AN ANALYSIS OF THE REFERRAL SYSTEM TO THE NEURODEVELOPMENTAL CLINIC AT A TERTIARY HOSPITAL IN THE EASTERN CAPE

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A research report submitted to the Faculty of Health Sciences, the University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine in Child Health Neurodevelopment

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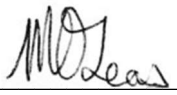
DECLARATION

I, Michelle Lee Olander-Deas, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Medicine in Child Health Neurodevelopment in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signature 

_16th___day of _November__ 2021 in __East London_____

DEDICATION

To my amazing husband Matthew for your never-ending love and support, and my two beautiful children Luke and Hannah.

ABSTRACT

Early diagnosis and initiation of management of neurodevelopmental disorders improve outcomes. Time from caregiver initial concern to the point when a diagnosis is made has not been described in patients attending a tertiary-level hospital in the Eastern Cape. A descriptive cross-sectional study was conducted to assess waiting times before the neurodevelopmental clinic (NDC) appointment and to describe the range of neurodevelopmental disorders seen at the NDC Frere Hospital, Eastern Cape, South Africa. A total of 50 children were enrolled in the study. The mean time from initial parental concern until the NDC appointment was 19.3 months, with half of this time being before accessing the healthcare system. Time spent on the waiting list of the NDC contributed 20.2% to the total waiting period. The top two neurodevelopmental diagnoses seen at the NDC were attention deficit hyperactivity disorder (n=21; 42.0%) and autism spectrum disorder (n=12; 24.0%). Several components within the referral pathway which resulted in prolonged referral timelines have been identified. Recommendations are made for further avenues of research and service improvements.

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NOMENCLATURE

ASD	Autism spectrum disorder
ADHD	Attention deficit hyperactivity disorder
CI	Confidence interval
COVID-19	Coronavirus disease of 2019
CP	Cerebral palsy
DBST	District-based support team
DSM-V	*Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*
GDD	Global developmental delay
ICD-10	*International Statistical Classification of Diseases 10th Revision*
ICD-11	*International Statistical Classification of Diseases 11th Revision*
ID	Intellectual disability
NDC	Neurodevelopmental clinic
NDD	Neurodevelopmental disorders
ODD	Oppositional defiant disorder
SD	Standard deviation
SE	Standard error
USA	United States of America

CHAPTER 1 – INTRODUCTION

This introduction chapter consists of five sections. The first section is background information, briefly introducing neurodevelopmental disorders (NDDs) and other disorders which form part of this study. This will be followed by the study rationale, which will introduce the neurodevelopmental clinic (NDC) environment, where the research was conducted, and the unique challenges faced by this clinic. The final three sections briefly explain the research question, followed by the aims and objectives, and why these were included in the research study.

1.1 Background

The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-V) describes NDDs as a group of disorders with onset in the developmental period[1]. Typically, symptoms manifest early, frequently before the child enters formal schooling[1]. These disorders result in impairments in different spheres of development, such as personal, social and academic functioning, and the ranges of deficits vary, from very specific areas of limitations to involvement of several or all the spheres of development[1].

The disorders listed in the DSM-V and classified in the *International Statistical Classification of Diseases 10th Revision* (ICD-10) as NDDs include disorders such as the following: attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), intellectual disability (ID), global developmental delay (GDD), specific learning disorders and various communication (speech and language) disorders[1,2]. These disorders, however, are not the full spectrum of disorders seen at the Frere Hospital's NDC, where the research study was conducted.

Disorders which are classified in the DSM-V as other psychiatric disorders, including certain anxiety disorders, elimination disorders, conduct disorder and oppositional defiant disorder (ODD), and disorders which are classified by the ICD-10 as medical and neurological disorders, such as certain genetic syndromes and cerebral palsy (CP) are also encountered[1,2].

Most, if not all the disorders listed, benefit from early identification and appropriate intervention[3-7]. The reality, however, is that early management of these disorders especially in South Africa is extremely challenging[6,8].

1.2 Study Rationale

The Eastern Cape Province, in 2016, had an estimated total population of 6.99 million people[9]. There are three large cities within the Eastern Cape Province, with tertiary level services. Each tertiary level service has its own district-level health services, which refer patients. East London thus, provides tertiary services to the Central Eastern Cape Province, which has an estimated population of 2.8 million people[9].

Frere Hospital is one of the two public hospitals in East London, Eastern Cape, South Africa[10]. It offers tertiary level specialized services, such as the NDC[10]. The role of the NDC is to assess and offer medical management, if applicable, to children with NDDs. East London does not have a developmental paediatrician or child and adolescent psychiatrist subspecialist and Frere Hospital does not have a general psychiatry or psychology department. The NDC is staffed by two Paediatricians, one is a general paediatrician, the other is registered as a paediatric neurologist in Europe. Due to the workloads of the paediatric services the NDC is limited to a clinic once a week.

The NDC accepts referrals from doctors (paediatricians and general practitioners), other healthcare providers (such as occupational and speech therapists, and psychologists) in the public and private sector, from school teachers, and on occasion parental self-referral. The clinic numbers are limited to ten patients per clinic: five new referrals and five patients returning for follow-up. Known patients, who require adjustments of medication or any other assistance, but do not have an appointment, are also assisted. In 2016 and 2017 all available appointments for new patients were filled ten months to over a year in advance (unpublished data). Follow-up care of patients, within reasonable time-frames, was also challenging.

1.3 Research Question

As previously stated, early diagnosis and intervention have the potential to significantly improve the prognosis of many NDDs[3-7]. As previously stated, new patient appointments were filled up to a year in advance in 2016 and 2017. This waiting period added a year to the time between the initial concern of an NDD and a formal diagnosis. It was imperative to know the impact the NDC waiting list time had on the process of diagnosis and management of an NDD. In order to answer this question, research was required to ascertain the total time taken from a concern of an NDD to the child's first appointment at the NDC.

When developing the research proposal and reviewing the available literature, the researcher discovered that there are other questions that require answers. For example: "Due to the overlap of specialities providing care, and differences in terminology and classifications of these disorders, what disorders are specifically seen in the Frere Hospital's NDC setting?" These questions became the basis of the secondary objectives of the research study.

1.4 Study Aim

The aim is to describe and assess the current pathways of referral, to the NDC, at a tertiary level care facility in the Eastern Cape.

1.5 Objectives

1.5.1 Primary objective

To describe and map out the referral process, by for example: looking at where and by whom patients are referred, and where time delays may occur.

1.5.2 Secondary objectives

1. To describe the demographics of the patients referred to the NDC.
2. To describe the spectrum of NDDs seen at a tertiary level care facility in the Eastern Cape.

CHAPTER 2 – LITERATURE REVIEW

2.1 Overview of the Literature Review

This research study has two main themes of interest: the spectrum of disorders seen at the NDC and the referral pathway to the NDC. The literature review is thus divided into two sections each providing information on one of these themes. The first section explores the prevalence of NDDs in the paediatric population, the data is presented in the text as per the original source. Prevalence rates presented in the text have been summarised where possible at the end of the subsection in tables 2.2 and 2.3, data presented in the table is converted to percentages for ease of comparison. The second section presents literature about the referral process and includes the referring entities, the time taken from being placed onto a waiting list, time until consultation at the NDC, the age of children at initial concern, and the age of children at initial assessment for or diagnosis of an NDD. The difference between the age at initial concern and diagnosis can be used as a marker of the total time taken in obtaining a diagnosis of an NDD.

Information for this literature review was obtained from a wide variety of sources. Database searches were conducted using Pubmed, Scopus, Google Scholar, ClinicalKey and AccessPediatrics. The main search terms utilised included: “neurodevelopmental disorder”, “neurological disability” and “neurodevelopmental disability” which are often used interchangeably in the literature, followed by searches relating to specific disorders of interest.

In order to find relevant literature and research assessing the referral pathways of children with NDDs, these terms were searched in conjunction with variations of additional search terms which included “waitlist”, “wait time”, “waiting list time”, “time delays”, “time taken”, “timeline”, “time to referral”, “time to diagnosis”, “access to healthcare services” and “referral pathways” The literature publication period was set between 2000 - 2021 except for meta-analyses and scoping reviews. Reference lists of meta-analyses and scoping reviews presented were scrutinised for duplication of studies presented in their original format in this review.

2.2 Neurodevelopmental Disorders Defined

The term NDDs covers a wide range of well-defined and less well-defined disorders. As a broad group, they are defined in the DSM-V as: "a group of conditions, with onset in the developmental period. The disorders typically manifest early on during development, before the child enters grade school, and are characterised by developmental deficits that produce impairments of personal, social, academic, or occupational functioning."[1] The following disorders are included under NDDs in the DSM-V: ID, communication disorders, ASD, ADHD, specific learning disorder, motor disorders and other NDDs[1]. The Frere Hospital's NDC provides management for a wide range of these disorders listed in the DSM-V, as well as psychiatric disorders such as ODD, anxiety and depression. The clinical management of the disorders which are encountered, as well as the literature available on these disorders, tends to be divided among the following three subspecialities: paediatric neurology, neurodevelopmental paediatrics, and child and adolescent psychiatry.

2.3 The Burden of Neurodevelopmental Disorders

Due to the very wide scope of disorders encompassed under the umbrella term of NDDs, the estimated prevalence of NDDs differs widely between publications.

2.3.1 Global burden

An analysis study published in The Lancet Global Health in 2018, estimated the global prevalence of epilepsy, ID, hearing and vision loss, ASD and ADHD in children from birth to five years old[11]. The total number of children younger than 5 years old with any of the six NDDs – after the authors adjusted for comorbidity between ID and ASD – was 52.9 million (95% Uncertainty Index 48.7–57.3) in 2016[11]. They also concluded that of the children with NDDs, only 5.1% lived in high-income countries whilst the majority (94.9%) lived in low- and middle-income countries[11]. Approximately 54.0% of children with any NDD were male, although the ratio of male to female children varied by type of impairment[11]. Polanczyk et al. conducted a meta-analysis to estimate the worldwide prevalence of mental disorders (ADHD, disruptive,

anxiety and depressive disorders) in children and adolescents[12]. Studies conducted between 1985 and 2012 from 27 countries were included, the pooled prevalence was found to be 13.4% (95% CI 11.3 – 15.9)[12].

2.3.2 High-income countries

In high-income countries the reported prevalence of NDDs is high[13,14]. Data published in 2019, estimated the overall prevalence of NDDs, in American children between the ages of 3-17 years old, as 17.8%[13]. This study included ten categories of disabilities/disorders, including ADHD, ASD, sensory disabilities, ID, learning disability and a catch-all category "other developmental delay."[13] Gyllenberg et al. utilised the *Medical Birth Register* and *Finnish Hospital Discharge Register*, to investigate specialized service use for psychiatric disorders and NDDs in Finland[14]. They found the cumulative incidence, in children from birth to 14 years old, to be 12.9%[14].

2.3.4 Low to middle-income countries

Very few studies have investigated the prevalence of NDDs in low- to middle-income countries. A study by Arora et al. conducted in five regions of India on children aged 2-9 years reported an overall confirmed prevalence of a single NDD as 12.0% (95% CI 11.0-13.0)[15]. Of the children classified as having an NDD, 21.7% (95% CI 18.1-25.7) had two or more NDDs[15]. The prevalence for moderate/severe neurological impairment in six- to nine-year-old children in rural Kenya, according to Mung'ala-Odera et al., was 61/1000 (95% CI 48–74)[16].

A South African study by Couper J. conducted in rural KwaZulu-Natal included 2 036 children from birth to ten years of age and reported a confirmed disability rate of 60/1000 (95% CI 50-71)[17]. The disabilities with the highest prevalence were reported as mild perceptual or learning disability (17/1000), CP (10/1000) and hearing loss (10/1000)[17].

Both the studies by Couper J. and Arora et al. identified children with concerns regarding the following six areas: motor, cognitive, vision, hearing, speech and seizures[15,17]. The study by

Arora et al. also included ASD in all children, and ADHD and learning disorders in children aged six to nine years old[15]. The study by Mung'ala-Odera et al. identified children in five of the six areas as speech disorders were not included[16].

2.4 The Spectrum of Disorders of Interest - Prevalence of Specific Disorders

The NDDs discussed in this section were decided according to the disorders most commonly encountered at the Frere Hospital's NDC. A summary of recently published prevalence rates of the disorders of interest, in the United States of America (USA) will be presented first. International and local prevalence rates will be presented depending on the availability of data. Each disorder of interest in this research study will then be briefly defined and discussed. The subsection will be concluded by the presentations of a study which was designed to assess the prevalence of neurodevelopmental and psychiatric disorders in a primary paediatric clinic, rather than the general population, and a study which was of a similar study design to this research study, as these studies represent an expected match to the anticipated results of this study.

2.4.1 Prevalence of specific disorders - a summary of a national survey

Table 2.1 summarises recently published prevalence rates (2015-2017) of some of the disorders of interest, all sources extrapolated the data from the USA's National Survey of Child Health[13,18,19]. The data displayed will be discussed in the section relevant to the disorder.

TABLE 2.1 Summary of the prevalence rates of neurodevelopmental disorders in the USA

Diagnosis (age of population)	Prevalence %
ADHD (3-17 years)[13]	9.5
ADHD (2-17 years)[18]	9.4
Learning disability (3-17years)[13]	7.9
Behavioural/conduct problems (3-17 years)[19]	7.4
Anxiety (3-17 years)[19]	7.1
Depression (3-17 years)[19]	3.2
ASD (3-17 years)[13]	2.5
Stuttering and stammering (3-17 years)[13]	2.1
ID (3-17 years)[13]	1.2
Seizures (3-17 years)[13]	0.8
CP (3-17 years)[13]	0.3

2.4.2 Attention deficit hyperactivity disorder

In the DSM-V ADHD is broadly defined as "a neurodevelopmental disorder defined by impairing levels of inattention, disorganization, and/or hyperactivity-impulsivity."[1] The DSM-V proceeds to explain and provide examples of each component of the definition. The disorder has strict criteria which need to be met for the diagnosis to be made, which is beyond the scope of this review.

A meta-analysis estimating the global prevalence of ADHD in children and adolescents, based on studies published between 1994 and 2010, calculated the prevalence of ADHD to range from 5.9 to 7.1%, depending on the ADHD definition criteria of the study (e.g., parental or teacher rating vs. formal diagnosis)[20]. Another report which included studies from a broader time frame (1985 to 2012), reported a prevalence of 3.4% (95% CI 2.6-4.5)[12]. Contrasting this, a meta-analysis by Fayyad et al. estimating the prevalence of AHDH in the adult population including literature published between 2001-2012 reported an ADHD prevalence of 2.8%[21]. Higher rates were reported in high- (3.6%) and upper-middle- (3.0%) than in low-/lower-middle- (1.4%) income countries[21].

The estimated prevalence in the USA (table 2.1) in child and adolescent populations is 9.4-9.5%[13,18]. Zablotsky et al. reported an increase in the prevalence of ADHD from 8.5% in 2009-2011 to 9.5%[13]. The authors postulated that this increase was a result of better identification of children who meet the criteria for ADHD[13].

A review by Bakare M. on studies conducted between 1998 and 2010 in African countries including studies from South Africa, found the prevalence to be 5.4 to 8.7% in school-going children[22].

2.4.3 Global developmental delay and intellectual disability

These two disorders are described together as they are considered to be on a continuum which is illustrated by the overview descriptions of the disorders within the DSM-V[1]. ID is described as being "characterized by deficits in general mental abilities, such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and learning from experience."[1] GDD is defined in the DSM-V as: "reserved for individuals under the age of 5 years when the clinical severity level cannot be reliably assessed during early childhood. This category is diagnosed when an individual fails to meet expected developmental milestones in several areas of intellectual functioning."[1]

ID is estimated (1980 - 2009 data) at 10.37/1000 population (95% CI 9.55–11.18) worldwide[23]. Higher prevalence rates are seen in low- and middle-income countries, 16.41 (95% CI 11.14–21.68) and 15.94 (95% CI 13.56–18.32) /1000 population, compared to lower rates in high-income countries 9.21 (95% CI 8.46–9.96) /1000 population[23]. Current prevalence estimates in the USA are 1.2%, whilst in India a large study (12 520 children aged 0-5 years) found a mere 0.16% of the children suffered from "mental retardation and related disorders."[13,24] Included in the meta-analysis estimating the worldwide prevalence of ID is a local study by Christianson et al. which was conducted in Bushbuckridge, located in the south-eastern part of Limpopo and north-eastern part of Mpumalanga Province[25,26]. Christianson et. al. reported a prevalence rate of 35.6/1000 children aged 2-9 years[26].

Estimates for GDD are not widely reported and generally, the figures are extrapolated from ID figures. The 2010 report by the Quality Standards Subcommittee of the American Academy of Neurology and The Practice Committee of the Child Neurology Society's estimates the prevalence between 1-3%[27].

2.4.4 Learning disorder

The term specific learning disorder is the umbrella term used by the DSM-V, and is diagnosed "when there are specific deficits in an individual's ability to perceive or process information efficiently and accurately."[1] The description specifies that the disorder "is characterized by persistent and impairing difficulties with learning foundational academic skills in reading, writing, and/or math."[1] These disorders thus differ from ID, as they are impairments in specific academic and not global intellectual skills[1]. Within the literature however, the terms "learning disability" or "learning disorder" are more frequently utilised, and the ICD-11 (which comes into effect on 1 January 2022), has renamed the group of disorders "developmental learning disorder", from the term "specific developmental disorders of scholastic skills" used in the ICD-10[2,11,13-15,17,23,28-30]. It is important to note that mild forms of ID can also be reported as "learning disability" in the literature[23,30].

Global prevalence data for learning disorders has not been published. In the USA, however, it is the second most prevalent disorder of interest with a reported prevalence of 7.9%[13]. A study conducted in Brazil by Fortes et al. found prevalence rates in children, in their second to sixth grade of school to range between 5.4% for impairments in writing skills to 7.6% for global (reading, writing and mathematic) skills[31]. In Northern Ireland among children in years 4 to 6 of school, Morsanyi et al. found a prevalence rate of 5.7% of a learning disorder in mathematics[32].

2.4.5 Speech and language disorders

The DSM-V lists four disorders as communication disorders, these are:

- Language disorder, which is defined as "deficits in the development and use of language."[1] Language is defined as "the form, function, and use of a conventional system of symbols (i.e., spoken words, sign language, written words, pictures) in a rule-governed manner for communication."[1]
- Speech sound disorder, which describes a deficit in the development and use of speech, and encompasses aspects such as "articulation, fluency, voice, and resonance quality."[1]
- Childhood-onset fluency disorder (stuttering) which is "characterized by disturbances of the normal fluency and motor production of speech, including repetitive sounds or syllables, prolongation of consonants or vowel sounds, broken words, blocking, or words produced with an excess of physical tension."[1]
- And social (pragmatic) communication disorder, which is a deficit in the development of social communication[1]. Communication is described as "any verbal or nonverbal behavior (whether intentional or unintentional) that influences the behavior, ideas, or attitudes of another individual."[1]

The first three disorders listed above are all new names for disorders included in previous versions of the DSM e.g., language disorder replaced expressive and mixed receptive-expressive language disorders, whilst social communication disorder is a new diagnostic category[1,33]. It is important to note that social communication disorder's diagnostic criterion is similar to diagnostic criterion section 'A' of ASD[1]. The defining difference between the two diagnoses is the presence of "restricted/repetitive patterns of behavior, interests, or activities" in ASD, with the absence of these behaviours in social communication disorder[1].

Prevalence statistics on speech and language disorders is limited, outdated, and variable depending on the subtype and the age of the population studied. In the report entitled *Speech and language disorders in children: Implications for the Social Security Administration's Supplemental Security Income program* the variability is well illustrated[34]. The prevalence of the different speech and language disorders range from 3.2% to 15.6%[34]. In broad disability or neuro-disability studies the speech disorder is often restricted to specific disorders such as

"stuttering and stammering" which Zablotsky et al. reported as 2.1%, while 0.6% are reported by Nair et al., to have "inadequate and unclear speech and stammering."[13,24]

2.4.6 Autism spectrum disorder

According to the DSM-V ASD is "characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships."[1] In addition to the social communication deficits, the diagnosis of ASD requires "the presence of restricted, repetitive patterns of behavior, interests, or activities." [1] A meta-analysis published in 2012 reported a median prevalence estimate over many years and many countries of 6.2 / 1000 children[35]. In the USA the latest figures are higher, ranging from 1.9% to 2.5%[13,36]. This is in keeping with the trends of ASD prevalence as there has been a steady increase in the prevalence of ASD[37,38]. The hypotheses for these increased figures are extensive and are not included in this literature review.

A 2016 review article on the research available on ASD in Sub-Saharan Africa found only three small studies published between 2012 and 2014 which were designed specifically to estimate the prevalence of ASD, thus the authors concluded that the research was "too scanty to provide the required information to plan adequately for effective intervention strategies for children with ASD in sub-Saharan Africa."[39] Two of the three studies estimated prevalence in specific and not the general population, the third reported an unadjusted prevalence of 6.8/1000[39,40].

2.4.7 Psychiatric disorders

Conduct disorder, ODD, anxiety and depressive disorders are not listed as NDDs in the DSM-V[1]. Conduct disorder and ODD are included under the umbrella of "Disruptive, Impulse-Control, and Conduct Disorders" as disorders in this category of the DSM-V relate to "conditions involving problems in the self-control of emotions and behaviors."[1] Anxiety and depressive disorders are umbrella terms with several disorders listed under each term[1]. All these

disorders however are disorders of interest, they are suspected and screened for by the medical personnel working in the NDC, as they are common and occur frequently as comorbid disorders in children with other NDDs[12,14,18,19,22,31,41].

Certain literature uses the umbrella term of "disruptive disorders" while others prefer "behavioural/conduct problems". Regardless of the terminology used, the current estimates of the prevalence of these disorders, in children and adolescents are 5.7% (95% CI 4.0–8.1) globally and 7.4% in the USA[12,19]. Anxiety disorders were reported as having a prevalence of 6.5% (95% CI 4.7–9.1) globally and 7.1% in the USA[12,19]. Depressive disorders prevalence rates are reported at 2.6% (95% CI 1.7–3.9) globally and 3.2% in the USA[12,19].

2.4.8 Other disorders

Other disorders that may be encountered occasionally by the Frere Hospital's NDC are CP; delays in motor skills that are not caused by CP or as part of GDD; epilepsy and other neurological disorders; and genetic syndromes. It is clear from the literature presented in table 2.1 that seizures and CP are common disorders with prevalence rates in the USA of 0.8% and 0.3% respectively[13]. Sub-Saharan Africa does however have a high proportion (30.4%) of the world's children under five with epilepsy[11]. Worldwide, in children born between 1985 and 2011 CP was found to affect 2.11/1000 live births (95% CI 1.98–2.25)[42]. Children with these disorders however are more likely to be referred to the neurology clinic at Frere Hospital and thus are not anticipated to be encountered as frequently as the other disorders presented in this review.

2.4.9 Prevalence of specific disorders in general paediatric and neurodevelopmental clinics

This literature review would not be complete without discussing the expected profile of the disorders seen by NDCs. For this estimation, two studies will be discussed. The first is a multi-centre study conducted in Spain by Mariño et al. designed to find the prevalence of NDDs and psychiatric disorders in children presenting at a general paediatric outpatient clinic[41]. ADHD

was found to be the most common disorder of interest identified (5.4%), followed by speech and language disorders and learning disability (3.4 and 3.3% respectively)[41]. Anxiety (2.3%), behavioural/conduct disorders (1.9%), ID (1.0%), ASD (0.9%) and GDD (0.5%) were the least frequently seen, and disorders such as seizures and CP was not reported in this study[41].

The second study is a study by Shevell et al., which is of a similar design to the current study presented in this research report[43]. Unfortunately, this study was conducted on children five years old and younger, and thus only a few of the disorders of interest are represented[43]. The study gives the frequency of the disorders diagnosed by the developmental paediatric and paediatric neurology clinics in a single tertiary hospital in Montreal, Canada and compares the diagnoses to the reason for the referral[43]. The most frequently diagnosed disorders were: GDD (35.7%), developmental language disorder (32.1%), and ASD (22.3%)[43]. The fourth diagnostic category which could be assigned to the population was motor delay/CP and was diagnosed in 9.8% of the study population[43].

2.5 The Spectrum of Disorders of Interest – Further Challenges: The Confounding Factor of Comorbidity

A major challenge, when estimating the prevalence of NDDs and child psychiatric disorders is that comorbidity is a common occurrence[12,14-16,18,19,21,22,31,32,34,38,41,44]. Mariño et al. reported comorbidity in 47% of the study population[41]. In Finland it was found that 51.4% of children with ASD and 45.1% of children diagnosed with ADHD, were also diagnosed with learning and coordination disorders[14]. In the same study, almost a quarter of the children diagnosed with ASD also fulfilled the diagnostic criteria for ADHD[14]. This is echoed in a report by Ghandour et al., reporting on the findings of the 2016 USA's National Survey of Child Health, nearly three-quarters of children who were currently depressed had a comorbid anxiety disorder and a third of children with anxiety disorders fulfilled the criteria for a depressive disorder[19]. These examples illustrate why it can be extremely difficult to ascertain the true numbers of children with NDDs per capita purely by pooling prevalence statistics.

2.6 The Spectrum of Disorders of Interest - Demographic Effect

The prevalence of NDDs can also be affected by population demographics. The age of the population affects the prevalence of disorders[13-15,18,19,21,23,31,34,35,41]. Based on data from the USA's National Survey of Child Health, Zablotsky et al. reports the prevalence of ADHD as: 2.13% in 2–5-year-olds, 9.26% in 6–11-year-olds, and 12.30% in 12–17-year-olds[13]. Similarly, the age of the population affects the comorbidity patterns[14,44]. Comorbidity of ADHD and behavioural disorders are higher in childhood, whilst comorbid depressive disorders are less frequent[14,44]. In contrast depressive disorders were the most common comorbidity reported by first-year university students with ADHD[44].

Gender has also been reported to affect the prevalence of certain NDDs[11,13,14,17-23,26,31,34-36,41,43,45]. The literature reviewed on pooled NDDs revealed a male predominance regardless of the economic status of the country[11,13-15,17,41,43]. In certain disorders, the male to female ratio can vary dramatically, especially among different age groups and geographical locations[18,45]. ADHD in the USA has an overall gender ratio of 2.3 males to 1 female, however the ADHD Observational Research in Europe (ADORE) study, which is a longitudinal observational study in 10 countries in Europe (population aged 6–18 years) found that the ratio (male : female) varied from 3:1 in Norway to 10:1 in Denmark and 16:1 in Austria[18,45]. Potential reasons for this gender difference is that boys present with more hyperactivity, impulsivity and externalising behaviours compared to girls, who present with more inattention and internalising behaviours, thus girls are often overlooked as they are less disruptive[46-48]. Girls also tend to be more perfectionistic and thus they compensate for inattention until academic demand exceeds this capacity[46,48].

Geographical location, race, ethnicity, culture and socio-economic status have also been reported to affect the prevalence rates of NDDs[11,13,18,19,21-23,31,36,49]. In Africa, CP is often secondary to birth asphyxia / neonatal encephalopathy, hyperbilirubinemia and neurological infections such as meningitis and cerebral malaria[8,50,51]. The World Health Organisation reports that the African region accounted for about 94% of malaria cases worldwide in 2019[52]. This is in contrast to high-income countries where the major risk factors for CP are prematurity, and birth weights in the extremely low birth weight (<1000g) and very low birth weight (1000 -

1499g) categories[43,54]. This example illustrates how the underlying aetiology of disorders differ by geographical location and socio-economic status, and that this may affect prevalence rates.

2.7 Closure of the Neurodevelopmental Disorders Literature Review and Introduction of the Referral Pathways Literature Review

This ends the presentation of the available literature on potential NDDs that are of interest in this research study. Relevant data presented is summarised where possible in tables 2.2 and 2.3. The remainder of the literature review will now focus on the referral pathways to neurodevelopmental services. Included in this final component of the literature review is any literature found about the timing or ages of initial concerns and diagnoses of children with NDDs, the availability of subspecialists, trends in referring healthcare providers and waiting list times.

TABLE 2.2 Summary of the literature review prevalence of disorders – part 1

	Estimated prevalence based on meta-analyses, scoping reviews, academic consensus and large surveys			
	Globally[12,20,23,27]	Africa[22]	USA[13,19,34]	Finland[14]*
Diagnosis				
ADHD	3.4 – 7.1%	5.4 – 8.7%	9.5%	2.0%
ID	1.0%	-	1.2%	-
GDD	1.0 – 3.0%	-	-	-
Learning disorders	-	-	7.9%	5.5%
Speech & Language disorders	-	-	2.1% - 15.6%	-
ASD	0.6%#	-	2.5%	1.0%
Behaviour & conduct disorders	5.7%	-	7.4%	1.7%
Anxiety disorders	6.5%	-	7.1%	2.2%
Depressive disorders	2.6%	-	3.2%	1.4%
CP	-	-	0.3%	-
Epilepsy	-	-	0.8%	-

* Cumulative incidence, not prevalence reported
# Based on a meta-analysis which included studies conducted 1966 – 2012

TABLE 2.3 Summary of the literature review prevalence of disorders – part 2

	Prevalence in different countries based on original studies					Prevalence in a paediatric population accessing healthcare
	India[15,24]	Uganda[40]	South Africa[17,26]	Brazil[31]	Northern Ireland[32]	Spain[41]
Diagnosis						
ADHD	1.0%	-	-	-	-	5.4%
ID	0.16 - 5.2%	1.8%	0.6 – 3.6%	-	-	1.0%
GDD	-	-	-	-	-	0.5%
Learning disorders	1.6%	-	1.7%	5.4 – 7.6%*	5.7%	3.3%
Speech & Language disorders	0.6 - 1.6%	-	-	-	-	3.4%
ASD	1.4%	0.7%	-	-	-	0.9%
Behaviour & conduct disorders	-	-	-	-	-	1.9%
Anxiety disorders	-	-	-	-	-	2.3%
Depressive disorders	-	-	-	-	-	0.2%
CP	1.3%	0.4%	1.0%	-	-	-
Epilepsy	2.2%	1.3%	0.4%	-	-	-

* Disorder dependant

2.8 Referral Pathways - Timelines, Ages of Children and Origin of Referrals

Few studies state the origins of referrals, whilst several state the mean age of children with NDDs, at the time of initial concern and the age at diagnosis of the NDD. The age of the initial concern can be subtracted from the age at diagnosis to calculate the time taken from a concern noted by a caregiver to diagnosis.

The study by Shevell et al., briefly described in section 2.4.9 of this literature review, included the age of children at initial concern (mean age 22.86 [SD ± 11.45] months) and compared it to the age at time of diagnosis (mean age 38.23 [SD ± 13.63] months)[43]. A mean total time of 15.5 months was calculated by the authors for the time taken from initial parental concern to specialist assessment[43]. Children with possible motor delays/CP were referred early at a mean of 11.68 (SD ± 5.01) months and children with speech delay were referred later at a mean age of 27.3 (SD ± 9.4) months[43]. Referral patterns were also reported, with 75% of the referrals generated by paediatricians, general practitioners contributed 8.9% and specialist physicians 7.1% of the referrals[43]. Therapists generated 5.4% of the referrals and the remaining 3.6% were self-referred[43]. No comparison between the age of children at referral and the origin of the referrals were made[43].

Looking retrospectively at the referral patterns of children who were diagnosed with CP by a single paediatric neurologist, Hubermann et al. found a mean age at the time of referral of 16.6 (SD ± 19.2) months, with a wide range of 0.1 to 89.9 months[55]. Similar to Shevell et al., Hubermann et al. found a high rate of referrals from specialists (78.6%), the remainder of the referrals (21.4%) were generated by primary care providers[43,55]. The mean age of referral between the two groups differed significantly, with the specialists referring at a mean age of 13.6 (SD ± 15.7) months and the primary care providers referring later at a mean age of 28.8 (SD ± 27.1) months[55].

A third study by Boychuck et al., assessed services relating to CP at four sites and found a high variability between the sites[56]. The mean age at referral was 12.7 (SD ± 14.3) months and 18.9 (SD ± 12.8) months at diagnosis, therefore the time from referral to diagnosis was 6.2 months[56]. Boychuck et al. reported a lower specialists referral proportion (53.8%) with the remaining

46.2% of referrals originating from primary care[56]. The mean age at referral was younger in the specialist group (9.1 [SD ± 12.5] months) and older in the primary care provider group (17.5 [SD ± 15.3] months)[56].

All three of the studies presented thus far were conducted in Canada[43,55,56]. A study entitled *Autistic disorder in Nigeria: Profile and challenges to management*, actively screened children in an academic hospital's paediatric neurology clinic for symptoms of ASD[57]. Children who screened positive were referred to a child psychiatrist for a definitive diagnosis of ASD[57]. The authors Lagunju et al., reported a mean age of 22.1 (SD ± 6.6) months for parents first noticing a "deviation in development."[57] The mean age of ASD diagnosis was 44.7 (SD ± 21.2) months, which was similar to the mean age of referral (18.92 [SD ± 12.41] months) and diagnosis (39.30 [SD ± 10.17] months) for ASD reported by Shevell et al.[43,57]. It is important to note that as this study utilised active screening for ASD, the age of the children at diagnosis may be younger than if they had followed the standard referral pathways of the hospital. The average time of 22.6 months from initial concern to diagnosis may therefore have been longer if the study was designed differently[57]. In West Bengal, India, Chakrabarti S., surveyed children and caregivers of children diagnosed with ASD[58]. "Delayed/deviant speech and language development" was reported as the commonest early concern of parents[58]. Parental recognition of a potential problem was at an average age of 23.4 months (SD ± 11.3) and diagnosis at 55.2 months (SD ± 25.6) of age[58]. The average time taken from parents identifying a concern to consulting a medical professional was reported as 4 months and 68% of cases first consulted with a paediatrician[58]. Other studies found the median age of an ASD diagnosis to be 42 months in the Western Cape, South Africa and 5.7 years (SE 0.08) in the USA[59,60]. Several studies found the mean age of initial concern of ASD, in the USA, to be 10-16 months[61-64]. Parents identified concerns earlier in girls, children with older siblings who have been diagnosed with ASD, and children who are diagnosed with ASD rather than other NDDs presenting with similar features[62-64]. Despite parents identifying concerns in their children at a young age, in the study entitled *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016,* only 44% of children were reported to have been evaluated for ASD by the age of 36 months[36].

2.8.1 Surveillance and screening – a factor which can affect the age of identifying developmental concerns

In 2006 the American Academy of Pediatrics released a policy statement entitled *Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening*[65]. Recommendations are made within this document on surveillance and interval screening of all children for concerns of deviations or delays in development[65]. The document includes an algorithm advising healthcare providers on when these screening intervals should occur and to refer in the event of a positive or concerning screening outcome[65].

In South Africa, the *Road to Health* booklet is issued to children for recording childhood healthcare visits from birth to 12 years of age[66]. Data recorded in this booklet include birth details, vaccination, illness history, and has sections for recording the growth and development of the child[66]. The booklet includes advice for parents on a range of topics including feeding and danger signs of illnesses requiring urgent medical care[66]. The latest version, published in 2017, includes four pages dedicated to child development and includes a developmental screening checklist and recommendations on which services to refer to if a concern is identified[66]. The previous version (2011) had a single page dedicated to child development[67].

Studies have assessed the communication of healthcare messages contained within the booklet as well as the completeness of data recorded in sections of the 2011 version[68,69]. A masters research report by Naborn B. assessed the utilisation of the 2011 version's developmental section[70]. Health messages were reported to have only been relayed to the caregivers in half of the cases and data such as birth weight was reported to be completed frequently, but other parameters, such as head circumference were recorded in a mere 3.1% of booklets[68,69]. Naborn B. reported that the developmental checklist was completed by primary clinics in 40% of the study's population[70].

2.9 Waiting List Times of Neurodevelopmental Services and Availability of Subspecialists

Lengthy waiting lists, whilst not always clearly measured, are definitely a barrier to obtaining a diagnosis and managing NDDs[71-77]. In the study entitled: *Early Hearing Detection and Intervention: Parent Experiences with the Diagnostic Hearing Assessment*, limited appointment availability was the most common reason given by caregivers for a delay in accessing audiology testing services before the benchmark age of three months[71]. Saloojee et al. investigated caregivers' perceptions of rehabilitation therapy services for children with CP at public sector hospitals in South Africa[72]. Appointment waiting lists and time delays when accessing the services, such as the collection of files before attending therapy, were highlighted by caregivers as barriers to care[72]. Caregivers perceived reoccurring barriers such as waiting for files and medication, or sessions feeling rushed with inadequate communication, as higher priority concerns than the length of the appointment waiting list[72].

Two studies were found which specifically looked at the waiting list times in neurodevelopmental and mental health care services[78,79]. The first study assessed the mean waiting times for children accessing child and adolescent mental health services in Canada[78]. Waiting times differed in this study based on urgency, with children with suicide ideation, considered extremely urgent and seen within 3.4 days[78]. Children classified as "high priority level" for example "a child who has been suspended from school for serious aggressive behaviour", waited an average of 24.4 days, whilst those classified as "moderate priority level" described as "a child who is failing school secondary to serious ADHD behaviour" waited for 75.8 days[78].

The second study from Bisgaier et al. was conducted in Chicago Illinois, USA, where there is a high concentration of developmental-behavioural or neurodevelopmental disability subspecialists[79]. The study was specifically designed to assess the waiting list time in children who required an ASD assessment and to determine if insurance cover status would affect the waiting time[79]. The mean waiting time for an evaluation for suspected ASD was three months[79]. The difference between the insurance cover status was a mere 8 days and thus was not considered significant[79].

Both of these studies were conducted in high-income countries where there are significant differences in resources from low- to middle-income setting. Bisgaier et al. described a total of 30 subspecialists working in Chicago, USA, who could potentially assess a child for ASD[79]. This is in stark contrast with South Africa, where a manual evaluation of the Health Professional Council's online register by the researcher, performed in January 2021 listed: 18 developmental paediatricians, 33 paediatric neurologists and 50 child and adolescent psychiatrists[80]. Of these three subspecialties only 1 paediatric neurologist and 1 child and adolescent psychiatrist are listed on the Health Professional Council's register as residing in the Eastern Cape[80]. Whilst overlap between the three subspecialties exist, certain cases may specifically require a developmental paediatrician. The lower number of developmental paediatricians, in comparison to the other subspecialties, may further limit access to services. This phenomenon is not unique to South Africa. In 2007 Pletcher et al. investigated the satisfaction of primary care paediatricians in the USA with subspecialty care[81]. The number of primary care paediatricians included in the study was 595[81]. The percentage of primary care paediatricians reporting too few child and adolescent psychiatry, and developmental-behavioural paediatric subspecialists, to meet the needs of patients in their practice, was 95.8% and 86.6% respectively[81]. By comparison 66.7% of respondents reported a lack of paediatric neurologists[81]. This may be because the field of neurodevelopmental paediatrics is a relatively young subspecialty[82]. The American Board of Medical Specialties approved the proposal for subspecialty certification in neurodevelopmental disabilities in March 1999, compared to 1969 for the subspecialty of child neurology[82]. The first class of neurodevelopmental disability subspecialists graduated in 2001 in the USA[82].

When preforming a wider search for studies evaluating waiting times for therapy services, or other services which may affect the management of children with suspected NDDs, several studies were found. Deslauriers et al. investigated the access to general outpatient physiotherapy services in Quebec, which were publicly funded[73]. Ninety-seven sites were included in the study, the mean maximum waiting time (which was the mean waiting time of the three patients who had been on the waiting list the longest) was 15.6 months[73]. Similarly, Boshof et al. found a mean waiting time for an occupational therapy assessment in South Australia to be 93 days (with a range of 7 - 200 days) and the average waiting time for intervention was 110 days[74]. Ruggero et al. reported on speech and language pathology assessments in Australia[75]. The most common length of time waiting for an assessment (just under a quarter of the respondents) was 2 – 6 months, there was however a range of waiting times from less than a week to over a year[75].

Following initial assessment, children most commonly waited up to 1 month for therapy to commence[75]. By comparison McGill et al. investigated the waiting lists and prioritization of children for services by speech-language pathologists in ten countries, including one respondent from South Africa[76]. Waiting times for assessments ranged from 0 to 20 months, with a mean of 5.20 months (SD = 3.93), whilst intervention waiting lists ranged from 0 to 22 months, with a mean of 3.13 months (SD = 3.74)[76]. The South African respondent reported a waiting list of 12 months for an assessment, but only a month for intervention[76]. Otitis media is a common and reversible cause of acquired hearing loss which leads to speech and language delays[6,34,83,84]. A study by Pokorny et al. investigated the waiting times for paediatric ear nose and throat outpatient services in Queensland, Australia[77]. The authors reported a median waiting time from referral to the first offered appointment of 417.5 days[77]. For children receiving grommets, the median waiting time from initial referral to grommet insertion was 627 days[77].

2.9.1 Factors that could affect waiting list times

Three factors have been identified in the literature, as possible factors contributing to increased length of waiting list times[13,37,38,81,82,85]. Two of these reasons: the limited number of subspecialists and increasing prevalence rates of certain NDDs such as ADHD and ASD, have already been briefly discussed[13,37,38,81,82]. The other possible factor will now briefly be considered – that of inappropriate referrals[85].

In an article that discussed the experiences and frustrations of paediatric neurologists in Armenia, the neurologists reported that there was a high rate of inappropriate referrals from general paediatric services[85]. Disorders which in their opinion, could be managed by general paediatricians were referred frequently resulting in an overburdened clinic and longer waiting periods for children whom they felt did require management by a paediatric neurologist[85].

In contrast, inappropriate referrals were not found in the study by Shevell et al., with the authors concluding "when primary care providers are prompted to refer for a developmental disability, there can, indeed, be reasonable certainty that a developmental delay exists."[43] As it was unknown if inappropriate referrals are a factor contributing to the lengthy waiting list of the Frere Hospital's NDC, it was included as an outcome of interest.

2.10 Summary of the Literature Review

The DSM-V classifies several disorders under the umbrella term NDDs. Other conditions that are not strictly termed NDDs also present to NDC services either as a comorbid disorder or by affecting a child's developmental trajectory. Some disorders are well researched, whilst others are poorly reported on. The majority of available literature is from high income countries and thus may not relate to the setting where this study was conducted. Very few studies have explored the referral pathways of neurodevelopmental services or the time taken from initial concern to a diagnosis of an NDD. In addition, no literature was found which specifically divided the process into individual components or formally assessed how waiting lists contribute to the overall time taken to reach a diagnosis.

CHAPTER 3 - METHODOLOGY

This chapter will explain the methodology used in this research study, concluding with the ethical considerations of the study.

3.1 Study Design

A descriptive cross-sectional study was conducted, as this allowed the researcher to gather all variables required to answer the objectives of the study simultaneously. The study could therefore, be conducted in a feasible time-frame without loss to follow-up of participants.

3.2 Location of the Study

Data were collected from the NDC, Paediatric Department Third Floor, Frere Hospital, East London, Eastern Cape, South Africa.

Frere Hospital is one of the two public hospitals in East London, offering tertiary level specialised services. The role of the NDC is to assess and offer medical management, if applicable, to children with NDDs, such as ADHD, ASD, and a variety of other disorders which present with developmental delays. The NDC takes place once a week on a Wednesday morning and is staffed by two Paediatricians. Children seen at this clinic are mainly from East London, as there are no secondary or district level hospitals in East London. However, as the hospital is a tertiary level hospital, children seen at this clinic could be referred from any town or city within the catchment area (e.g., Maletswai, formerly known as Aliwal North, which is 357.8 km from East London)[86].

3.3 Study Population

All new referrals to the NDC were approached by the study researcher and invited to take part in the study. All children whose legal guardians signed the informed consent form and who met the inclusion criteria, without exclusion criteria, were enrolled in the study. The following inclusion and exclusion criteria were applied:

3.3.1 Inclusion criteria

- All newly referred patients to the NDC between 1st July 2019 and 31st May 2020 (adjusted to 31st March 2020).
- At the time of the clinic visit the child was under the age of 18 years and was accompanied by a legal guardian able to provide informed consent.

The study data collection period was originally planned to end on the 31st May 2020, however, due to the Coronavirus disease of 2019 (COVID-19) pandemic the study time frame was adjusted to the end of March 2020.

3.3.2 Exclusion criteria

- Patients who did not have a legal guardian accompanying them to provide consent.
- A child, who was chronologically and mentally, above the age of seven and did not provide assent.

3.3.3 Review of the data collection form

Upon the completion of enrolling the first five children into the study, the data collection form was reviewed to ascertain whether changes were needed to improve the data collection form.

3.3.4 Required study population and sample size

Due to a lack of adequate prevalence statistics, an adequate target study population or sample population size, could not be calculated. For the study to be viable a target study population of 100-150 potential participants was set. It was anticipated that 15 to 20% of potential participants would be excluded due to not meeting the inclusion and exclusion criteria above, and therefore the study would enrol 80-130 children.

According to the paediatric department's administrative data, 110 new patients arrived for their appointments at the NDC within the first 26 clinics of 2018, this equates to 4.2 children per clinic (unpublished data). The researcher however knew from working in the clinic, that occasionally follow-up patients were incorrectly counted as new, or new patients may arrive in the mid to late afternoon after the clinic had been completed. Late arrivals are accommodated if reasonably possible, by the clinicians returning after their afternoon clinical responsibilities. The researcher however would not be able to access these children. It was postulated that a realistic number of children the researcher would have access to, would be 2-3 children per clinic. A time frame of 11 months (45 clinics) for the study was thus planned with the aim of reaching the minimum potential participant number target of 100-150. This was revised to nine months due to the COVID-19 pandemic, as the NDC services were closed for several months, and upon reopening, social distancing protocols did not allow for the study to continue.

3.4 Study Procedures

3.4.1 Identification, enrolment and data form completion

All patients seen at the paediatric outpatient clinics were first seen by the paediatric department's admission clerk. The child's details were entered into an electronic system and their name marked off in a backup paper-based clinic appointment book. They were then seen by nursing staff, for height, weight and blood pressure measurements. Upon completion of this process children and caregivers were sent to different waiting areas for the commencement of the respective clinics (e.g., cardiology, general paediatrics or neurodevelopmental) which all take place on a Wednesday.

The researcher identified potential participants, who had arrived for their NDC appointments from the paper-based appointment book, before the start of the clinic. These children and their caregivers were asked for a few minutes of their time, whilst awaiting the commencement of the clinic. They were then taken to a private space such as an available office or consulting room for a brief introduction to the research study. If time allowed and consent was granted, the required consent and assent forms were signed before the clinic commenced. Upon commencement of the clinic, the researcher attended the consultations of these newly referred children and completed the data form during the consultation.

If children and caregivers arrived after the commencement of the clinic, the nursing staff and doctors staffing the NDC were aware of the research study and informed the researcher of a potential participant. The appointment book was also periodically checked between patients by the researcher. These potential participants and their caregivers were then approached upon completion of their assessment by the clinic. The same procedure, as above, of introduction and obtaining consent was followed. Once consent was granted the data form was completed.

The NDC is staffed by two clinicians – a general paediatrician and a paediatric neurologist. Occasionally, both clinicians were in the process of assessment of new patients at the same time, however, as the clinicians were aware of the research study the researcher was able to attend at least part of these consultations. The introduction of the research, consent, assent and completion of the data form was always completed by the researcher; assisted by nursing staff for translation when required, if the child and/or caregivers were not English or Afrikaans speaking.

3.4.2 Data form and outcomes measured

Appendix A is the data form used by the researcher. The study data form was comprised of five sections, which included general demographic information of the child; the referral pathway of the child to the clinic; the investigations already performed on the child; the NDC's presumptive diagnosis; and the management plan including whether the referral was deemed appropriate or not.

- **General demographic information** included:
    - Place of residence,
    - Age,
    - Gender,
    - Race,
    - Home language.

The demographic data was collected to fulfil the first of the secondary objectives of the study: To describe the demographics of the patients referred to the NDC.

- **Information regarding the referral pathway** provided information detailing:
    - The date of initial concern and by whom was the concern raised,
    - Date and type of the initial healthcare provider seen,
    - Was the public or private healthcare system accessed,
    - Were they seen for an extended period of time by another service similar to the NDC
    - Date of referral to NDC and by which health care professional was the referral made
    - Reason for the referral

The information collected fulfilled the aim and primary objective of the research of describing and assessing the current pathways of referral to the NDC. The dates of each step in the referral process were used to create timelines, tracking the time from the initial concern of an NDD until NDC assessment.

- **NDC consult diagnosis** provided the presumptive diagnosis of the child by the NDC.

This data forms the basis of the spectrum of disorders seen, which represents the second of the secondary aims of the study. Diagnoses were only assigned if the DSM-V diagnostic criteria were met, in cases of diagnoses contained in the DSM-V for example ADHD, ASD and GDD. Other disorders not defined in the DSM-V were coded based on standard clinical diagnostic

criteria found in standard textbooks or the availability of testing. For example, participants who had a genetic disorder which was confirmed by genetic testing requested by the referring healthcare providers, or whose clinical examination revealed sufficient evidence of specific known genetic disorder, were coded as diagnosed with a genetic disorder. In cases where genetic disorder was considered and therefore tested for, but there was insufficient clinical criterion for a genetic disorder to be diagnosed, it was documented in section 5 (b) of the data capture form under further testing requested by the NDC, but not in section 4 (a) which captured the diagnoses assigned.

The final question of the data form was whether the researcher considered the case to have been:

1) **An appropriate referral**, which was defined as either:

   - A definite diagnosis could be made - based on the case fulfilling clinical criteria or the diagnosis was supported by other relevant investigations (e.g., neuro-imaging, psychometric testing or genetic testing). Such a patient would be followed up periodically at the NDC; or the caregiver would be counselled and referrals to appropriate services, such as therapy services, would be arranged.

     Or

   - A probable diagnosis could be made based on fulfilling some of the clinical criteria but requiring further investigations. These patients would have been issued with a follow-up appointment for the NDC.

2) **An inappropriate referral**, which was defined as:

   - No clinical criteria or investigations point to a diagnosis of an NDD, requiring management by the NDC. These cases should not have been referred to the NDC.

3.4.3 Definitions of terms used in the presentation of the results

Self-referral: Children who are not referred by a healthcare provider to the NDC. The request for the child to be assessed by the NDC originated from the caregiver or the child's school, with or without the input of a healthcare provider. If a child saw a healthcare provider the healthcare provider did not recommend or generate a referral to the NDC.

Children transferred from other healthcare facilities: Any child who was managed for an extended period of time, either within the private healthcare system or another public service which offered similar services as the services offered by the NDC. These children were not referred for an assessment, diagnosis and further management by the NDC, but rather transferred to the NDC for the continuation of care of their individual disorders.

Time from initial concern to the initial presentation (depicted in blue in figure 3.1): the period between the initial concern noted by the child's caregiver or school and presentation at a healthcare provider. In self-referred children, the definition is the period between the initial concern and the date of booking the NDC appointment.

Healthcare provider time (depicted in orange in figure 3.1): the time from the initial presentation at a healthcare worker, to the booking of the NDC appointment.

NDC waiting list time (depicted in grey in figure 3.1): the time from the NDC appointment booking, requested by the healthcare provider who referred the child, or by the parent or school, to the child being seen at the NDC.

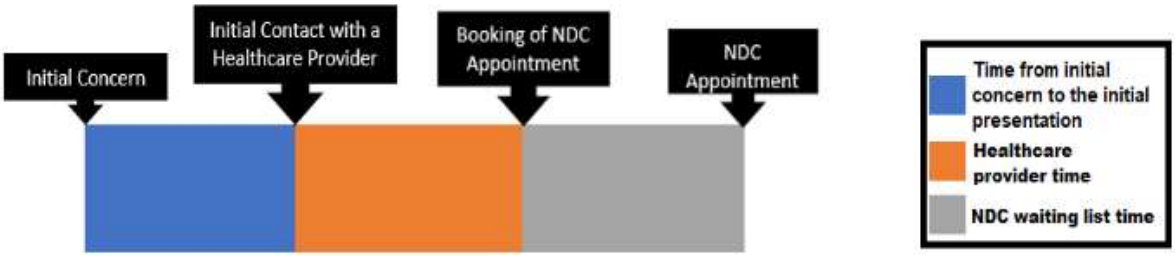

FIGURE 3.1: The referral pathway timeline graphic representation

3.4.4 Data form review

The data form was created based on the researchers' personal clinical experiences, working within the neurodevelopmental field, and the unique problems faced by the NDC. The researcher thus planned to perform a brief assessment of the data collected for the initial five participants in order to ensure that the following criteria were met:

- The data collection form was comprehensive, easy to complete and the collected data were accurate,
- The data collected would allow for analysis that would answer all research aims and objectives.

The data form was assessed from the first five patients seen at the NDC in July 2019. One of the participants had relocated to East London from a district within the Eastern Cape which fell into another tertiary hospital's catchment area. They were thus referred having been diagnosed with and managed for an NDD for an extended period of time, by a similar service as the Frere Hospital's NDC. The researcher did not account for the bias this potentially could create, in the calculation of the time taken between "initial health care provider seen" to "NDC appointment". The form was modified by adding a single question during this phase of the study: "Were they seen for an extended period of time by another service similar to the NDC?" to ensure accurate representation of referral timelines. Children with this referral pattern could be separated and not included in the description of the timeline related to time spent between the consult with an initial healthcare provider and the appointment booking at the NDC, referred to as "healthcare

provider time". These children are referred to as "children transferred from other healthcare facilities"

3.5 Data Management and Analysis

To maintain confidentiality no patient names or identification numbers were captured on the data form. A unique patient identifier was awarded to each file with a separate list kept by the researcher of the participants identifying details. The data were coded and captured into an Excel spreadsheet (dataset) by the researcher. The dataset was password protected and stored on the researcher's personal computer which is not accessed by anyone other than the researcher.

Descriptive statistical analysis was utilised to analyse the data. Categorical data such as gender, race and diagnoses have been reported as counts, proportions and percentages. Continuous variables - ages and timeline components, are presented in terms of means and ranges. A bar chart was used to graphically represent the mean time spent within each individual component of the timeline. All statistical analyses were conducted using Excel.

3.6 Ethical Considerations

The study involved a vulnerable population, as all the patients were minors and many had degrees of intellectual impairment. Therefore, ethical approval to conduct this research trial was obtained from the Committee for Research in Human Subjects at the University of Witwatersrand (Medical). HREC number M190247 (Appendix B). Permission was also obtained from the Head of the Department of Paediatrics, Frere Hospital's Head of Clinical Governance and the Frere and Cecelia Makiwane Ethics Committee (Appendix C).

Informed consent was signed by the parents or legal guardians of all participants enrolled in the research study. The consent form was available in English (Appendix D), Afrikaans (translated by the researcher) and isiXhosa (translated by colleagues of the researcher who are first language isiXhosa speakers). Assent was obtained from children with a chronological and

mental age of seven or older. The Assent Form (Appendix E) was only available in English. The consent and assent forms were based on the World Health Organisation's templates for qualitative studies involving children[87-89].

Potential conflict of interest was that the researcher was part of the assessment team working in the NDC and thus, caregivers may have felt obligated to participate, under the false assumption that participation in the study would change their child's management plan. The researcher attempted to combat this assumption in the consent form and the point was highlighted verbally before obtaining consent.

CHAPTER 4 – RESULTS

4.1 Study Population

The Frere Hospital's NDC, as previously mentioned, operates one day a week, and only has the capacity to assess five new patients per clinic, but not all patients arrive for their appointments. As per the methods chapter - the 2018 clinic attendance records and the researcher's personal experiences were combined with a study time frame of 45 clinics, to reach a target population of 100 to 150 children, with 80 – 130 children enrolled once inclusion and exclusion criteria were applied. Unfortunately, the research study which commenced on the 3rd of July 2019, was closed prematurely due to the COVID-19 pandemic, at the end of March 2020. During this study time frame 37 clinics were held, as the clinic closes for a couple of weeks over the Christmas and New Year festive period. The researcher attended 36 of the 37 clinics. During the study period, 63 potential participants were approached, 13 (20.6%) potential participants were excluded, either due to refusal to participate (n = 4) or the caregiver was unable to legally consent (n = 9) thus 50 participants were included in the study.

Table 4.1 summarises the study population demographic data. The age of the study population ranged from 1 year 0 months of age to 13 years 10 months, with a mean age of 6 years 7.4 months (79.4 months). As depicted in figure 4.1 there were two distinct peaks: the three-year-olds (n=9, 18.0%) and the six- to eight-year-olds (n=19, 38.0%). The predominant gender was male (n=40, 80.0%). The majority of the participants were Black African (n=30, 60.0%) and recorded as residing in Buffalo City Municipality (n=43 or 86.0%).

English was the most widely spoken home language, with 37 children speaking English, with or without a second language, which equates to 74.0% of the study population. isiXhosa was spoken by half the study participants (n=25, 50.0%) and 15 children (30.0%) spoke Afrikaans at home. Over half the population (n=29, 58.0%) were from bilingual households, no participants spoke three or more languages at home.

TABLE 4.1 Demographic data of the children referred to the Frere Hospital's neurodevelopmental clinic during the study period

	N = 50	%
Age		
1 year – 1 year 11 months	4	8.0
2 years – 2 years 11 months	1	2.0
3 years – 3 years 11 months	9	18.0
4 years – 4 years 11 months	4	8.0
5 years – 5 years 11 months	3	6.0
6 years – 6 years 11 months	6	12.0
7 years – 7 years 11 months	8	16.0
8 years – 8 years 11 months	5	10.0
9 years – 9 years 11 months	2	4.0
10 years – 10 years 11 months	3	6.0
11 years – 11 years 11 months	0	-
12 years – 12 years 11 months	3	6.0
13 years – 13 years 11 months	2	4.0
Gender		
Male	40	80.0
Female	10	20.0
Race		
Black African	30	60.0
Caucasian	12	24.0
Coloured	7	14.0
Indian	1	2.0
Residential Area		
Buffalo City Metropolitan Municipality	43	86.0
Amathole Municipality	5	10.0
Alfred Nzo Municipality	2	4.0
Home Language		
English	8	16.0
isiXhosa	11	22.0
Afrikaans	2	4.0
English and isiXhosa	14	28.0
English and Afrikaans	13	26.0
English and Other	2	4.0

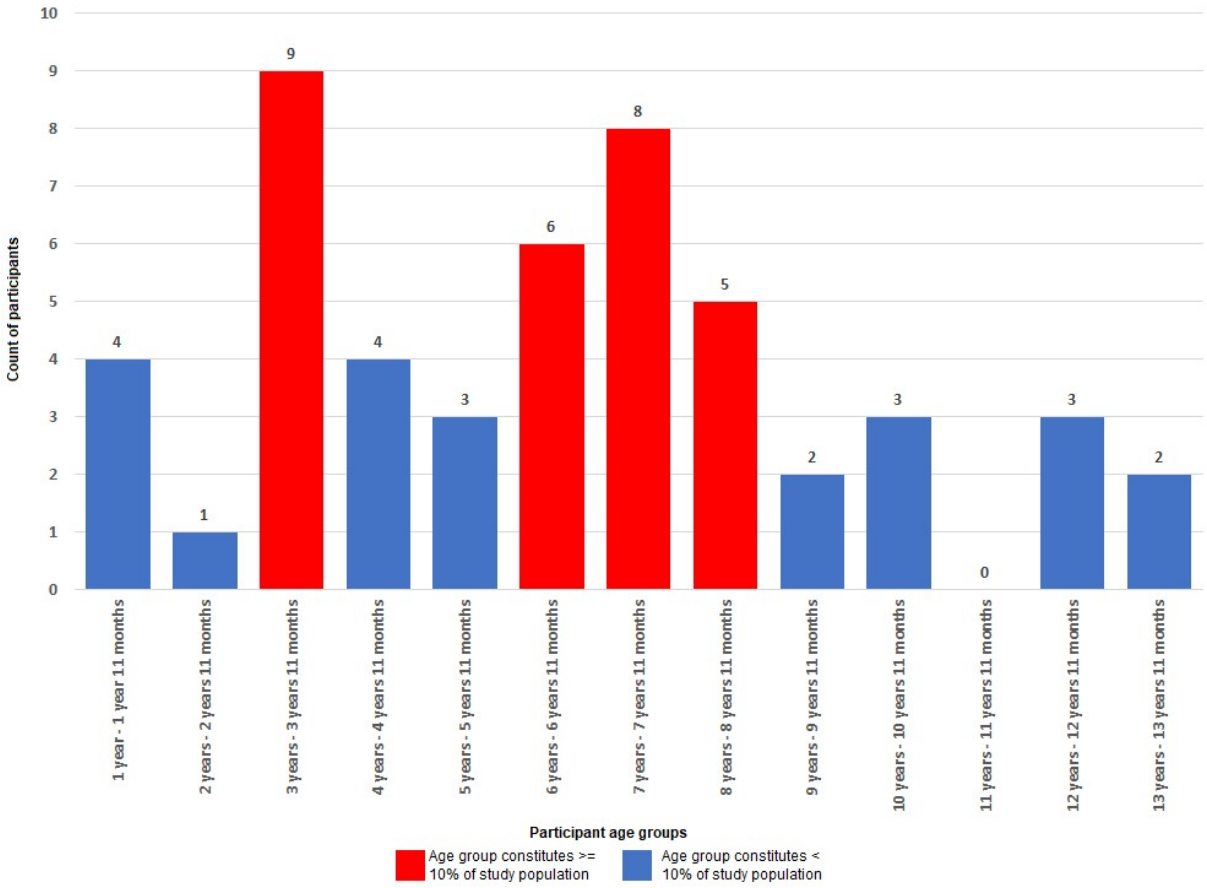

FIGURE 4.1: Bar graph depicting the age distribution of the cohort

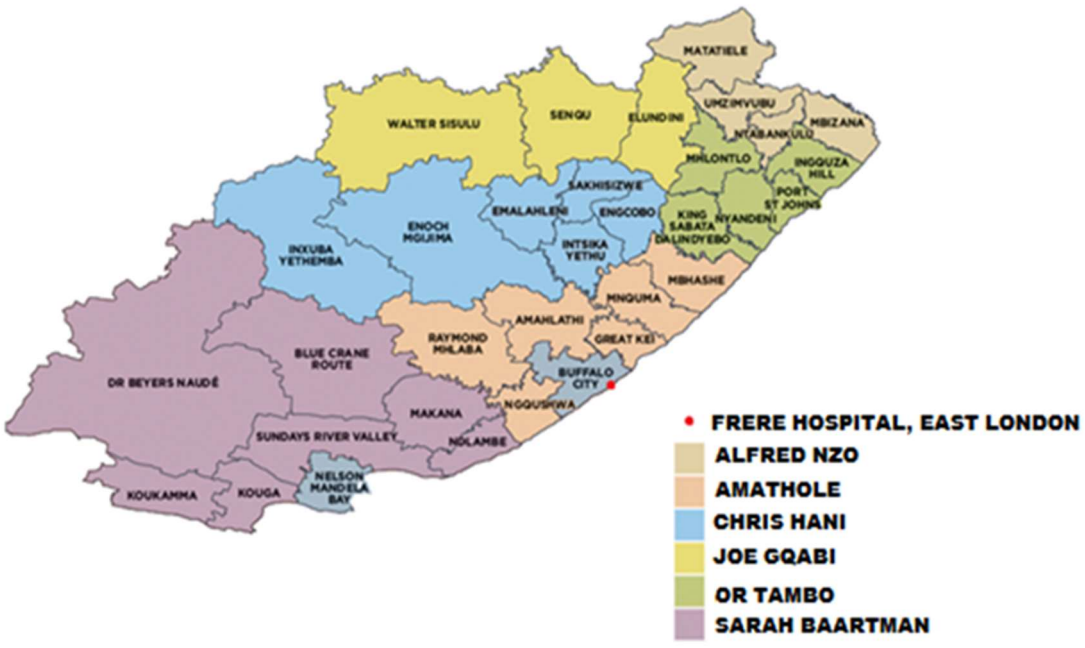

FIGURE 4.2: Map of Eastern Cape Districts in relation to Frere Hospital[90]

As mentioned, the majority of the population are recorded as residing in Buffalo City Municipality. The remainder of the study population were from the Alfred Nzo and Amathole Municipal Districts. As seen in figure 4.2: Amathole Municipality directly surrounds Buffalo City Municipality, whilst Alfred Nzo is further from East London. Thus, if adding the five participants from Amathole Municipality to those residing in Buffalo City Municipality, there were 48 children (96.0%) who lived within a 170-kilometre radius of the NDC at Frere Hospital[90].

4.2 The Spectrum of Disorders seen by the Neurodevelopmental Clinic

The diagnoses assigned to the study population are summarised in table 4.2. One child (2.0%) was not diagnosed with an NDD and 31 children (62.0%) were diagnosed with a single NDD. The number of children with two diagnoses was 15 (30.0%) and three children (6.0%) were diagnosed with three diagnoses. Table 4.3 lists the total number of diagnoses categorised from most to least prevalent. The most common diagnoses were ADHD, which was diagnosed in 21 children (42.0%), and ASD (n=12, 24.0%). Pertinent demographic data of these two common disorders will be briefly presented for completeness.

There were 21 children diagnosed with ADHD, 12 children were aged six to eight years old, which equals 57% of the children who were diagnosed with ADHD, and 63.2% of the cohort who were aged six to eight years old. The male to female ratio was 20:1.

Of the nine children who were aged three years old (as per table 4.1), eight were referred by healthcare providers with ASD being the main differential diagnosis, the diagnosis was confirmed in six of these, which constitutes half of the children diagnosed with ASD (n=12). The mean age of the children diagnosed with ASD, was 4 years 11.5 months (59.5 months), as three children were seven years old at presentation to the clinic. Nine boys and three girls were diagnosed with ASD, thus the male to female ratio is 3:1.

TABLE 4.2 Spectrum of neurodevelopmental disorders diagnosed by the neurodevelopmental clinic – arranged according to number of diagnoses assigned

	N = 50	%
No developmental disorder diagnosed – Neurotypical child	1	2.0
Single diagnosis		
ADHD	12	24.0
Speech / language delay	6	12.0
ASD	5	10.0
ID	3	6.0
GDD	2	4.0
Learning disorder	2	4.0
CP	1	2.0
Two diagnoses		
ADHD		
and ASD	4	8.0
and ID	2	4.0
and speech / language delay	1	2.0
and learning disorder	1	2.0
and ODD	1	2.0
ASD		
and GDD	1	2.0
and ID	1	2.0
ID		
and epilepsy	1	2.0
and a clinical genetic syndrome	1	2.0
GDD		
and a clinical genetic syndrome	1	2.0
Speech / language and a gross motor delay	1	2.0
Three diagnoses		
GDD		
and ASD, and a clinical genetic syndrome	1	2.0
and CP, and epilepsy	1	2.0
ID		
and an anxiety disorder, and a clinical genetic syndrome	1	2.0

TABLE 4.3 Spectrum of neurodevelopmental disorders diagnosed by the neurodevelopmental clinic - diagnoses categorised from most to least prevalent

	N = 50*	%**
Diagnoses listed by order of prevalence in the cohort		
ADHD	21	42.0
ASD	12	24.0
ID	9	18.0
Speech / language delay	8	16.0
GDD	6	12.0
Clinical genetic syndromes	4	8.0
Learning disorder	3	6.0
CP	2	4.0
Epilepsy	2	4.0
Gross motor delay	1	2.0
ODD	1	2.0
Anxiety disorder	1	2.0

* Some children were diagnosed with more than one diagnosis; they are thus represented in the table more than once.

** The calculation of the percentages of the diagnoses were calculated using a denominator of 50, which is the number of children in the cohort, and not the total number of diagnoses (n=70), thus the percentages total exceeds 100.

4.3 Referral Pathways

This section of the results aims to map out the referral pathways to the NDC by presenting the age of the children at initial concern, which healthcare provider was seen at initial contact with the healthcare system, who referred the child to the NDC, and the mean time required for each step of the process.

4.3.1 The age of initial concern

Table 4.4 lists the ages of the children when the caregivers first noticed, the school initially raised, or a healthcare provider elicited a concern of an NDD. Over half of the children (n=29, 58%) were under 6 years of age and thus, had concerns of NDDs prior to reaching the compulsory age of formal education in South Africa (7 - 15 years old)[91]. Of the remaining 21,

the majority (n=16) were between the ages of 6 years and 8 years 11 months of age, with a mean age at the initial concern of the cohort of 4 years 9.0 months (57 months). The mean ages of the initial concern for the two most common disorders diagnosed in this study were: 2 years 11.8 months (35.8 months) in children who were diagnosed with ASD, and 6 years 6.9 months (78.9 months) in children diagnosed with ADHD.

There were 25 children who were diagnosed with the following disorders ASD, speech / language delay, GDD, CP and motor delay, the mean age of these children at initial concern was 2 years 5.8 months (29.8 months). This result is compared in the discussion chapter, to the single similarly designed study presented in the literature review.

TABLE 4.4 Ages of the children at initial concern noted by the caregiver, school or elicited by a healthcare provider

	N = 50	%
Age		
Under year of age	7	14.0
1 year – 1 year 11 months	3	6.0
2 years – 2 years 11 months	10	20.0
3 years – 3 years 11 months	4	8.0
4 years – 4 years 11 months	2	4.0
5 years – 5 years 11 months	3	6.0
6 years – 6 years 11 months	9	18.0
7 years – 7 years 11 months	5	10.0
8 years – 8 years 11 months	2	4.0
9 years – 9 years 11 months	0	-
10 years – 10 years 11 months	2	4.0
11 years – 11 years 11 months	0	-
12 years – 12 years 11 months	3	6.0

4.3.2 Initial contact with a healthcare worker

The type of healthcare provider seen by the cohort at the time of initial contact is listed in table 4.5. The initial healthcare contact was not necessarily the healthcare worker who referred the child to the NDC. The majority of children (n=29, 58.0%) were seen by medical doctors, with almost three quarters (n=21) of the medical doctors being a primary care doctor, such as private

general practitioners, interns, community service doctors and medical officers, working either at the local district level clinic or hospital general paediatric outpatient clinics. The eight paediatricians, eight of the nine psychologists, and three primary care doctors were consulted in the private healthcare sector. Seven children (14.0%) were initially seen by a nurse at the nearest clinic, nine (18.0%) saw psychologists (educational, clinical or counselling), two (4.0%) consulted with a speech or occupational therapist, and out of 6 self-referred children, three (6.0% of the cohort) did not see any healthcare provider before their appointment. Three children (6.0%) had a concern of an NDD raised by the healthcare provider, rather than by their caregivers.

TABLE 4.5 List of the healthcare worker, to whom the child initially presented

	N = 50	%
Healthcare workers listed by order of prevalence in the cohort		
Doctors – Primary care	21	42.0
Paediatricians	8	16.0
Nurse	7	14.0
Educational Psychologist	5	10.0
Psychologist – Clinical or Counselling	4	8.0
No Healthcare worker seen	3	6.0
Speech therapist	1	2.0
Occupational therapist	1	2.0

4.3.3 The source and appropriateness of referrals to the neurodevelopmental clinic

As per table 4.6, more than half the children (n=30, 60.0%) were referred to the NDC by healthcare professionals working in the public healthcare sector. The referrals were from medical doctors, other healthcare providers (speech or occupational therapists) or a combination of both a doctor and other healthcare providers. The private healthcare sector generated 14 (28.0%) of the referrals, and in this group other health care providers included speech and occupational therapists, as well as psychologists (educational, clinical and counselling). In total, 44 children were referred through the healthcare system structure and six were self-referred i.e., the caregiver or school directly referred the child to the NDC. Of the 44

children referred through the healthcare system, 34 (77.3%) were referred by a medical doctor, with or without the input of a therapist.

Six children (12.0%) were self-referred i.e., the caregiver or school directly referred the child to the NDC. Half of the children who were self-referred (6.0% of the cohort), did consult with an educational psychologist before their NDC appointment; however, the educational psychologist did not refer to the NDC, and in two of the three cases, their assessments were still in progress at the time of the NDC booking, this will be further highlighted in the section of this report pertaining to the referral pathway timelines.

Three children (6.0%) were deemed inappropriate referrals as per the definition in the methodology chapter. One was referred via the public healthcare sector and was inappropriate, as the child was found to be neurotypical and the referral was generated based on an incorrect head circumference measurement. The remaining two were self-referrals, both these cases were deemed inappropriate as they did not require management by the NDC, which shall be discussed in depth in the discussion chapter.

TABLE 4.6 Source of the referral to the neurodevelopmental clinic and the appropriateness of the referral

	Referral outcome			**Referring healthcare provider**		
	Total	Appro-priate	Inappro-priate	Doctor	Other healthcare provider	Referrals generated by both the doctor and another health-care provider
Referred from the						
Private sector	14	14	-	6	3	5
Public sector	30	29	1	15	7	8
Self-referred	6	4	2	N/A	N/A	N/A

4.3.4 Comparison between the initial healthcare contact and the source of referral

The majority of the children, who were referred to the NDC by healthcare providers (N=44), were referred from the same healthcare sector (i.e., private or public) as the initial contact healthcare provider (n=40). Four children initially saw private healthcare providers, who referred them to providers within the public healthcare system, these providers subsequently referred the children to the NDC.

4.3.5 The referral pathway timeline

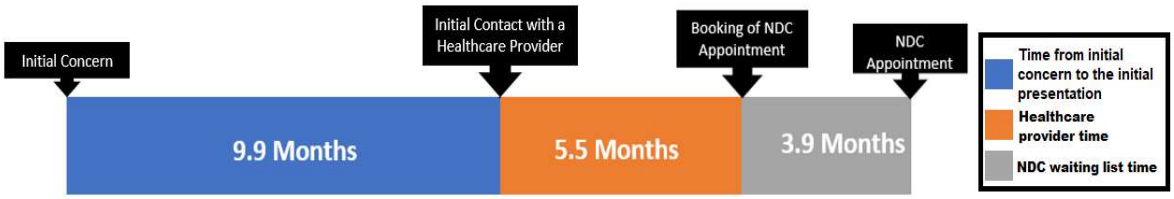

FIGURE 4.3: The referral pathway timeline

The referral pathway's timeline is depicted in figure 4.3. The first component of the timeline, referred to as "time from initial concern to the initial presentation", is the period between the initial concern raised and presentation at a healthcare provider. The majority of concerns were initially noticed by the child's caregivers (n=26, 52.0%), or were noticed by both the caregivers and the child's school (n=3, 6.0%). In just over a third of cases (n=18, 36.0%) the initial concern was noted by the school exclusively and in three children (6.0%) concerns were elicited by healthcare providers during visits for other unrelated ailments, routine well-baby check-ups and vaccinations.

For the calculation of this time component the date of booking the NDC appointment was used in children who were self-referred, instead of the presentation to a healthcare worker, irrespective of whether any prior consultation with a healthcare provider had occurred, as the healthcare provider did not generate a referral. The mean time from initial concern to the initial presentation for the cohort was 9.9 months (51.3% of the total timeline). The time spent in this

phase of the referral pathway ranged from no time spent in this phase, due to concerns not noticed by the caregivers and rather been elicited by healthcare workers, to 4 years and 1 month. Seventy percent (n=35) of the children saw a healthcare worker within the first year of concerns noticed.

The second component of the timeline is the time from the initial presentation at a healthcare worker, to the booking of the NDC appointment, which is referred to as the "healthcare provider time". The six children who were self-referrals and seven children who were transferred from other health care facilities offering similar services as provided by the NDC (please see section 4.3.6) did not contribute to this component of the timeline. The mean healthcare provider time was 5.5 months (28.5% of the total timeline), and ranged from no time delay (i.e., the NDC booking was made at the initial contact with the healthcare provider) to 4 years 8 months. The majority of the children contributing to this component of the timeline (n=28, 75.7%) spent six months or less in the healthcare system before their appointment was scheduled, four (10.8%) spent six to 12 months in the healthcare system and five children (13.5%) were booked after 12 months. Of the five children who were booked after 12 months, two had a complex referral pathway which will be further explored in section 4.3.7 entitled: Complex referral pathways.

The third component of the timeline depicts the time from the NDC appointment booking, requested by the healthcare provider who referred the child, or by the parent or school, to the child being seen at the NDC, and is referred to as the "NDC waiting list time". The mean waiting list time was 3.9 months (20.2% of the total timeline). One child waited over a year due to missing the original appointment date and therefore required rebooking. A single child was seen within the same week of the school contacting the NDC. The remainder of the cohort waiting list time ranged from 1 month to 7 months.

The mean total time spent within the healthcare system, from initial presentation at a healthcare provider to the NDC assessment was 9.4 months (48.7% of the total timeline). The mean total time from initial concern to NDC appointment was 19.3 months (range 5.0 – 60.4 months).

4.3.6 Children transferred from other healthcare facilities

Seven children (14.0%) were transferred from other healthcare facilities, for the continuation of their care by the Frere Hospital's NDC. Five children were transferred from private healthcare services and two children were referred from public institutions. Reasons for transferring the children were: from private, the inability to afford the cost of continuing their care in the private healthcare sector, and in public due to relocating from districts in the Eastern Cape which are serviced by other tertiary level hospitals to East London. The mean time of concern to initial presentation, for these children was 8.2 months and the NDC waiting time was 5.3 months, whilst the mean time they were treated by the other institutions before the NDC booking was 2 years 8.4 months.

Children transferred from other healthcare facilities had received formal diagnoses, and interventions in the form of appropriate medications and extensive therapies when required. They differ from the remainder of the cohort who may have commenced therapy, but received no medications to address their NDDs, except for treatment of co-morbid epilepsy.

4.3.7 Complex referral pathways

In general, children who accessed the NDC via a healthcare system, followed a similar pathway of referral. The process of referral was generally a smooth transition from primary and specialised healthcare services onto the NDC. Within the cohort, however, two children were identified who had a referral pathway that was more complex, these cases warrant a brief description as they illustrate several points within the referral pathway of children with suspected NDDs which could lead to delays in a formal diagnosis and early intervention.

In the first case the caregiver took the child to a primary healthcare doctor within a month of noticing the child may be developmentally delayed. The child was 2 years 1 month old, and the doctor's assessment was that the child was typically developing. Almost two years later the caregiver was still concerned and thus took the child for a second opinion. A speech delay was

detected and the child was referred for speech therapy for 3 months before a referral was made to the NDC. The time taken to being seen at the NDC was 3.5 months.

In the second case the child was seen by a psychologist at the age of 2 years 10 months, approximately a month after the concerns were detected by the caregivers and the child's nursery school teacher. It is unclear if any diagnosis was made at this point in time, but the child did not have any form of therapeutic interventions. There was then a time-lapse of approximately 4 years 8 months before the parent obtained a second opinion from a primary healthcare doctor, who referred the child immediately to Occupational therapy services, who assessed and started therapy and referred to the NDC after 3 months of treatment. The NDC waiting time was 3.5 months.

These cases and the points which they illustrate will be further discussed in the discussion chapter which is the next chapter of this report.

CHAPTER 5 – DISCUSSION

This chapter will discuss the results of the study in three sections, starting with the demographic data, followed by the spectrum of disorders recorded in the study population. The third section comprises the assessment of the referral pathways. This will then be followed by a discussion of the study's limitations and recommendations arising from the study, and suggestions for further research.

5.1 Demographics of the Study Population

The age range of the study population (1 year 0 months to 13 years 10 months) is a reflection of the age range seen by the Frere Hospital's paediatric department, which does not accept new referrals of adolescents 14 years or older. The most common age groups: the three-year-olds and the six- to eight-year-olds can be attributed to the two most prevalent disorders (ASD and ADHD). These age groups correlate with the reported age at diagnosis of these two disorders[43,57,58,92]. The reported mean age of diagnosis of ASD ranges from 3.28 to 4.6 years, and the prevalence of ADHD rises rapidly from the age of six years, with an average age at the time of diagnosis of seven years old[43,57,58,92]. The study population was predominantly male which correlates with the gender demographics of NDDs[11,13-15,17,18,20-23,26,31,34-36,39,41,43,45]. Literature that pooled multiple NDDs revealed a male predominance, regardless of the economic status of the country or the NDDs studied[11,13-15,17,41,43]. The male predominance described is not as pronounced as the results of this study. The relatively small numbers of girls in the study population could be attributed to the small study population size or may be explained by the profile of the disorders seen[13,18,20-23,26,34-36,39,40,43,45,57-60]. In particular, ADHD was the most common disorder recorded in the study population. The male to female ratio in children diagnosed with ADHD was 20:1 and half of the males in the cohort were diagnosed with ADHD. ADHD has a ratio of 2.3 males to 1 female in the USA[18]. ADHD male to female ratios of 16:1 have, however, been reported in literature from Europe[45].

The racial demographics recorded by Statistics South Africa for the Eastern Cape (2016) differ significantly from the figures recorded in this study cohort[9]. According to the official published data Black Africans comprise 86.4%, while Caucasians comprise 4.6% of the Eastern Cape

population[9]. The referral pattern to the NDC may have influenced the different demographic noted in this study, as explained below.

English is spoken at home by just under three-quarters of the study population, and more than half the population were bilingual. According to Statistics South Africa, 3.9% of the Eastern Cape population speak English as a first language whilst 82.7% of the population's first language is isiXhosa, bilingualism figures are not reported[9].

In the study population just over a quarter had accessed the NDC via the private healthcare sector and 38.0% were able to see a private healthcare provider at initial contact. In 2010, 15% of South Africans were reported to be covered by private healthcare insurance[93]. Generally, only people who are covered by private healthcare insurance can access the private healthcare sector, this points to an overall higher socio-economic status compared with the general population of South Africa within the cohort[93].

Despite the Frere Hospital's NDC accepting referrals from towns such as Maletswai, formerly known as Aliwal North, which is 357.8 km from East London, the majority of the study population were found to reside in Buffalo City[86]. Possible reasons for the low rate of referral from towns further away from the NDC include the inability of the patient to attend the NDC appointment due to the high cost of transport and a lack of awareness of the NDC by peripheral referring entities. Certain NDDs may also be managed in outlying areas by paediatricians who are employed at district or secondary level healthcare facilities or by Frere Hospital's paediatricians during general paediatric outreach clinics. The catchment area of Frere Hospital does not include Mdantsane which is the largest informal settlement within the Buffalo City Municipality and for many years was reputed to be the second-largest township in South Africa after Soweto[94]. Mdantsane refers to Cecilia Makiwane Hospital – a tertiary level hospital situated in Mdantsane. This geographical referral bias is the most likely reason for the difference between the socio-economic status, language and racial demographics of the study population compared to the Eastern Cape general population which may limit the study's generalisability to the Eastern Cape population.

5.2 The Spectrum of Disorders Seen

This section will discuss the results of the disorders diagnosed and compare these findings to the available literature.

5.2.1 Comorbidity in the study

Comorbidity is a common occurrence in NDDs[12,14-16,19,21,22,31,32,34,38,41,44]. The presence of comorbid psychiatric disorders has been reported to occur in up to 75% of patients attending mental health services[19]. Published literature varies with the reporting of overall pooled comorbidities in a specific population or comorbidities reported as being specific to individual diagnoses[14-16,19,21,38,41,44]. The NDC at which this study was conducted actively screens patients for the presence of comorbidities at the initial assessment, hence many of the patients in the cohort had more than one NDD recorded. It is important to note that the results of this study are based on the initial assessment by the NDC. Certain disorders such as behavioural, anxiety and depressive disorders may be underrepresented because they may become more apparent during follow-up consults or only manifest at a later stage. Similarly, children were only assigned the diagnosis of a genetic disorder if there was a well-known clinical genetic syndrome on examination or a confirmed genetic diagnosis. The comorbidity figure most likely would have been higher had the study design incorporated follow-up over time.

5.2.2 The prevalence of the disorders seen

The most common NDD diagnosed in the study population was ADHD. It is evident from the published literature that ADHD is the most prevalent NDD for which children access healthcare services[13,14,18,20,22,41]. ASD was the second most common disorder diagnosed in this cohort. Based on the literature this finding was not anticipated, as disorders such as learning disorders, speech and language disorders, and psychiatric disorders are encountered 1.3 - 4 times more frequently than ASD in the general paediatric population and children accessing healthcare[13-15,19,31-32,34-36,40,41,43]. Speech and language disorders specifically were diagnosed in populations accessing healthcare and NDD services approximately 1.4 - 4 times more frequently than

ASD[41,43]. Within this cohort, ASD was diagnosed 1.5 times more frequently than speech and language disorders. This finding does need to be interpreted with caution due to the small size of the study population. Possible explanations may be that speech and language disorders are not being identified in the community, or children presenting with difficulties in speech and language skills are identified and referred directly to the speech and language department, which manages these children without referring to the NDC for assessment. Further research is required assessing the referral patterns to, and management by, the speech and language department before definite conclusions can be drawn.

In the study population, more children were diagnosed with ID than with a learning disorder (3rd vs 7th most common diagnosis). ID and learning disorders are only diagnosed in children older than five years of age, whilst GDD is diagnosed in children less than 5 years old and was found to be the 5th most frequently diagnosed disorder in this study[1]. The prevalence of ID and GDD in the global general population is reported to be 1 - 3%[23,27]. Learning disorders are reported to occur in 5.4 - 7.9% of children depending on the country reporting and specific type of learning difficulty[13,31,32]. In Finland and Spain, the prevalence rate of learning disorders is reported as higher than ID and GDD in children accessing general paediatric and NDD services[14,41]. GDD is, however, a common diagnosis in children under the age of five accessing NDD services[43]. This difference between available literature and the study population was an anticipated outcome of the study, as the NDC can assign the diagnosis of GDD and moderate, severe and profound ID at the initial assessment. In cases where it is uncertain if the child has mild ID or a learning disorder, the diagnosis is queried in the clinical notes but deferred pending further assessment. To differentiate, or assign the diagnosis of a learning disorder the NDC requires intellectual and scholastic assessments, performed by a psychologist. Children assigned the diagnosis of a learning disorder were referred with intellectual and scholastic assessments performed by private psychologists. Clinical and educational psychologists performing intellectual and scholastic assessments are not available within the public healthcare sector in East London, as these services fall under the jurisdiction of the Department of Education and the District-based Support Team (DBST)[95]. As schools are aware of these services, children with a suspected learning disorder without other concerns should be referred to the DBST and not to the NDC, which would reduce the number of children with learning disorders seen at the NDC. The DBST is also responsible for recommendations for correct school placement[95]. The distinction between services may, however, not be well known as two of the children classified as inappropriate referrals were school directed referrals, and both were

deemed inappropriate because the child required the services which the DBST offers. This will be further explored in the recommendations of this report.

A second possible reason for the high number of children diagnosed with GDD and ID is the high rate of comorbidity. Two-thirds of the children who were diagnosed with GDD and ID were also diagnosed with comorbid disorders which required assessment or management by the NDC. All children in the cohort assigned the diagnosis of a genetic disorder were diagnosed with ID or GDD as the primary NDD. This is in keeping with recommendations in the literature that genetic testing be performed on children with ID and GDD, as genetic disorders are a common aetiology in these NDDs[27,96-98].

Within the study population behavioural, depressive and anxiety disorders, and neurological disorders (CP and epilepsy), were not frequently encountered. Psychiatric disorders are reported in the literature as prevalent in the general population and are frequently encountered as comorbid disorders in children diagnosed with NDDs[12,14,19,22,31,41]. The limited numbers of psychiatric disorders are likely a reflection of the study design, as previously discussed. Epilepsy and CP are not as prevalent in the general paediatric population as NDDs[13]. The limited numbers of these neurological disorders were expected due to separate neurology clinics at Frere Hospital which manages these disorders.

5.3 The Assessment of the Referral Pathways

This section of the discussion will focus on the referral pathways to the NDC. The age of the children at initial concern; the age of diagnoses; which healthcare provider was seen at initial contact within the healthcare system; who referred the child to the NDC; and the mean time required for each step of the referral process, will be discussed.

5.3.1 The age of diagnosis, initial concern and initial contact with a health care provider

The mean reported age of initial concern for the children in the study population was 4 years 9.0 months (57 months) and over half of the children were under 6 years of age. The age of initial concern of ADHD is not reported in the literature, however, the average age at diagnosis of ADHD, which is the most common diagnosis in the study population, is reported to be seven years[92]. Children classified as severe ADHD are diagnosed at a younger age (five years old) and those with mild ADHD at an older age (eight years old) according to the Centers for Disease Control and Prevention[92]. ASD, speech and language delays and GDD, which were other common diagnoses in the study population are typically diagnosed in children less than six years of age[43,57-60].

Within the cohort, 25 children were diagnosed with the following disorders: ASD, speech delay, GDD, CP and gross motor delay. The mean age of these children at initial concern was 29.8 months. Shevell et al. reported 22.86 (SD ± 11.45) months as the mean age at initial concern for the same 5 disorders[43].

The mean age of the initial concern for ASD reported in the literature, ranged from 10 to 23.4 months[43,57,58,61-64]. The range reported includes two studies from middle-income countries (India and Nigeria)[57,58]. By comparison, the mean age of initial concern in children diagnosed with ASD in this research study was at an older age of 35.8 months.

There are several possible reasons for the difference between the age of initial concern reported in the literature and the result of the cohort. Firstly, the differences may be secondary to bias created because of the study population size. Secondly, it may be due to the socio-economic and healthcare differences between countries, particularly when comparing high-income and middle-income countries. The study by Shevell et al. was conducted in Canada, which as a high-income country has significantly more resources than South Africa[43]. Higher socioeconomic status and maternal education are associated with earlier diagnosis of an NDD[56]. The socioeconomic difference between Canada and South Africa could explain the older age at initial concern for the five disorders. The difference of the age of initial concern for ASD between other middle-income countries and the study population is, however, an interesting

finding and points to factors beyond socioeconomic status. It is possibly a marker of a difference in the Eastern Cape community of what is considered typical or atypical development, to be an indication of lack of awareness of atypical development, or due to acceptance of atypical development. Further research is required to ascertain if this finding is merely due to the sample size limitation or a true difference in the community. If the finding is reproducible possible reasons for the difference require investigation.

Another factor is routine "well-baby" care and appointments for minor ailments are opportunities to enquire about development concerns. Within the cohort, 6% of the children's concerns were identified by healthcare professionals during "well-baby", vaccinations and minor ailment consultations. In 2006 the American Academy of Pediatrics released a policy statement in which recommendations are made on surveillance and screening of all children for deviations from, or delays in, normal development[65]. In South Africa, the Road to Health booklet's 2017 version, includes four pages dedicated to child development[66]. Included is a developmental screening checklist and recommendations on which services to refer to if concerns are identified[66]. The utilisation by caregivers and healthcare providers of the 2017 version is as yet unreported. Studies have, however, assessed the utilisation and effectiveness of the 2011 version of the booklet[68-70]. The utilisation, completeness of data recorded and the communication of health messages contained within the booklet was poor[68-70]. Based on the findings of the reported literature it is reasonable to assume that lack of utilisation of the booklet is prevalent. This leads to a lack of awareness of, and screening for, NDDs, and is a likely contributing factor to an older average age of identifying concerns of NDDs in the population served by the NDC. The completion of the developmental screening information within the Road to Health booklet was not included in the data collected, therefore, further investigation is required to confirm this hypothesis and, if confirmed, to ascertain the magnitude of its contribution.

5.3.2 The source and appropriateness of referrals to the neurodevelopmental clinic

Published literature reports that half to three-quarters of referrals to subspecialised care is generated by specialists, with rates of therapists' referral or self-referral of less than 6%[43,55,56]. By comparison, this research study had much higher rates of self-referral and referrals by other healthcare providers without a medical doctor's input, and specialist care was accessed by very

few children. Whilst this may be a bias caused by the study population size, it may also be a marker of the difference in healthcare systems between Canada and South Africa, despite both countries offering free healthcare services. In South Africa, free primary clinic healthcare is mainly provided by nurses. Nurses then refer to the next level of care - primary care doctors or therapists. In the two public hospitals in East London, general paediatric outpatient services are mainly staffed by junior staff (interns, medical officers and registrars) with available paediatricians providing oversight. Junior staff thus generate the referrals to the NDC, with or without a paediatrician's input. Two studies from Canada reported that specialists referred children earlier to subspecialist care than primary health care providers[55,56]. As it was found that specialist access is limited in the Eastern Cape, it is imperative that primary care providers' knowledge of NDDs, including awareness of the importance of screening, be optimised.

Despite the wide range of healthcare providers utilised by the study population, the vast majority of the children were appropriately referred. This finding contradicts the study by Bingham et al. which reported subspecialists' frustration with inappropriate referral patterns and aligns with the study by Shevell et al, which reported "when primary care providers are prompted to refer for a developmental disability, there can, indeed, be reasonable certainty that a developmental delay exists."[43,85] Whilst the number of self-referrals were small, there was a higher rate of inappropriate referrals among the children who were self-referred. Limiting self-referrals and requiring children attending the NDC to be referred by a healthcare professional may work to decrease inappropriate self-referrals. This is further explored in the recommendations section 5.5.1: Improving the Referral Pathways.

5.3.3 Time taken from initial concern to diagnosis

The mean time taken from the initial concern to the NDC appointment was 19.3 months (range 5.0 – 60.4 months). This figure falls within the range of 15.37 to 31.8 months reported in the literature for the time from initial concern to a diagnosis of an NDD[43,57,58]. It is important to note, however, that there was a wide range of time spent in each component of the timeline, with some children spending years between certain time points, which will now be discussed.

A single study reported the time spent in the first phase of the timeline, which was the time from initial concern to the child's initial contact with a health care provider[58]. The study, conducted in India, reported the mean age of first concern in children diagnosed with ASD as 23.4 months (SD 11.3) and a mean age of 27.7 months (SD 11.9) for the initial contact with a healthcare provider: the difference between these two time points is 4.3 months[58]. By comparison, children in this study waited a longer time (mean 9.9 months) before being seen by a healthcare provider. The time spent in this first phase constituted just over half the mean total time taken from initial concern to the NDC assessment and there was a wide range of time spent in this phase. Factors influencing the time taken was not established in this research. Possible reasons, however, for parents not accessing healthcare services sooner could be a lack of knowledge of the benefits of early intervention, denial of the child having a potential disorder or belief that the child will overcome their challenges if given enough time[3-7]. There may also be parental financial constraints particularly when attempting to access private healthcare services, and parents and schools may not be aware of all the services available in the public sector and how to access them. Waiting lists particularly in the private sector (private paediatricians and psychological assessments) could also have affected this component of the timeline. Further research into the reasons for caregivers not accessing healthcare services sooner is required.

The mean time spent under the care of a healthcare provider, before a referral to the NDC being generated, was 5.5 months. No literature was found which specifically assessed this component of the timeline. There are different referral pathways to the NDC, for example, a child with a speech delay may be referred by a nurse working in the local clinic to a speech therapist, who has a waiting list. The child may also be referred to the general paediatric outpatient clinic, which does not have a waiting list. The child may be referred to the speech therapist, by the doctor assessing the child in the general clinic, without arranging an NDC appointment, or may simultaneously generate a referral to the NDC. The nurse at the local clinic may also elect to refer to the general outpatient clinic and the speech therapist simultaneously. Whether there was a difference between the time taken by these different referral pathways, or if healthcare providers such as speech therapist's waiting lists impacted the time taken from initial concern to the assessment by the NDC, was not assessed. Waiting lists and step-wise referral pathways, however, may significantly impact the meantime from the initial contact with the healthcare system to the assessment of the child by the NDC.

The mean time spent waiting for an assessment by the NDC was 3.9 months. The total time from accessing a healthcare provider to the NDC appointment was 9.4 months. This is approximately a third of the total time taken from the initial healthcare provider seen to a diagnosis of ASD reported by Chakrabarti S[58].

Reported (Specialist) clinic waiting list times differed significantly. Children accessing child and adolescent mental health services in Canada were prioritised based on urgency[78]. Extremely urgent cases were defined as children presenting with mental health crises and suicidal ideation and were seen within 3.4 days of the initial referral[78]. Within the context of this study setting, those urgent cases would be referred as an emergency to the on-call paediatrician or psychiatrist at Frere or Cecilia Makiwane Hospitals and are not referred to the Frere Hospital's NDC. The appointment date which is given upon booking an initial assessment by the NDC is the first available appointment. Exceptions can however be made, if necessary, by contacting the clinicians working in the Frere Hospital's NDC. One child in the study cohort was considered urgent and was seen at the NDC within days of the school directly contacting the clinician. The range of time found in the literature for the waiting list of children with NDDs or mental health concerns of similar urgency to those seen routinely at the NDC is 24.4 days to 6.2 months[78,79].

Studies that assessed waiting list times for therapy services found a wide range of less than a month to almost two years[73-76]. The limited data from South Africa, which included data from a single speech therapist included in the study by McGill et al., reported a 12-month waiting list time for an assessment[76]. Waiting times for paediatric ear nose and throat outpatient services in Australia reported a median waiting time of 13.7 months (reported as 417.5 days) to see the specialist and 20.6 months (627 days) for grommet insertion[77]. The Frere Hospital's NDC waiting list time falls well within the range of times presented in the literature for similar medical services and is considerably less than the literature assessing waiting lists for therapy and other services that children with NDDs may need access to[73-79]. It is, however, important to note that the NDC waiting list time has significantly decreased from almost a year during the study conception phase to 3.9 months during the data collection phase of the study. The number of children booked to be assessed by the NDC, per clinic, did not change during the study period, thus other unknown factors resulted in the decrease in the waiting list time.

Only the duration of time the children spent on the NDC waiting list was directly assessed in this research study, however, waiting lists could be a contributing factor to time delays in each component of the timeline. Waiting lists can also contribute to delays in the management of children with NDDs once assessed by the NDC. For example, if a hearing loss is suspected as the cause for a child presenting with a speech and language delay formal audiology tests are required. According to Catherine Richter, head audiologist at Frere Hospital's Audiology Department, tests such as an auditory brainstem response which requires sedation, have waiting lists of 6-8 weeks (Richter C, 20 November 2019, oral communication, unreferenced). Similarly, there are waiting lists for therapy and other services that children with NDDs may require. Due to the potential compounding of waiting list times, a parallel rather than a step-wise approach in the management of these children may be beneficial, this will be further explored in the recommendations arising from this research report.

The two complex cases presented in the results section, highlight possible reasons for delays in referral to the NDC which have not yet been explored. Healthcare practitioners may allay the caregiver's fears on the initial assessment and fail to continue to monitor the child's development, therefore caregivers may not request a second opinion until a significant time has lapsed. Another reason for the delay may be that the healthcare practitioner's management plan is to monitor the child's developmental trajectory and to defer the initial referral for further investigations. It is also possible that the caregivers may have limitations such as financial constraints which limit them from returning for follow-up consultations.

This ends the discussion of the three objectives of this research. The study challenges and recommendations will now be discussed.

5.4 Study Challenges

The following section briefly discusses the challenges faced in conducting the research study and potential adjustments which could be made to mitigate these challenges in future.

5.4.1 Sample size

This study's main limitation was the study population size. During the planning stages of the study, a study population of approximately double (80-130) the number achieved (50) was projected. The reasons for the smaller number were twofold. Firstly, due to the COVID-19 pandemic, the NDC services were suspended for several months from the last week of March 2020. The clinic did not reopen before the end of May 2020, which was the approved date of closure of the study. The study was thus prematurely closed at the end of March 2020, which decreased the anticipated number of clinics for data collection by nine clinic days. Secondly, in 2019 there were several clinics where none of the booked new patients arrived for their appointment. This resulted in a decrease of participants the researcher could approach to enrol in the study. It was anticipated that 100 -150 potential participants would be approach, but only 63 new patients arrived for their appointments during the study period (July 2019 – March 2020). The reasons, for the decrease in the clinic attendance numbers, particularly in the fourth quarter of 2019, are unknown and require further investigation.

The small sample size impacted the statistical analysis with certain analyses not being accurate when conducted with small numbers. The reporting of the results was therefore limited to unadjusted means and ranges.

Components of the original study design were abandoned due to the smaller than anticipated study population. For example, section 3 (a) of the data form collected specialised investigations and assessments already preformed prior to the NDC appointment. The data was collected to see if there were differences in the investigations requested by different healthcare workers and systems utilised by the study population. The study population however was too small for stratification.

The generalisability of the results is also limited by the small sample size. A larger study population could be achieved by repeating the study prospectively with a longer data collection time or by performing a multicentred study. Including children who are being followed up by the NDC would also increase the study population size. Certain NDDs are not followed up long term by the NDC and all follow-up patients are appropriate referrals. Due to these factors, if

follow-up patients are included, they will need to be analysed separately to avoid biasing the results of the spectrum of disorders and the appropriateness of referrals.

5.4.2 Language barrier

Within the cohort 88% of the participants and their caregivers spoke English or Afrikaans as a home language, the researcher is fluent in both these languages but does not speak isiXhosa which was spoken exclusively by 22% of the study population. Translation by NDC nursing staff was required in the data collection of isiXhosa speaking participants. Communication barriers may have affected the accuracy of the data collected from these participants. Identifying a designated translator, who is trained in data collection and is aware of the intended outcomes of the study would potentially improve communication with isiXhosa speaking study participants if the study were repeated.

5.4.3 Generalisability of results

The racial and socio-economic demographic of the study population differed significantly from that of the South African population. This may possibly limit the generalisability of the results of the spectrum of disorders seen and certain components of the referral pathways including the timeline. As studies have shown that higher socioeconomic status and maternal education lead to earlier diagnosis of NDDs; the results of the ages of initial concern, age of the cohort at diagnosis and the time taken from initial concern to addressing the concern may be biased[56]. Higher socioeconomic status also affects the type of healthcare system accessed. The time taken from the initial consult to NDC booking was not analysed for differences between the private and public healthcare sector. Paediatricians, however, were exclusively accessed in the private sector and the literature reports earlier referral by specialists, thus the time spent within the healthcare system before the NDC booking may also be affected by the socioeconomic difference[55,56]. A multi-centre study, including children from Cecilia Makiwane Hospital's neurology clinic, who may also be diagnosed with an NDD, could lead to a more generalisable result.

5.4.4 Recall bias

The timeline calculation, especially before entering the healthcare system, relied on caregiver recall, which does introduce the potential of recall bias. The researcher did attempt to combat this by the phrasing of the verbal questions asked during the clinical assessment, and by inquiring further to facilitate recall, for example asking about significant events such as a birthday or a visit from relatives who were also concerned about the child. The timeline calculations could be either an over or underestimation of the true time taken. The comparisons in the literature also relied on caregiver recall of initial concern and thus it is assumed that the same potential bias existed[39,55,57,58]. If follow-up is included in a repeat study, the timeline questions could be repeated at the follow-up to ascertain the degree of potential difference in caregiver recall.

5.5 Recommendations

5.5.1 Improving the referral pathways to the neurodevelopmental clinic

The researcher would propose the following changes, which may reduce inappropriate referrals to the NDC, reduce waiting times and delays in diagnosing an NDD, and improve the care received while awaiting an assessment by the NDC.

The NDC should no longer accept self-referrals and all children referred to the NDC must be seen at the general paediatric clinic before the NDC booking is made. Exceptions can be made for patients who live far from the hospital, these patients could rather be discussed telephonically with the clinicians who staff the NDC. The rationale for the recommendations is the finding that whilst self-referrals were a small proportion of referrals to the NDC, self-referrals had a higher rate of inappropriate referrals. There are other potential benefits of all children being seen at the general outpatient clinic. For example, referral for tests or assessments provided by other departments (e.g., a formal hearing test) can be arranged whilst the child is awaiting the NDC appointment. The results of these tests would then be available, to aid in assigning an accurate diagnosis at the initial contact with the NDC and decrease the

number of follow-up appointments required for reviewing test results. Decreasing the number of children requiring follow-up appointments with the NDC may lead to increased capacity for new patient referrals. Children would simultaneously be booked for any therapy services required; this would specifically improve outcomes of younger children requiring early intervention. Older children who would benefit from earlier NDC appointments, for example a child facing expulsion due to severe impulsivity, can be discussed with the clinicians and be accommodated sooner.

As the staff of the general paediatric clinic are predominantly junior staff, if the above recommendations are implemented, they would require adequate support and would need to be equipped with sufficient knowledge on the services required in managing NDDs. By increasing the knowledge of the general paediatric clinic staff in the diagnosis and management of NDDs, certain children could potentially be adequately managed without referral to the NDC. This would decrease the NDC waiting list for new patients. Uniform management by using diagnostic algorithms may aid in this regard, an example of such has been created by the researcher (figure 5.1). The speech and/or language delay algorithm was created based on the researcher's experiences and information gathered during the review of literature[83,84,96-100]. Further diagnostic algorithms could be created for the other presenting disorders to the NDC.

The algorithm created is a proposed example and would require peer review, and would need testing for sensitivity, specificity and accuracy before implementation. Suggested time frames such as the follow-up of two months for a speech delay are not necessarily based on best practice, but rather are an attempt to balance the resources that are available within Frere Hospital and the resources of the population the NDC serves, with clinical guidelines of best practice. The algorithms could not be utilised by other centres without assessment of their resources. Similarly, the proposed algorithms should supplement and not replace resources available such as the *Eastern Cape handbook of child and maternal health* which is issued to all doctors working in child or maternal health services at Frere Hospital and contains chapters on behavioural and psychiatric disorders, and disability[99].

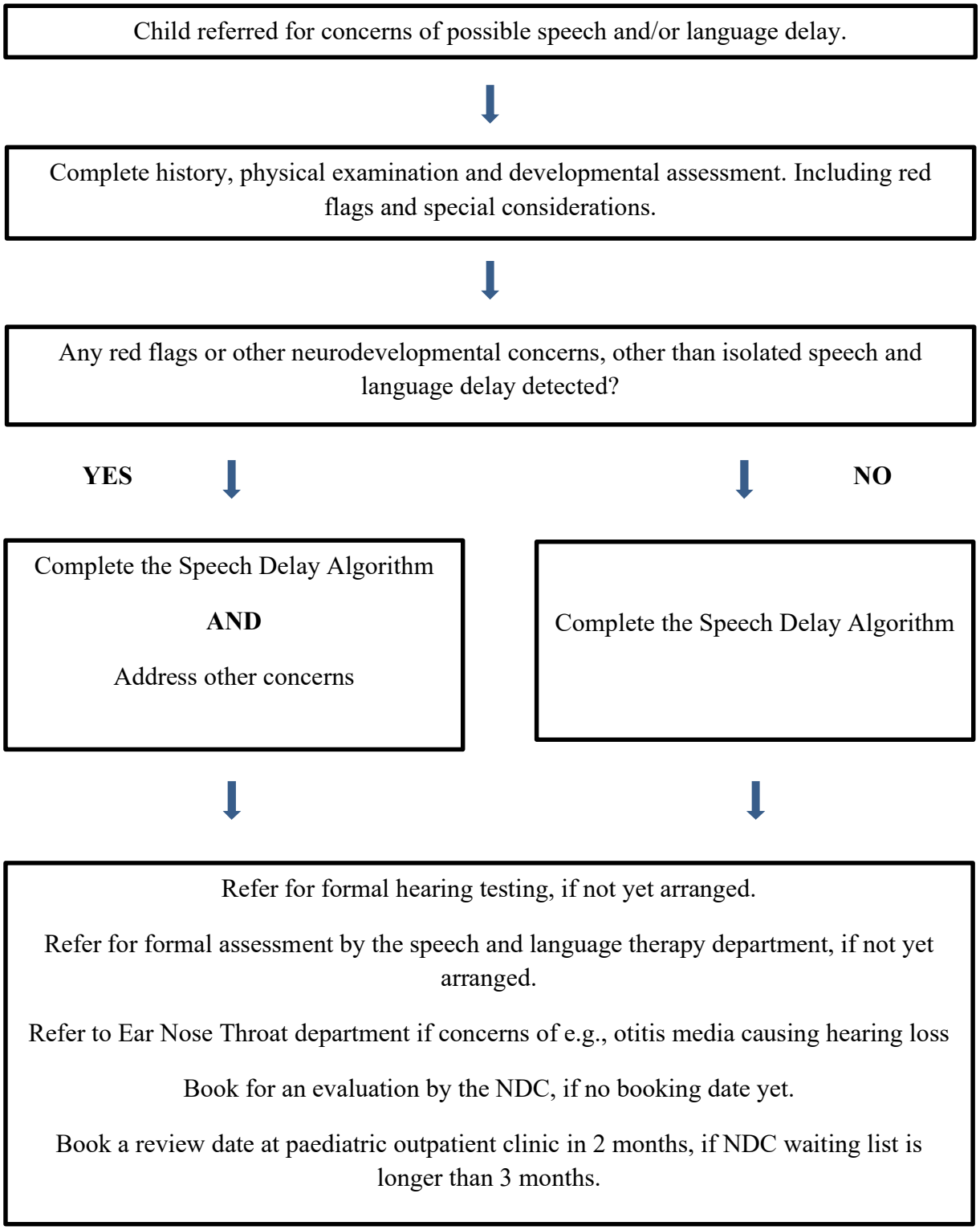

FIGURE 5.1: Diagnostic algorithm for children presenting with a speech and language delay – Page 1

Red Flags and Special considerations

History:

- Abnormal antenatal or peripartum history including substance abuse during the pregnancy, prematurity, or possible hypoxic ischaemic encephalopathy.
- Regression – any loss of previously gained milestones or a significant change in behaviour.
- Any concerns of abuse or neglect.
- Seizures
- Family history of possible inborn errors of metabolism, developmental or intellectual disorders, unexplained neonatal or sudden infant deaths, or a history of consanguinity.

Examination:

- Micro or macrocephaly.
- Dysmorphic facial features.
- Neurocutaneous markers.
- Abnormal neurological examination including hyper/hypotonia.
- Organomegaly – cardiomegaly, hepatomegaly, splenomegaly.

Any child presenting with these features requires discussion with the paediatrician in the general clinic as they may require urgent further investigations or management

FIGURE 5.2: Diagnostic algorithm for children presenting with a speech and language delay – Page 2: Red flags and special considerations

5.5.2 Further recommendations on improving services

An apparent lack of understanding of the types of services offered by the NDC resulted in incorrect referrals. Healthcare providers and educators should be informed about the DBST, the NDC and the services each offer. The DBST falls under the Department of Basic Education and is defined as "Groups of departmental professionals whose responsibility it is to promote

inclusive education through training, curriculum delivery, distribution of resources, identifying, assessing and addressing barriers to learning, leadership and general management."[95] The professionals included in these services provide intellectual testing and other assessments to advise on appropriate school placement. Unfortunately, there is no psychologist able to provide intellectual testing or assessment for learning disorders, in the public health care sector in East London. The reasons for the apparent lack of insight into whether a child requires the services of the NDC or the DBST was not an objective of this study, but improving lines of communication would improve the care of children with NDDs who require the services of the DBST.

5.5.3 Recommendations for further research

Due to a paucity of literature assessing the prevalence of individual disorders in the population accessing NDC services, further research, internationally and locally, is required to ascertain if other NDCs see a similar or a different spectrum of NDDs, to those presented in this study.

It is well documented that early intervention improves outcomes however the gold standard of acceptable waiting times could not be found in the literature. Further research and academic deliberation are required to address this.

Research studies that calculate the total time taken from initial concern to diagnosis and divide the time into individual components, are required, as worldwide knowledge in this regard is lacking. Further research is also required to ascertain the factors which may affect each component of the timeline. Possible factors warranting further investigation which could affect the time from initial concern to children accessing healthcare services are: caregivers' awareness of deviations or delays in child development; what caregivers consider typical or atypical development, and caregiver awareness of services available to them if there are concerns. Factors that could contribute to delays within the healthcare system need further investigation. For example, the awareness and knowledge of healthcare workers of identification, management, and appropriate referral of children with suspected NDDs, including knowledge of locally available services and utilisation of screening tools. Finally, the contribution of waiting lists, in each component of the timeline, requires further investigation.

CHAPTER 6 – CONCLUSION

Early diagnosis and intervention have the potential to significantly improve the prognosis of many NDDs, therefore it is imperative to have as short a time as possible from the initial point of concern of an NDD to the diagnosis and management of the patient[3-7]. One of the factors that impact this time is the NDC waiting list, but to know the impact a waiting list time has, the total time from initial concern to a diagnosis needs to be known. There is limited literature available exploring the total time taken from an initial concern to a diagnosis of an NDD, but no literature was found which specifically divided the process into individual components, or formally assessed how waiting lists contribute to the overall time taken to reach a diagnosis. The research presented, whilst limited by factors such as the sample size, has contributed towards the body of knowledge of the referral timeline components. Currently, on average, just over half the time taken in obtaining a diagnosis is spent before accessing health care services in the Eastern Cape. Whilst time spent on the NDC waiting list contributed the least to the total time taken to obtain a diagnosis of an NDD.

The appropriateness of the referral was added as an outcome of interest in this research study. The study revealed that healthcare providers generated very few inappropriate referrals, and whilst the proportion of self-referrals to the NDC was small, self-referrals were more frequently inappropriate. This finding, combined with the data gathered that assessed the referral pathways have allowed the research study to highlight several areas within the referral pathway where further investigations are required or improvements could be implemented.

The study has also contributed to the limited knowledge of the spectrum of disorders. The most frequently encountered diagnoses were ADHD and ASD. Literature was not found which could be directly compared to the findings of this secondary study objective, highlighting the need for further research locally and internationally which describes the spectrum of disorders encountered by neurodevelopmental services.

CHAPTER 7 – REFERENCES

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APPENDIX A - DATA CAPTURE FORM

1. Demographic information Unique ID:_____

1 (a) Current Date:

1 (b) Residence (town only):

1 (c) Age: Years:_____ Months:_____

1 (d) Gender: Female ☐ Male ☐

1 (e) Race: Black ☐ White ☐ Coloured ☐ Indian ☐ Other ☐

1 (f) Home language: English ☐ Afrikaans ☐ Xhosa ☐ Zulu ☐ Sotho ☐
Other ☐

2. Pre-Neurodevelopmental clinic

2 (a) Date of first concern:_____

2 (b) By whom: Caregiver ☐ School ☐ Other ☐

2 (c) Date of first consult with any health care provider:

2 (d) Who was seen at first consult:

2 (e) Sector of first consult: Private ☐ Public ☐
None (self or school referral directly to NDC) ☐

2 (f) Date referred to NDC (earliest referral if multiple)_____

2 (g) Were they treated for an extended period in private/another NDC? Yes ☐ No ☐

2 (h) Who referred to NDC? (if multiple referrals, tick all that apply)

Doctor (Not a Paediatrician)	☐
Doctor (Paediatrician)	☐
Speech therapist	☐
Occupational therapist	☐
Clinic nurse	☐
Educational psychologist	☐
Clinical psychologist	☐
School/education department	☐
Physiotherapy	☐
Unspecified	☐

2 (i) Reason for referral (if multiple, tick all that apply)

- Speech delay ☐
- Suspected Autism ☐
- Hyperactivity ☐
- Inattention/ poor concentration ☐
- Behaviour challenge ☐
- Poor progress at school ☐
- Fine motor delay ☐
- Cognitive delay ☐
- Gross motor delay ☐
- Seizures ☐
- Suspected Syndrome ☐
- Unspecified/Reason for referral unclear ☐

2 (j) Co-morbid conditions and risk factors:

Does the child have seizures? yes ☐ no ☐
If yes approximately how many in a month? _____
Does the child have hydrocephalus? yes ☐ no ☐
Does the child have microcephalus? yes ☐ no ☐
Does the child have a known genetic syndrome? yes ☐ no ☐

Was the child a:

- Extreme Preterm (before 28 weeks) ☐
- Very Preterm (28-32 weeks) ☐
- Moderate to Late Preterm (32-37 weeks) ☐
- Term ☐
- Caregiver uncertain ☐

Birth Weight:

- Extreme Low Birth Weight (less than 1000g) ☐
- Very Low Birth Weight (less than 1500g) ☐
- Low Birth Weight (less than 2500g) ☐
- Normal Birth Weight (2500g-4000g) ☐
- High Birth Weight (above 4000g) ☐
- Caregiver uncertain ☐

3. Work-up done pre NDC consult

3 (a) Specialized Investigations:

Neuro-imaging CT	yes ☐	no ☐
Neuro-imaging MRI	yes ☐	no ☐
Audiometry	yes ☐	no ☐
Eye test/Optometry	yes ☐	no ☐
Occupational therapy assessment	yes ☐	no ☐
Formal education psychology assessment	yes ☐	no ☐
EEG	yes ☐	no ☐

4. NDC consult outcome

4 (a) Suspected diagnosis

Autistic spectrum disorder	yes ☐	no ☐
ADHD/ADD	yes ☐	no ☐
Global developmental delay	yes ☐	no ☐
Intellectual impairment	yes ☐	no ☐
Cerebral Palsy	yes ☐	no ☐
Epilepsy	yes ☐	no ☐
Suspected genetic syndrome	yes ☐	no ☐
Learning disability	yes ☐	no ☐
Specific delay in a certain area:	yes ☐	no ☐

If YES, which area:

- Gross Motor ☐
- Speech ☐
- Fine motor ☐
- Personal ☐
- Social ☐

Psychiatric disorder yes ☐ no ☐

If YES, which diagnosis

- Adjustment disorder ☐
- Anxiety ☐
- Depression ☐
- Conduct disorder ☐
- Oppositional defiant disorder ☐
- Unspecified ☐

5. Management at NDC

5 (a) Medication given yes ☐ no ☐

If YES, which of the following were prescribed (tick all that apply)

- Stimulant (e.g. Methylphenidate) ☐
- Atypical anti-psychotic (e.g. Risperidone) ☐
- Anti-epileptics (e.g. Sodium Valproate) ☐
- Anti- depressants (e.g. Fluoxetine) ☐
- Hormones (e.g.Melatonin) ☐
- Anti-histamine (e.g. Promethazine) ☐

5 (b) Further investigations requested by NDC (not previously performed)

- Neuro-imaging CT yes ☐ no ☐
- Neuro-imaging MRI yes ☐ no ☐
- EEG yes ☐ no ☐
- Blood tests yes ☐ no ☐

If YES, which tests (tick all that apply)

- Full blood count ☐
- Urea and creatinine ☐
- Calcium, magnesium and Phosphate ☐
- Liver functions ☐
- Thyroid functions ☐

- Genetic tests yes ☐ no ☐
- In born errors of metabolism yes ☐ no ☐

5 (c) Referral recommended to

- Physiotherapy yes ☐ no ☐
- OT yes ☐ no ☐
- Eye clinic/ Optometry yes ☐ no ☐
- Audiology yes ☐ no ☐
- Speech therapy yes ☐ no ☐
- Remedial teaching/extra lessons yes ☐ no ☐
- Psychology (for counselling) yes ☐ no ☐
- Psychology (for formal testing e.g. IQ) yes ☐ no ☐
- Education Department yes ☐ no ☐
- Social welfare yes ☐ no ☐
- Psychiatry yes ☐ no ☐

5 (d) Schooling/care placement suggested

- Parental home and mainstream schooling ☐
- Parental home and school offering mainstream and additional services (e.g. Arcadia) ☐
- Parental home and school for hearing impaired ☐
- Parental home and Special needs school (e.g. Parklands) ☐
- Long term care/boarding Special needs facility ☐

5 (e) Outcome

- Appropriate referral ☐
- Inappropriate referral ☐

APPENDIX B - ETHICAL CLEARANCE CERTIFICATE UNIVERSITY OF THE WITWATERSRAND

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Dr Michelle Lee Olander-Deas

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M190247

NAME: (Principal Investigator)	Dr Michelle Lee Olander-Deas
DEPARTMENT:	Paediatrics Frere Hospital, East London - Eastern Cape The Neurodevelopmental Clinic
PROJECT TITLE:	An analysis of the referral system, to the Neurodevelopment clinic, at a tertiary hospital in the Eastern Cape
DATE CONSIDERED:	22/02/2019
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr A. Rossouw and Dr J. Bezuidenhout
APPROVED BY:	Dr. CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	30/05/2019

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 on the 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 **February** and will therefore be due in the month of **February** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX C - ETHICAL CLEARANCE LETTER FRERE AND CECELIA MAKIWANE ETHICS COMMITTEE

EASTERN CAPE PROVINCE

DEPARTMENT OF HEALTH **ISEBE LEZEMPILO**

FRERE AND CECILIA MAKIWANE HOSPITALS RESEARCH ETHICS COMMITTEE

DEPARTMENT OF INTERNAL MEDICINE
PRIVATE BAG X 9047
EAST LONDON
5200

Assoc Prof AG Parrish
Cell: 082 5765930
E-mail: andygp@mweb.co.za

30 June 2021

To Dr M Olander-Deas

Dear Dr Olander-Deas

Re: An analysis of the referral system, to the neurodevelopmental clinic, at a tertiary hospital in the Eastern Cape

Your study was reviewed at the FCMREC meeting of 17 April 2019. The proposed study is observational and does not entail substantial clinical risk. The study was approved from an ethics perspective and may proceed. Compliance with standards of Good Clinical Practice in terms of anonymizing information and data security is still essential.

Please note that the clinical governance structure of the institution(s) in which you intend to perform this structure still need to be contacted both for permission to work within their clinical domain, and so that they are aware of your activity on site.

Yours sincerely

Assoc Prof AG Parrish
MBChB, DA(SA), MMed(Med), MMedSci, FCP(SA)
Chair, CMH and Frere Ethics Committee

APPENDIX D - CONSENT FORM

Informed Consent Form for Parents/Legal Guardians of children referred to the neurodevelopment clinic at Frere Hospital in East London. Who are invited to participate in the research study titled "An analysis of the referral system, to the neurodevelopmental clinic, at a tertiary hospital in the Eastern Cape"

Name of Primary Investigator: Dr Michelle Olander-Deas

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the study with you)**
- **Certificate of Consent (for signatures if you agree that your child may participate)**

If you choose to participate, you will be given a full copy of the complete Informed Consent Form, a copy shall be kept in your child's hospital folder and a third copy I shall keep.

Part I: Information Sheet

Good day. I am Dr Michelle Olander-Deas, a medical doctor with an interest in children with developmental concerns. East London is my hometown and I have been assisting in the Neurodevelopment Clinic at Frere Hospital for over a year. I am currently a masters student affiliated with The University of the Witswatersrand.

As you will be aware, you have waited quite a long time for your child's assessment at the clinic and thus, I have decided to do research into what is causing our waiting list to be lengthy and how we can possibly shorten this. I invite you and your child to be part of this research study.

Please take your time to read this information provided and ask me for clarity on anything you do not understand. I am fluent in English and Afrikaans, but unfortunately cannot speak isiXhosa, so if you require a translator please inform me. (The consent form has been translated into Afrikaans and isiXhosa, please inform me if you require/would prefer a translated form).

Purpose of the research

As mentioned above, we have a long waiting list of children needing to attend the Neurodevelopment Clinic. I am trying to ascertain the reasons for this and if more can be done for these children, before they are seen at our clinic, to try to save time.

Type of Research Intervention

I am requesting your permission to gather certain facts about your child's case. For example their age, why they were referred to the clinic and by whom, what tests have been done on your child and what treatment decisions have been made. This will not require any extra time from you or your child, other than completing this consent form. It will also not change how we assess your child or the clinic's suggestions, tests or treatment offered to your child. Participation is completely voluntary and not participating will also not affect your child's assessment or management in any way.

Participant Selection

All newly referred children to the Neurodevelopment Clinic have been invited to participate in this study. As mentioned previously your participation is completely voluntary, you are also free to withdraw your consent at a later stage and I shall then not include your child's case in my study.

Your name and your child's name, South African Identity number and physical address or any other identifying data, will not be captured on the form I shall use to record your child's case. I shall, however, need your child's date of birth and age on the form. You are welcome to see a blank data capture form before you agree to participate in this study and your child's form once I have written the information I require.

A separate list will be kept by me personally so that I know which child's case relates to which form. Thus if you decide at a later stage to withdraw your permission to participate in the research I will know which form to exclude from the study. I assure you that this list will be password protected and kept completely separate from the forms related to your child's case.

Duration

All of the information required I should be able to capture today. **Please note** that this will not impact how your child is managed, nor will your child's follow-up date be earlier if you participate in this study. Your child will also not be disadvantaged in any way if you do not agree to participate.

Risks and benefits

There are no risks to participating in this study, I am already part of the clinic's management team and shall assist you and your child to the best of my ability regardless of whether you participate or not in the study. I, or one of the other doctor's in the clinic, will ask you/ have access to the answers to most of the questions on the form, as part of our assessment of your child and thus this should not add to the time you will spend in the clinic.

Whilst this study may not directly benefit your child today, it may benefit your child in the future, as depending on your child's condition, your child might need to be seen a few times a year at the clinic. The clinic's list for follow-up patients is also increasing and this research hopes to indirectly assist in shortening this too. The greatest benefit, however, will be to future new patients as hopefully, they will not have to wait as long as you and your child have.

Reimbursements/incentives

There is no incentive for you or your child to participate in the study.

Confidentiality and sharing of results

As mentioned previously no identifying information is captured on the form. The data forms will be kept at my home, in a locked cupboard, separate from the list of names of participants and the consent forms.

The final study report will discuss the referral procedure as a whole and recommendations made to improve the running of the clinic and not the management of individual cases. The study

report will be kept by the University of the Witwatersrand and a copy will be given to the Frere Hospital Board, but the original data I capture will be kept by me and I shall not grant anyone other than my thesis supervisors, Dr Anastasia Rossouw and Dr Jacqui Bezuidenhout, access to this. No one else will have access to the file number list.

The study report may be used to write an academic paper for publication or results presented at an academic conference.

Any beneficial clinic changes will be implemented and there will be feedback to the centres that refer children to the clinic.

Right to Refuse or Withdraw

As mentioned previously participation is voluntary and you can withdraw your consent at any time before I publish my report in 2020.

Who to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact me:

Dr Michelle Olander-Deas
Telephone 0723713922
E-mail: mlolander@gmail.com

This proposal has been reviewed and approved by the University of the Witwatersrand Human Research Ethics Committee, which is a committee whose task it is to make sure that research participants are protected from harm.

If you wish to find out about more about the University of the Witwatersrand Human Research Ethics Committee or if you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

You can ask me any more questions about any part of the research study if you wish to. Do you have any questions?

Part II: Certificate of Consent

I _____ and my child _____ have been invited to participate in a research study about referrals of patients to the Pediatric Neurodevelopment Clinic, Frere Hospital, East London.

I have read the foregoing information, in English / Afrikaans / isiXhosa or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily, on behalf of my child, to be a participant in this study. I also declare that I am the parent/legal guardian of _____.

Print Name of Parent / Legal guardian_____
Signature of Parent / Legal guardian _____
Date _____
Day / month / year

If illiterate:

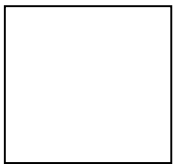
I have witnessed the reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____

Signature of witness _____

Date _____
Day / month / year

Thumb print of participants parent / legal guardian



Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant and the participants' parent/legal guardian, and to the best of my ability made sure that the participant and parent/legal guardian understands that the following will be done: Demographic and referral data on the child and the outcome of the child's visit to the Neurodevelopment Clinic will be collected.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent form has been provided to the participants' parent/legal guardian.

Print Name of Researcher/person taking the consent_____

Signature of Researcher /person taking the consent_____

Date _____

APPENDIX E - ASSENT FORM

Informed Assent Form for children between the ages of seven and eighteen, referred to the neurodevelopment clinic at Frere Hospital in East London. Who are invited to participate in the research study titled "An analysis of the referral system, to the neurodevelopmental clinic, at a tertiary hospital in the Eastern Cape"

Name of Primary Investigator: Dr Michelle Olander-Deas

This Informed Assent Form has two parts:

- **Information Sheet (gives you information about the study)**
- **Certificate of Assent (this is where you sign if you agree to participate)**

You will be given a copy of the full Informed Assent Form, a copy will be kept in your hospital folder and a third copy by the researcher.

Part I: Information Sheet

Introduction

My name is Dr Michelle Olander-Deas and my job is to try to help children like yourself, who are having certain difficulties in their life, for example, problems with concentrating in school. Unfortunately, there are a lot of children with difficulties that we need to see and because of this you and your parents have had to wait a rather long time to come to see us. I have thus decided to try to do some research to find out how we can make our list shorter and get you help quicker.

I am going to give you information and invite you to be part of this research study. You can choose whether or not you want to participate. We have discussed this research with your parent/guardian and they know that we are also asking you for your agreement. If you are going to participate in the research, your parent/guardian also need to agree. But if you do not wish to take part in the research, you do not have to, even if your parents have agreed.

You may discuss anything in this form with your parents or friends or anyone else you feel comfortable talking to. You can decide whether to participate or not after you have talked it over. If you decide today that you want to participate and then at a later stage change your mind, you can withdraw your permission, before the end of the year.

There may be some words you don't understand or things that you want me to explain more about because you are interested or worried about it. Please ask me to stop at any time and I will take the time to explain.

Choice of participants: Why are you asking me?

All the children we are seeing for the first time this year are been invited. Some children are too young to understand the point of research, so they have not been given this information, but your parent/guardian and I feel that you are old enough to understand and decide for yourself if you want to take part.

Participation is voluntary: Do I have to do this?

You don't have to be in this research if you don't want to be. It is up to you. If you decide not to be in the research, it is okay and nothing changes. This is still your clinic, everything stays the same as before. Even if you say "yes" now, you can change your mind later and it is still okay. We will still give you all the help we can.

Unfortunately, you can't say no to the treatment we (the doctors at the clinic) are going to suggest to your parents, as your parents can overrule you, but you are able to say no to being added to the research.

Do you under everything so far or would you like anything explained? Would you like a few minutes to speak privately with me and/or your parent/guardian if there is anything you want to ask but are too shy?

I have checked with the child and they understand that participation is voluntary
_____(initial)

Procedures: What is going to happen to me?

This research won't require you to do anything extra. During your visit to the clinic, we are going to ask you and your parent/guardian a lot of questions to try to decide how we can best help you. We will also need to examine you (for example listen to your heart) and might need to send you for some special tests. We will do all these things regardless of whether you participate in the research or not.

I am only asking you and your parent/guardian's permission to copy the answers to some of those questions onto a special form.

Benefits: Is there anything good that happens to me?

No, unfortunately, you aren't going to be advantaged in any way

Negatives: Is there anything bad that is going to happen to me?

You will not be disadvantaged in any way if you participate. We are not going to order any extra tests if say yes, if you need any blood tests etc., those will be ordered regardless of whether you take part in the study or not.

Do you understand everything so far or would you like anything explained? Would you like a few minutes to speak privately with me and/or your parent/guardian if there is anything you want to ask but are too shy?

I have checked with the child and they understand the procedure, benefits and negatives
_____ (initial)

Reimbursements: Do I get anything for being in the research?

Unfortunately no.

Confidentiality: Is everybody going to know about this?

We will not tell other people that you are in this research and we won't share information about you to anyone who does not work in this clinic or are supervising this research study.

Information about you that will be collected on a form which will not have your name or address on it and it will be put away and no-one but the researchers will be able to see it. The form will have a number on it instead of your name. Only Dr Olander-Deas will know what your number is.

I am happy to show you a blank form before you decide if you want to take part. I am also happy to show you, your filled in form at the end, if you wish and both you and your parent/guardian choose to participate.

Sharing the Findings: Who will you tell the results?

When we have finished the research, we will be telling people like other doctors, schools and other people who are involved in trying to help children like yourself, about the research and what we found. We will do this by writing and sharing reports and by going to meetings with people who are interested in the work we do.

We will discuss the research findings as a big group, not as individual cases. For example, we might say: we saw 100 children, 50 of them were under 5 years of age, 25 between 5 and 10 and the rest were older than 10. Of the 100 children, 60 were girls and 40 boys etc.

Right to Refuse or Withdraw: Can I choose not to be in the research? Can I change my mind?

As mentioned before you do not have to be in this research. No one will be mad or disappointed with you if you say no. It is your choice. You can say "yes" now and change your mind later and it will still be okay.

Who to Contact: Who can I talk to or ask questions to?

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact me:

Dr Michelle Olander-Deas
Telephone 0723713922
E-mail: mlolander@gmail.com

This proposal has been reviewed and approved by the University of the Witwatersrand Human Research Ethics Committee, which is a committee whose task it is to make sure that research participants are protected from harm.

If you wish to find out about more about the University of the Witwatersrand Human Research Ethics Committee or if you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be

contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

You can ask the nurse questions or the doctor that sees you in the clinic too. I have written a number and e-mail address where you can reach me. If you are nearby, we can also arrange a time that you can come and see me. If you want to talk to someone else that you know and trust like your teacher or family member, that's okay too.

If you choose to be part of this research I will also give you a copy of this paper to keep for yourself. You can ask your parents to look after it if you want.

You can ask me any more questions about any part of the research study, if you wish to. Do you have any questions?

Part II : Certificate of Assent

I understand the research is about patients seen for the first time at the Neurodevelopmental clinic, Frere Hospital, East London.

I have read this information (or had the information read to me). I have had my questions answered and know that I can ask questions later if I have them.

I agree to take part in the research.

OR

I do not wish to take part in the research and I have <u>not</u> signed the assent below._____(initialled by child/minor)

<u>Only if child assents:</u>

Print name of child _____

Signature of child: _____

Date:_____
day/month/year

If illiterate:

I have witnessed the accurate reading of the assent form to the child, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness (not a parent)_____ AND Thumb print of participant

Signature of witness _____

Date _____
Day/month/year

I have accurately read or witnessed the accurate reading of the assent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given assent freely.

Print name of researcher_____

Signature of researcher_____

Date_____
Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the child understands that the following will be done:

Demographic and referral data on the participant and the outcome of the participant's visit to the Neurodevelopment Clinic will be collected.

I confirm that the child was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this assent form has been provided to the participant.

Print Name of Researcher/person taking the assent_____

Signature of Researcher /person taking the assent _____

Date _____
Day/month/year

Copy provided to the participant _____(initialed by researcher/assistant)

Parent/Guardian has signed an informed consent ___Yes ___No _____(initialed by researcher/assistant)

APPENDIX F – PLAGIARISM DECLARATION

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Michelle Lee Olander-Deas (Student number: 1789563) am a student registered for the degree of Masters of Science Child Health Neurodevelopment in the academic year 2021.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated 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 that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: MOlean Date: 16/11/2021

APPENDIX G – TURN-IT-IN REPORT 1

M L Olander-Deas Research Report.pdf

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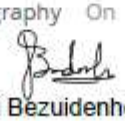

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