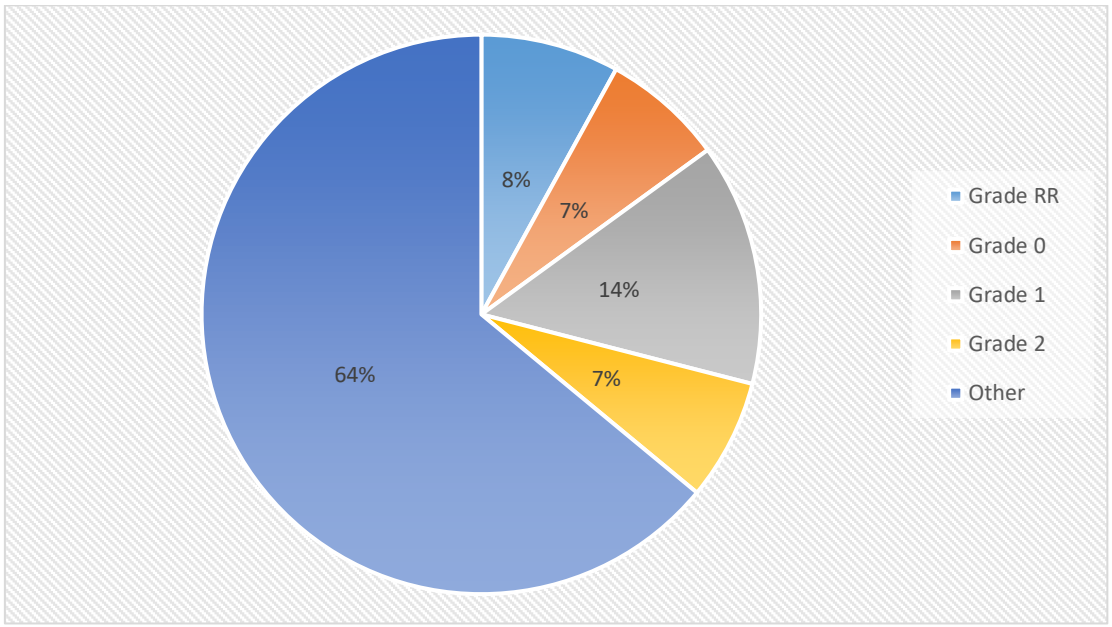

Figure 4. 4: School grades

4.7 School type:

55% of the patients attended mainstream school, as seen in Figure 4.5, while 12% were not at school. The grade achieved within each school type is tabulated in Figure 4.4 above.

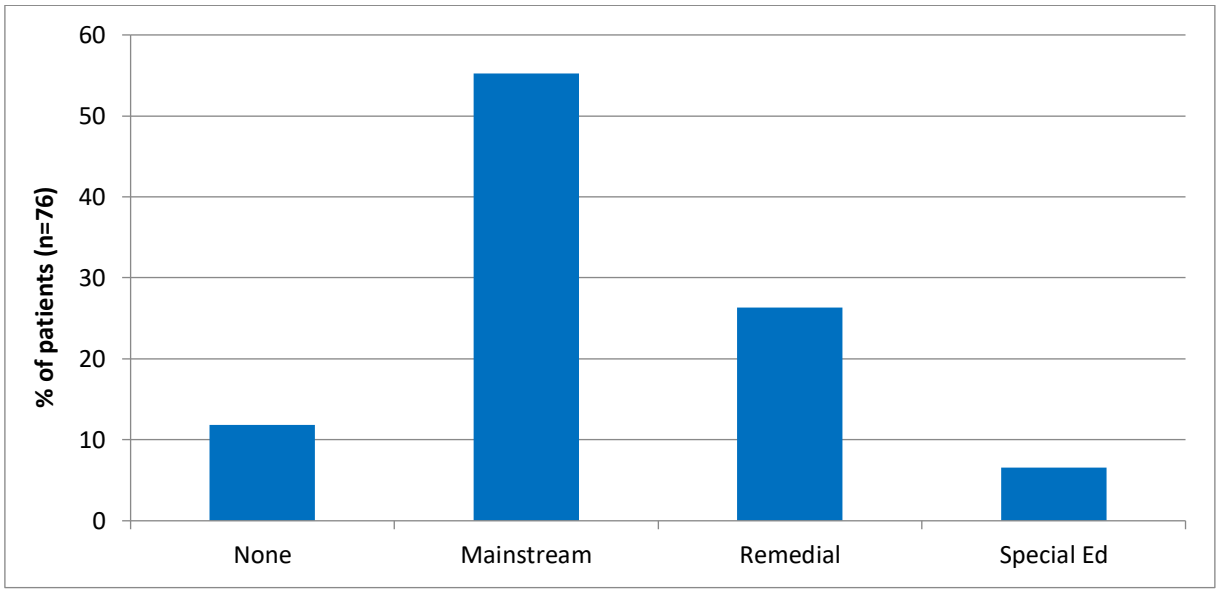

Figure 4. 5: School type

4.8 Patient Fee Classification:

South African public patients are classified into three major standardized categories according to how their hospital fees are paid. This comprises of free services, full paying patients and subsidised patients. The latter category is then further divided into four categories, below (Appendix 7)

H0: Children on a social grant and those who are legally adopted

H1: Unemployed parents or earning annual income less that R70 000

H2: Earning annual income between 70000 to 250000

H3: Earning annual income more than 250000

P: Private patient, on a medical aid scheme

Patients were fairly and evenly distributed across the H1 to H3 and P categories between 2012 and 2018 as seen in Figure 4.6.

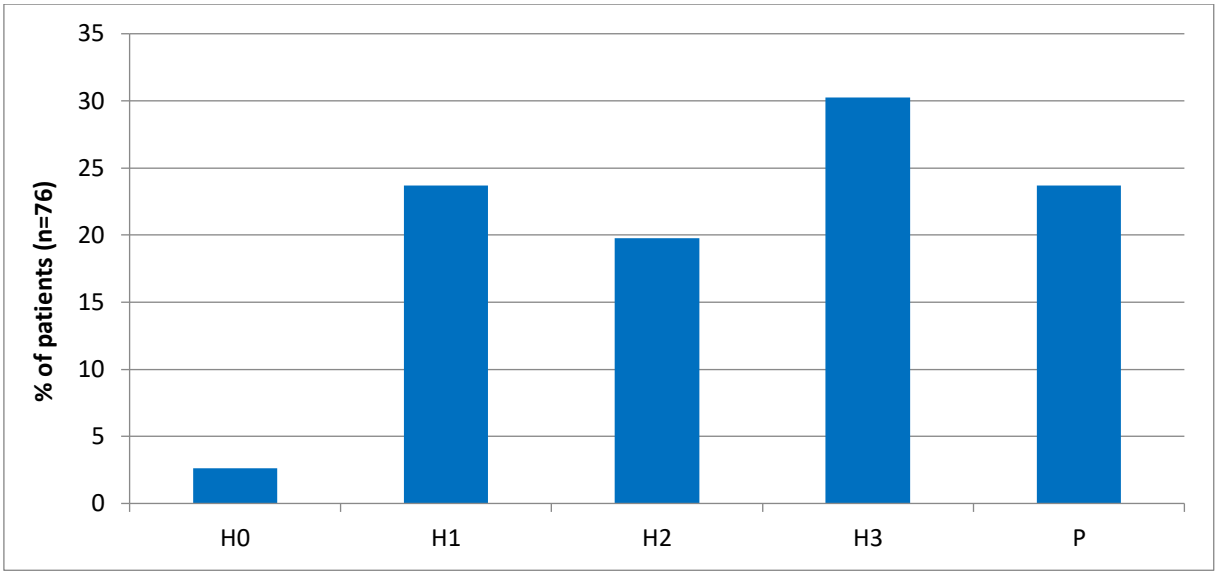

Figure 4. 6: **Family socio-economic status.**

4.9 Family history of autism:

Maternal, paternal, and sibling history of autism was present in 4%, 11%, and 12% of cases respectively, as seen in Figure 4.7.

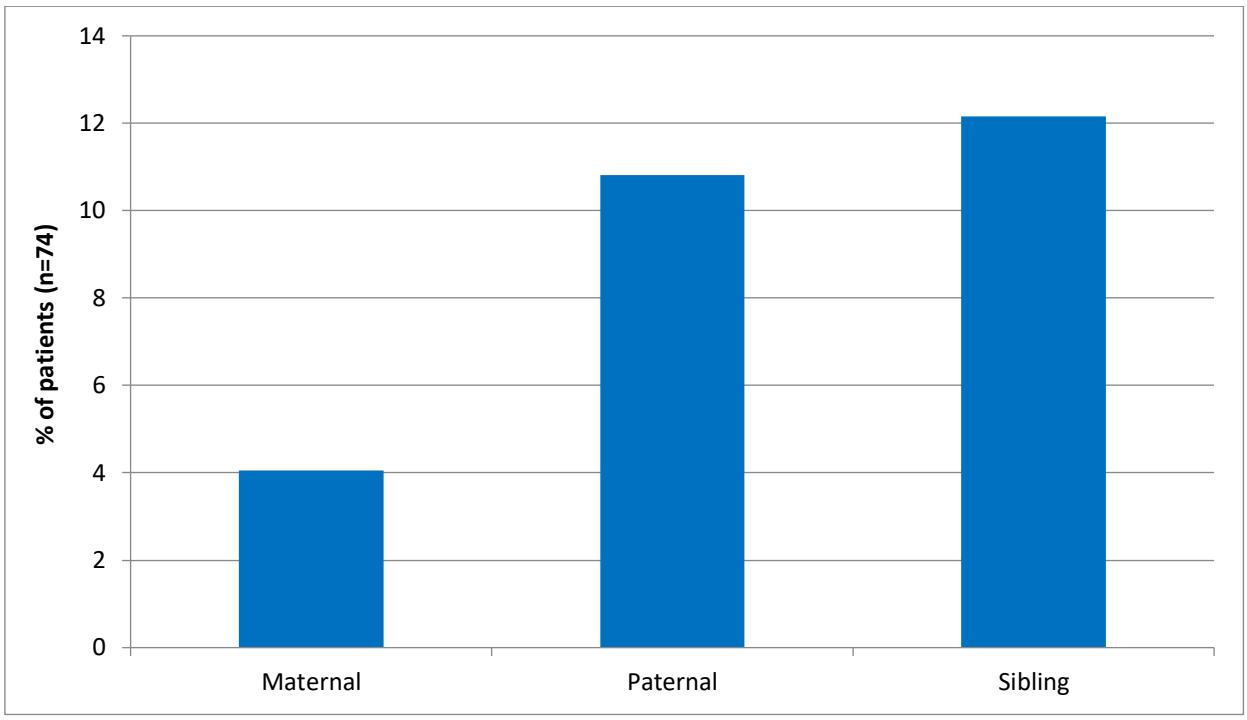

Figure 4. 7: Family history of autism.

4.10 Diagnostic profile of patients on DSM-IV-TR and DSM-5 criteria

According to the clinical records, 14 patients were diagnosed with ASD according to DSM-IV-TR criteria. However, these criteria were fully documented in only 11 of these patients (79%). Similarly, 62 patients were diagnosed with ASD according to DSM-5 criteria, these criteria were fully documented in only 46 of these patients (74%). Overall, the applicable DSM criteria were fully documented in 75% of the patients. This is shown in see Table 4.2.

Table 4. 2: DSM-IV-TR and 5 criteria as met by the patients

Variable	Category	Percentage
DSM-IV-TR criteria fully documented (n=14)	Yes	79
	No	21
DSM-5 fully documented (n=62)	Yes	74
	No	26
Applicable DSM criteria fully documented	Yes	75
	No	25

4.11 Psychiatric comorbidities:

The most common psychiatric comorbidity was ADHD (72%), followed by GAD (34%). Note that percentages do not sum to 100% since some patients had more than one comorbidity. The comorbid conditions may be seen in Figure 4.8.

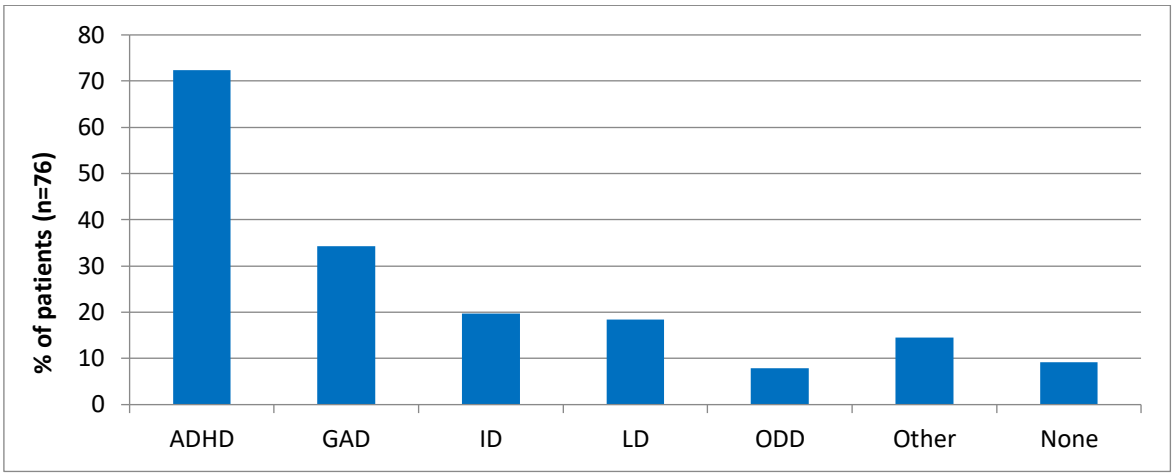

Figure 4. 8: Psychiatric comorbidities

4.12 Medical comorbidities

The medical comorbidities are tabulated in Table 4.3. The percentages do not sum to 100% since some patients had more than one comorbidity. 87% of the patients did not have any medical comorbidities.

Table 4. 3: Medical Comorbidities

Condition	Percentage
Epilepsy	6
Primary Enuresis	3
Eczema	1
Encopresis	1
Lactose Intolerance	1
Macrocephaly	1
None	87

4.13 Referral recommendations from the psychological reports:

38% of the patients had psychological reports and the recommendations were that 21% were referred to an occupational therapist (OT), while 17% were referred to remedial school. This can be seen in Figure 4.9.

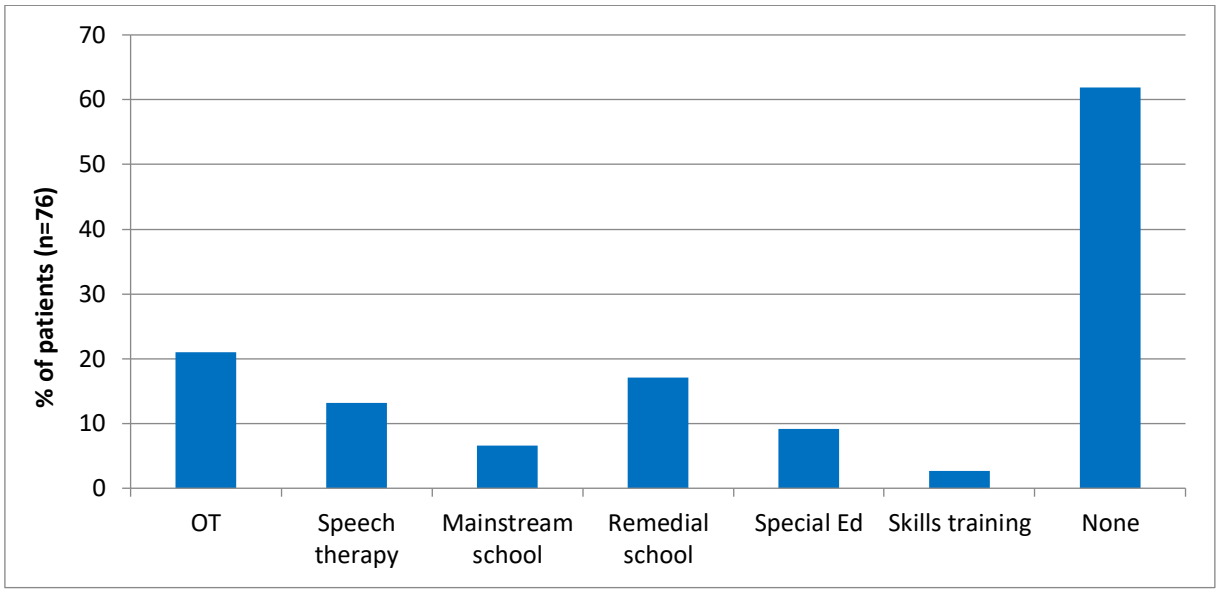

Figure 4. 9: Referral recommendations from the psychological reports

4.14 Summary of results

76 charts were reviewed. An ASD prevalence of 5.5% was established. It was found that the median index age was eight years old. The patients were predominantly males and most came from urban areas. The race of the sample was just over half white and most of the rest black. Most spoke English. The majority were in school, with just over half attending mainstream schooling. Socioeconomic status was evenly distributed. There was some evidence of ASD diagnosis in other family members. Diagnostic criteria were met fully in three quarters of cases. The most common psychiatric comorbidities were ADHD and GAD, while there were very few medical comorbidities. There was a low rate of referral out for other services.

CHAPTER FIVE: DISCUSSION

5.1 Age at presentation to Tara Child and Adolescent Clinic:

The median age of 8 years found in the present study corresponds with what has been found previously (1). Experienced clinicians can generally diagnose ASDs (as per DSM IV-TR and DSM-5) between the ages of two and three years of age. The gap between potential and actual age of identification for those identified is in the range of 2.7 – 3.7 years (21).

However, the fact that more than 75% of cases were over the age of 8 years at the time of diagnosis of ASD indicates significant weaknesses in the level of community screening and identification of this disorder. Various factors have been attributed to late ASD diagnosis (1, 6, 22, 23). These include race, ethnicity, level of child impairment and family income. Although there is no clear-cut borderline age of diagnosis based on racial and ethnic lines, certain cultural beliefs have accounted for late diagnosis of ASDs in some countries and communities. The beliefs and practices of parents with children diagnosed with ASD in SA is currently unknown and would be beneficial in shedding light on reasons for late presentation at a family level. Children with more severe impairments tend to be diagnosed at younger ages and children who live in moderate or severe poverty tend to be diagnosed at an older age. This may be attributable to parental distress or inability to cope with such a child, resulting in earlier help-seeking behaviours.

5.2 Gender

Males were the predominant gender found in the present study (84%) and previous studies reported the same. This is in line with the criteria set out in the DSM-IV-TR where it stated that these disorders appear to affect considerably more boys than girls with male-female ratios of about 3:1 (28).

A higher male-to-female ratio was therefore consistent with various studies that have been carried out. This is also consistent with findings from previous Autism and Developmental Disabilities Monitoring (ADDM) Network reports and other studies. Data from the 2006 surveillance year indicated that ASD prevalence was 4.5 times higher in males than in females and showed further that ASD prevalence among children aged 8 was 14.5 per 1,000 males compared with 3.2 per 1,000 females (29). The fact that ASD

is highly co-morbid with ADHD, which is also known to have a higher male-to-female ratio, deemed as a result of the predominance of externalising symptoms, is also noteworthy.

5.3 Geographical area of origin

The majority of charts reviewed in the current study were of patients from urban areas, whereas other studies have found most patients to be from rural areas. The reason for this is not surprising. Tara Hospital Child and Adolescent Clinic is situated in Sandton, which is an elite northern suburb of Johannesburg, which is a very large city, and would be serving a largely urban population. Those in rural areas would perhaps also lack the means to access such a facility.

5.4 Socioeconomic Status

One would not down-play the role socioeconomic status may have played in the findings of this study. Resilient factors such as higher socioeconomic status, social support, open and predictable patterns of communication between parents, supportive family environment, family hardiness, a positive outlook on life and a family belief system may have influenced some of the parents of the patients.

Reports about lack of social support, limited knowledge about ASD, lack of practical assistance, and uncertainty about their child's prognosis may also not have been distanced from the core socioeconomic issues that affected these parents.

Most patients who are referred to Tara Hospital are not eligible for a child grant because they come from communities with middle to high socio-economic status and the majority fall under H3 and P categories according to the patient fee classification system. Patients receiving child grants (H0) are few and usually come from the surrounding townships and informal settlements with low socio-economic status such as Alexandra and Diepsloot. These patients have access due to the referral system in place from the district to the tertiary level. The fact that these patients are fewer than those of higher socio-economic status suggests that perhaps awareness of ASD in those communities needs to be strengthened so that more children with ASD can be identified earlier and be given the necessary support through awareness campaigns.

In a report on South Africa, some parents highlighted the financial and marital strain they felt in the context of raising a child with ASD (31, 32). Others grappled with delays

in obtaining an ASD prognosis as well as shortage of facilities and support services for children with ASD.

5.5 Race

A higher prevalence of white patients (53%) was reflected in my study. This did not go against earlier studies where the prevalence of white populace with ASDs has been quite dominant. For example, in 11 cities of the United States of America, the estimated prevalence among white children was 15.8 per 1,000 compared to 12.3 per 1,000 for black children. It must be noted, however, that as the majority race group in SA is black, it would have been expected that the highest prevalence would have been of black patients. This speaks mostly to the fact that those of lower SES (likely black communities as a result of the legacies of apartheid) have difficulties accessing the services at Tara Hospital.

5.6 Home Language

The predominant home language was English (51%) which concurs with the higher racial prevalence of white patients in the period under study. Figure 4.5 also shows that eight percent of patients were Zulu and Afrikaans speaking, while Northern and Southern Sotho speakers were six percent. Tswana and Xhosa speakers were both three percent.

5.7 Schooling history

This study shows that 55 percent of the patients attended mainstream schools. It also shows that most children were identified to have ASD early between grade R and grade 2. In the view that children with ASD are on the spectrum, proper educational assessment is needed in order for them to be placed in the appropriate type of school. Lack of proper educational assessment accounts for the 12 percent of children who were not schooling at the time of their referral to Tara Hospital.

5.8 Family History of Autism

Studies regarding family and twins report that ASD has noteworthy heritable involvement although there seem to be no in-depth studies or knowledge of it.

Increased rates of ASD in siblings of an index child have been established to be as high as 50 percent, with two or more children with ASD in some families. In this study it has been demonstrated that 12 percent of cases have a sibling history of ASD which is in keeping with family and twin studies. Of interest is that more of the cases show high prevalence of a paternal heritable contribution than from the maternal side (30).

5.9 Psychiatric Comorbidities

The most common psychiatric comorbidity detected in this study was ADHD at 72 percent, followed by GAD at 34 percent. These high rates of ADHD are consistent with other previous studies reporting on children with ASDs and also with studies examining the occurrence of autistic symptoms among those with ADHD.

In a review of literature on comorbidities in 2013, the prevalence of ADHD in those with ASD was seen to have risen to 78%. It was found that in comparison with children with ASD to those without, that almost half (44.78%) of the ASD group met criteria for ADHD. Not only did they portray ADHD, but also other disorders such as depression and anxiety disorders, as had been systematically assessed in previous reports on children with ASDs (26).

5.10 Recommendations from psychological reports

Children with ASD attending mainstream schools have no greater academic success than those at special needs schools, but also benefit from referral to additional services (33). Speech and language therapy, occupational therapy and learning support assistants play a major role in promoting success. Although in this study 62 percent of cases did not have psychological reports, some of them were referred to either speech therapy or OT by the multi-disciplinary team (MDT) to improve their outcome. This correlates with other studies.

5.11 Limitations

As the study was conducted in a quaternary care hospital, and an “elite” facility, the patients may not be representative of children with autism in the general population and those presenting in primary, secondary and tertiary care. It has also been noted previously in this research report that lower SES groups lack access to this facility, offering a sample size not representative of the country’s population. Moreover, a

larger sample size could have generated a more representative outcome of the included variables in the study. Regarding the DSM criteria, factors relating to poor record keeping or lack of elaboration of documented symptoms made it difficult to decipher whether criteria had been met or not.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This study was a descriptive study that set out to establish the prevalence of ASD at Tara Hospital Child and Adolescent Clinic. In reviewing 76 charts an ASD prevalence of 5.5% was determined. The demographic profile of ASD patients attending the Clinic indicated a median index age of eight years with the patients being predominantly males from urban areas. The race of the patients was just over half white and most of the rest were black, most spoke English, and the majority were in school, with just over half attending mainstream schooling. Socioeconomic status was fairly evenly spread. There was some evidence of an ASD diagnosis in other family members. There was an incidental finding that showed a higher prevalence of paternal heritable contribution to ASD compared to the maternal side.

This study also aimed to determine the comorbid medical and psychiatric conditions identified in ASD patients at the clinic and found that the most common psychiatric comorbidities were ADHD and GAD, but there were very few medical comorbidities.

Finally, this study also aimed to investigate how ASD diagnoses are made in terms of DSM-IV-TR and DSM-5 criteria. It was found that diagnostic criteria were met fully in about three quarters of cases.

It can be concluded that the findings in this study are consistent with other studies conducted worldwide.

6.2 Recommendations

Ideally, all patients should have access to the appropriate level of their health care needs, regardless of their income status, but this research report has highlighted that this may not necessarily be the case, as alluded previously regarding patients of lower socio-economic standing. These are concerning limitations of the South African healthcare system as a whole and needs to be addressed. Community interventions such as advertising and educational campaigns, as well as open days in the hospital setting are just a few of the possible interventions that may be considered in addressing these.

Further research is needed to ascertain the factors that put certain persons at risk for ASD, as there is no known cause as yet. The health departments of low-income countries, especially in Africa, should put all available screening tools in place to address the issue of delayed diagnosis of ASD to ensure that there is timely and early diagnosis of ASD in children. Other areas of future research may include exploring the understanding, beliefs and practices of families of children diagnosed with ASD in SA about the condition, as they are the first contact of children with the condition. An investigation to correlate the severity of a child's ASD with their likelihood of attending school may also be a beneficial area of research.

There is an increasing need for training of educators, parents and health professionals on the early signs of autism. It is also necessary to develop strong linkages between all parties for early intervention systems to be successful. This is crucial to maximising a child's potential and quality of life.

Increasing public awareness of ASD in South Africa will improve identification of this developmental disorder.

Following on from this study, it would be interesting to measure the outcome of the cases that were referred based on the psychological report recommendations by the multidisciplinary team for further interventions.

Finally, concerted efforts are essential to provide support for persons with ASD, their families, and communities to improve long-term outcomes.

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APPENDIX ONE: DATA SOURCE SHEET

Confidential

Profile of patients attending at Tara Hospital Child and Adolescent Clinic

Age _____

Age at initial diagnosis _____

Gender
- ◯ Male
- ◯ Female

Race
- ◯ African
- ◯ Coloured
- ◯ Indian
- ◯ White
- ◯ Oriental
- ◯ Other

Home language
- ◯ English
- ◯ Afrikaans
- ◯ Zulu
- ◯ Xhosa
- ◯ N/S Sotho
- ◯ Other

Area of origin	◯Urban
	◯Rural
Highest Level of Education	◯Grade
	◯Level
Type of school attended	◯Main stream
	◯Remedial
	◯Special aid
	◯Skills training
Current State Grants	◯ Unknown
	◯ Care Dependency
	◯ Foster Grant
	◯ Child Support
	◯ Other
	◯ Nil
Income status	◯ H0
	◯ H1
	◯ H2
	◯ H3
	◯ P

Members of Household

	Zero	One	Two	Three	Four	Five	Six	Seven	More than seven
Adult Family	☽	☽	☽	☽	☽	☽	☽	☽	☽
Adult Other	☽	☽	☽	☽	☽	☽	☽	☽	☽
Minors	☽	☽	☽	☽	☽	☽	☽	☽	☽

Maternal Family Autistic History

☐ Nil

☐ Positive

☐ Not known

Paternal Family Autistic History

☐ Nil

☐ Positive

☐ Not known

Sibling Autistic History

☐ Nil

☐ Positive

☐ Not known

DSM-IV TR or DSM-5 Diagnostic Criteria met (11) ☐ Yes

☐ No

DSM-5 Diagnostic Criteria met (12) ☐ Yes

☐ No

Comorbid medical and psychiatric conditions:

1._____

2._____

3._____

4._____

Recommendations from psychological reports:

1._____

2._____

3._____

4._____

APPENDIX TWO: REQUEST TO CONDUCT RESEARCH AT TARA HOSPITAL

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
TARA the H. Moross Centre
Private Bag X7
RANDBURG 2125
(011) 535-3000
(011) 535-3026

TO : **DR. F.A OTIENO - CEO TARA HOSPITAL**

CC : **DR T. MADIGOE - CLINICAL HEAD**

FROM : **DR. R. PRICE-HUGHES – CHAIRPERSON TARA RESEARCH COMMITTEE**

DATE : **26 FEBRUARY 2018**

SUBJECT : **REQUEST FOR APPROVAL FOR DR M.P. PITJENG TO CONDUCT RESEARCH AT TARA HOSPITAL.**

NHRD Reference Number: 2018022018101115

---

1. Purpose

The purpose of this application is to request permission for Dr M.P.Pitjeng to conduct research at Tara Hospital. Dr Pitjeng is a registrar in the Department of Psychiatry and is currently enrolled as a Masters student at the University of the Witwatersrand. His research topic is The Prevalence of Autism Spectrum Disorders at Tara Hospital Child & Adolescent Clinic. This research will be a retrospective comparative study of adolescents with and without substance use who have been admitted in TARA hospital from 01 January 2012 till 31 December 2017. Files from that period will be used for data collection for this study. Protocol of this study will be sent to Ethics Committee and Research Committee in University of Witwatersrand for approval. No concerns were raised by the Tara Research Committee.

2. Background

Autism Spectrum Disorders (ASDs) prevalence estimates and increases have shown significant growth over shorter time frames and over decades, globally. In the population aged between 0-17 years, teenagers had the highest estimated proportion with diagnosis of ASDs with age. Sex, age, country of origin, familial income and education are factors that varied the proportion of children diagnosed with ASDs. Due to a sharp increase of ASDs without intellectual disability, the prevalence of children aged 0-17 years diagnosed with ASDs, had escalated by 3.5 fold between the years 2001 and 2011. It was widely speculated that a large number of the observed increase in the prevalence of ASDs might probably be due to increased awareness and ascertainment rates however, a true increase in incidence could not be ruled out.

3. Motivation

Autism Spectrum disorders have significant implications for health systems. Information obtained from this audit will improve our understanding and better inform our decision-making for this specific population of patients. Determining the prevalence of autism spectrum disorder will assist the public sector in ensuring service availability and awareness of the disorder.

Request by Dr Pitjeng to conduct research at Tara Hospital

4. Financial Implications

No costs will be incurred by either the hospital or the individual participants.

5. Recommendation

In view of the above it is recommended that permission is granted for Dr Pitjeng research at Tara Hospital pending registration through the NHRD database and Ethics Clearance from the Human Research Ethics Committee.

Proposer

Dr R. Price-Hughes

Chairperson Tara Research Committee

Date: 26 February 2018

Comments:

pending ethics approval.

Recommendation contained in paragraph 5: Recommended / Not Recommended/ As amended

pp

Dr T. Madigoe

Clinical Head

Date: 28.02.2018.

Comments:

Recommendation contained in paragraph 5: Approved / Not Approved/ As amended

Proof of registration on NHRD database must be provided
Ethical clearance must be available too.

Dr F.A Otieno

Chief Executive Officer

Date: 28/2/18

Request by Dr Pitjeng to conduct research at Tara Hospital

APPENDIX THREE: ETHICAL CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Dr Mokgadi Philemon Pitjeng

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M180413

NAME: (Principal Investigator)	Dr Mokgadi Philemon Pitjeng
DEPARTMENT:	Psychiatry Tara Hospital Child and Adolescent Clinic
PROJECT TITLE:	The Prevalence of Autism Spectrum Disorders at Tara Hospital Child and Adolescent Clinic
DATE CONSIDERED:	04/05/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr DCJ Hoffman

APPROVED BY: C B Penny

Prof C Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 09/05/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in April and will therefore be due in the month of April each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

17/05/2018
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX FOUR: APPROVAL OF TITLE

UNIVERSITY OF THE
WITWATERSRAND,
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Reference: Mrs Sandra Benn
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15 May 2018
Person No: 965989
PAG

Dr PM Pitjeng
Box 2080
Volkrust
2470
South Africa

Dear Dr Pitjeng

Master of Medicine: Approval of Title

We have pleasure in advising that your proposal entitled *The prevalence of Autism Spectrum Disorders at Tara Hospital Child and Adolescent Clinic* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX FIVE: DSM-IV CRITERIA

DSM-IV-TR Criteria

Pervasive Developmental Disorders

Autistic Disorder

An autism screening tool must meet all three primary areas defined by the DSM-IV-TR description for autistic disorder (numbers 1-3 under A below) to qualify for a positive rating from First Signs:

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) Qualitative impairment in social interaction, as manifested by at least two of the following:

(a) Marked impairment in the use of multiple nonverbal behaviours, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.

(b) Failure to develop peer relationships appropriate to developmental level.

(c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest).

(d) Lack of social or emotional reciprocity.

(2) Qualitative impairments in communication, as manifested by at least one of the following:

(a) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).

(b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.

(c) Stereotyped and repetitive use of language or idiosyncratic language.

(d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

(3) Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities as manifested by at least one of the following:

(a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.

(b) Apparently inflexible adherence to specific, non-functional routines or rituals.

(c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements).

(d) Persistent preoccupation with parts of objects.

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

1) Social interaction;

2) Language as used in social communication; or

3) Symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behaviour, interests, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes "atypical autism" – presentations that do not meet the criteria for autistic disorder because

of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Asperger's Disorder (or Asperger Syndrome)

An Asperger or HFA screening tool must meet all six areas defined by the DSM-IV-TR description of Asperger Syndrome (A-F below) to qualify for a positive rating from First Signs:

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

(1) Marked impairment in the use of multiple nonverbal behaviours, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.

(2) Failure to develop peer relationships appropriate to developmental level.

(3) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).

(4) Lack of social or emotional reciprocity.

B. Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

(1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.

(2) Apparently inflexible adherence to specific, non-functional routines or rituals

(3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).

(4) Persistent preoccupation with parts of objects.

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia (10).

APPENDIX SIX: DSM-5 CRITERIA

DSM-5 Criteria

Autism Spectrum Disorders

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour (e.g., extreme distress at small

changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hypoactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain or temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning (11).

Explanation of the Current Policy Regarding the Classification of Patients for the Determination of Fees

1. Introduction

Patients are classified into two main groups for the purposes of service fee determination:

a. Full paying patients

b. Subsidised patients

c. Free services.

This document explains the different categories of patients that have been identified and the associated fees for each category.

This classification of patient categories was accepted by the PHRC in April 2002.

Z Full Paying Patients

This category of patients includes but is not limited to externally funded patients, patients being treated by their private practitioner and certain categories of non-South African citizens. They are liable for the full UPFS fee as listed in Annexure A of this document. Table Ibelow gives full details of this category of patient.

Table 1 : Full Paying Patients

Group	Description
Externally funded patients	Patients whose health services are funded or partly funded in terms of: (a) the Compensation for Occupational Injuries and Diseases Act, 1993 (Act No 130 of 1993), (b) the Road Accident Fund created in terms of the Road Accident Fund Act, 1996 (Act No 56 of 1 996), (c) a medical scheme registered in terms of the Medical Schemes Act, 1998 (Act No 131 of 1998). 2. Patients treated on the account of: (a) another state department, (b) local authority, (c) foreign government, (d) any other employer.
Patients treated by a private practitioner	Any patient treated by his or her own private practitioner in a public health care facility will be liable to pay the full facility fee component for services rendered by the private practitioner at the facility and the full UPFS fee for any other service received by the patient.
Non South African citizens	Non South African citizens excluding the following: (a) immigrants permanently resident in the RSA but who have not attained citizenship (b) non South African citizens with temporary residence or work permits (c) persons from SADEC states who enter the RSA illegally.

3. Subsidised Patients

These are patients who do not fall in the category of full paying patients. Subsidised patients are categorised further based on their ability to pay for health services into four categories: HO, HI , H2 and H3. The fees payable by subsidised patients are expressed as a percentage of the fees payable by full paying patients as determined by the latest edition of the Uniform Patient Fee Schedule (UPFS).

The classification of dependants is determined by the classification of their guardians.

Subsidised patients are divided into two main groups:

34.1 a. Patients qualifying for full subsidisation: HO

Patients in this group receive all services free of charge. Patients must provide proof in terms of the conditions set out in Table 2 below in order to be classified into this group. Patients can only qualify for full subsidisation if they are referred to hospital from primary health care services.

This is not the default classification for a patient attending a public hospital. Unless proof of status is produced a patient is classified as HI to 3 depending on income. The default classification for a person without income is therefore HI .

Table 2: Patients qualifying for full subsidisation

Group	Description
Social pensioners	Recipients of the following types of pension/grants are classified as social pensioners: Old age pension Child support grant Veteran's pension Care dependency grant Pension for the blind Family allowance Maintenance grant Disability grant Single-care grant - Persons with mental disorders in need of care discharged from hospitals for the mentally ill but have not been decertified. Should the social pensioners also belong to a medical scheme, they will be regarded as full paying patients.
Formally unemployed	Persons supported by the Unemployment Insurance Fund (UIF). Proof of unemployment must be produced. (Contributors Record Card (UF74)).
Persons re-classified as HO	If a patient cannot afford the fees due on the basis of his or her original classification then the patient may be re-classified as HO by the person in charge of the health care facility.

34.2 b. Patients qualifying for partial subsidisation (HI, H2 &H3)

This is the default group for subsidised patients and the level of subsidisation depends on the assessment of income (frequently called the means test). The income cut-off point between HI and H2 patients is set at the 80^{ü1} income percentile as determined by Statistics South Africa. This means that 80% of employed individuals earn less than the cut-off amount per annum. Currently this amount is a yearly income of R36 000 for a single person. The cut-off between H2 and H3 is set at the 90th percentile,

namely R72 000 per annum. Patient earning above this amount will pay full UPFS fees. This is to encourage those individuals to take out medical aid. Table 4 below lists the subsidisation percentages for HI and H2 for the services covered by the UPFS. Illustrative amounts for some common services are listed in Table 5.

Table 3: Categories for Partial Subsidisation

Category	Means Test	Subsidisation (^{0}/0 of UPFS)
HI	Individual • Income less than R36 000 per annum Household : Income less than R50 000 per annum	Consultations : 20% with no differentiation for emergency consultations Inpatient : 1% of the UPFS general ward day tariff summed for 7 days for each 30 days or part thereof (Note 1). No differentiation on the basis of bed type. Patient and Emergency Transport: 5% Assistive devices : 25% All other services : Free Calculated amounts should be rounded to the nearest R5 to facilitate cash accounting.
	Individual • Income less than R72 000 per annum Household : Income less than RIOO 000 per annum	Consultations: 70% with differentiation for emergency consultations Inpatient days: 7% per day with differentiation on the basis of bed type Procedures, imaging and oral health: 50% Patient and Emergency Transport: 15% Assistive devices : 75% All other services : Free Calculated amounts should be rounded to the nearest R5 to facilitate cash accounting.
1-43	Individual Income greater or equal to R72 000 per annum Household : Income greater or equal to RI 00 000 per annum	All services listed in the UPFS at full price

Notes:

1 . The HI inpatient fee is expressed as a percentage of 7 days of the UPFS General Ward Inpatient fee to approximate the average length of stay of inpatients in this category. Although the fee calculation is based on 7 days, for HI patients this fee will be applicable for each 30 days of inpatient stay or part thereof. No differentiation is made on the basis of bed type.

Table 4: Illustrative Fees (based on 2002 UPFS fees)

Service	HI			
Hospital	Level 1 & 2	Level 3	Level 1 & 2	Level 3
Consultations Routine, General Practitioner Emergency, General Practitioner	 R20 R20	 R20 R20	 R70 R145	R85 RI 55
Inpatient day General ward, GP ICU, GP (per 12hours)	 R50 per 30d R50 per 30d	R60 per 30d R60 per 30d	 R50 per day R 110 per 12h	 R60 per day RI 35 per 12h

Procedure, Imaging & Oral Health			R155	R170
Ambulatory procedure Cat A (GP)		Free	RI	RI
Theatre procedure Cat C (GP)	Free	Free	420	643
Category A X-ray (Radiographer)	Free	Free	R30	R35
Category B Oral Health (Non specialist)	Free	Free	R40	R45
Patient & Emergency Transport				
Patient Transport (per 100km)	RIO	RIO		
Basic Life Support (per 50km)	R25	R25	R70	R70
Intermediate Life Support (per 50km)	R30	R30	R95	R95
Advanced Life Support (per 50km)	R50	R50	R155	R155

4. Free Services.

There exist certain circumstances under which patients will receive services free of charge independently of their classification as full paying or subsidised patients. These circumstances have a statutory basis and apply only to the episode of care directly related to the circumstances under which the patient has qualified for free services. Table 5 below summarises the circumstances under which patients will qualify for free services.

Table 5: Free Services

Service	Basis
Free health services for pregnant Women and children under the age of 6 years	NOTICE 657 OF 1994, 1 July 1994 As from 1 June 1994, free health services must be provided to . a. pregnant women for the period commencing from the time the pregnancy is diagnosed to forty-two days after the pregnancy has terminated, or if a complication has developed as result of the pregnancy, until the patient has been cured or the conditions as result of the complication has stabilised; b. children under the age of six years; c. non-citizens of South Africa who are in the groups mentioned in par (a) and (b), and who incidentally develop a health problem whilst in South Africa. Free health services included the rendering of all available health services to the persons mentioned in above, including the rendering of free health services to pregnant women for conditions that are not related to the pregnancy. The following persons are excluded from the free health services: a. Persons and their dependents who are members of a medical scheme. b. Non-citizens of South Africa who visit South Africa specifically for the purpose of obtaining health care.
Free primary health care services	Notice 1514 of 1996, dated 17 October 1996 1. Primary health care services are available free of charge at

	State health care facilities. 2. Services referred to in paragraph 1 are available at(a) State health care facilities, namely(i) clinics; (ii) community health centres; (iii) mobile clinics; (iv) satellite clinics; (b) health care facilities that are funded or subsidised fully or partly by the State; (c) hospitals in geographical areas where facilities referred to in subparagraphs (a) and (b) are not available and which are designated by a province for that purpose. 3. Persons receiving primary health care services at facilities other than those referred to in paragraph 2 shall be liable to pay existing rates and an additional fee as determined by the province. 4. An additional fee referred to in paragraph 3 shall not be payable in the case of emergency care. 5. Only South African citizens shall be entitled to free primary health care services. 6. The following persons shall not be entitled to free primary health care services: (a) Persons and their dependents who are members of a medical aid scheme; (b) Persons who make use of the services of medical practitioners of their choice instead of those made available by the health care facility.
Termination of Pregnancy	Act 92 of 1996. Services in respect of the termination of pregnancy to be rendered free of charge and, if complications have developed as a result of the termination, until the patient has been cured or the conditions as a result of the complication have stabilised, under the following conditions:- Upon request of a women during the first 12 weeks of pregnancy; 2. From the 13th to the 20th week of pregnancy if a medical practitioner, after consultation with the woman, is of the opinion that a. continued pregnancy poses a risk to the woman's physical or mental health b. a substantial risk exists that the foetus would suffer from a severe physical or mental abnormality c. the pregnancy resulted from rape or incest d. the continued pregnancy would significantly affect the social or economic circumstances of the woman 3. after the 20th week of pregnancy if a medical practitioner, after consultation with another medical practitioner or midwife, is of the opinion that continued pregnancy would a. endanger the woman's life b. result in severe malformation of the foetus c. would pose risk of injury to the foetus

Criminal Procedure Act	Act 51 of 1977 Services rendered in when requested by the Assault: Rape: Post mortem: Corporal Punishment: erms of the above act, as well as the following, responsible authorising body. The examination of the alleged victim and taking of samples and completion of the necessary documentation The examination of the alleged victim and taking of samples and completion of the necessary documentation The performance of autopsies and attendance at exhumations Preliminary examination for the administration of corporal punishment by the Police Service and attendance at the administration at corporal punishment in prisons.
Child Care Act	Act No 74 of 1983, Section 15. Children who in terms of the above Act are committed to the care of a children's home, industrial school or foster parents.
Persons with mental disorders	Mental Health Act (Act 18 of 1973) The examination of prisoners and detainees for medico-legal purposes with a view to their referral for observation in terms of the Act. Mentally disturbed patients admitted to psychiatric hospitals in terms of section 9 of the Act.
Infectious, formidable and/or notifiable Diseases	Venereal diseases (excluding complications) - only on an outpatient basis and including the following: Syphilis, gonorrhoea, chancroid, LGV (lymphogranuloma venereum), non-specific urethritis, venereal warts, granuloma inguinale, ulcus molle, herpes genitalis. 2. Pulmonary tuberculoses. 3. Leprosy. 4. Cholera. 5. Diphtheria. 6. Plague. 7. Typhoid and paratyphoid. 8. Haemorrhagic fevers. 9. Meningococcal meningitis. 10. Aids - only the initial diagnostic procedures and attendant laboratory services are free if patients specifically ask for the HIV test to be done. Patients requiring treatment are assessed at the prescribed tariffs for any hospitalisation and accompanying services.
Other exempt conditions	Persons suffering from the following diseases for treatment only relating to such diseases: 1. Malnutrition 2. Pellagra 3. Any other condition or service as determined by a province
Donors	A donor is a person who, of their own free will, presents themselves specifically for the donation of an organ, blood, milk or human tissue. The exem tion refers to services rendered in res ct of the donation.