

Neurodevelopmental disorders at Chris Hani Baragwanath Academic Hospital: a 4-year retrospective database review

Sarah Jane Lowick ^{1,2} Sibongile Mbatha^{1,2}

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ABSTRACT

Background Developmental paediatrics is a growing field both globally and locally with increasing demand for medical and educational resources.

Methods This retrospective, developmental database review is a baseline description of the Chris Hani Baragwanath Academic Hospital neurodevelopmental clinic population, and the service offered over the past 4 years. The population comprises all patients seen at the clinic from May 2020 to December 2024. Outcomes measured were total patient numbers, demographic, clinical and management variables.

Results The cohort comprised 1877 patients. An increase in total patient numbers was observed over the past 4 years. The ratio of male to female patients was 3:1. Median age at referral was 48.8 months with an average waiting period of 12 months. The median, mean and age range at first visit were 60, 66 and 5–192 months, respectively. Autism was diagnosed in 37.1%, non-syndromic intellectual disability in 16.6%, a confirmed genetic diagnosis in 11.8% and a 'likely genetic disorder' in 18% of patients. 98 different genetic conditions were identified. Comorbidity included cerebral palsy (11.4%), epilepsy (16.1%), hearing (5.2%) and visual impairment (5.5%). Associated behavioural disorders occurred in 52.8% of patients, predominantly attention deficit hyperactivity disorder (ADHD) (30%). At least one medication was prescribed in 58.2% of children. Over 40% of children were either at home or at crèche; 14.0% were attending mainstream school; 10.5% an autism school; 26.3% a special needs school. Of the 841 (44.8%) children in supported schooling, 47.8% were placed after 7 years of age.

Conclusions This study provides insights into the regional burden and clinical presentation of neurodevelopmental disorders. Trends in this region reflect broader global patterns, with increasing numbers of children presenting with complex conditions. Greater resources are needed for earlier diagnosis and therapy, access to all tiers of genetic testing and upscaling of inclusive and special needs education.

Trial registration number NHRD GP_202510_105.

INTRODUCTION

The 17 Sustainable Development Goals (SDGs) adopted in 2015 by the United Nations are centred around the principles of equality and non-discrimination, whether by income, sex, age, race, ethnicity, migration

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Developmental paediatrics is a growing field whose aim is the fulfilment of all children's cognitive potential.
- ⇒ One in 10 children globally has moderate to severe disability, and 94.5% live in low-income and middle-income countries.
- ⇒ Chris Hani Baragwanath Academic Hospital is a major regional referral centre for children with developmental disorders.

WHAT THIS STUDY ADDS

- ⇒ This study provided insights into the regional burden and patterns of developmental disorders; highlighted the importance of autism, genetic disorders and intellectual disability in this population.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ There is a need for additional health and educational services in this area.
- ⇒ We hope that this research assists in motivating for these improvements and facilitates future longitudinal and comparative studies.



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¹Department of Paediatrics and Child Health, Chris Hani Baragwanath Hospital, Johannesburg, Gauteng, South Africa

²Paediatrics, University of the Witwatersrand Johannesburg Faculty of Health Sciences, Johannesburg, South Africa

Correspondence to

Dr Sarah Jane Lowick; slowick@live.com

status, geographical location or importantly, disability. Most of the SDGs have direct and measurable health targets, and disability cuts across many of them. It is estimated that one in six people globally has a significant disability, and many experience stigmatisation, prejudice and social exclusion. Disabilities have profound impacts on the quality of life and social integration of individuals and impose enormous social and economic costs to nations.^{1 2}

There are six broad categories of disorders which contribute to childhood disability: congenital (genetic), infectious, neonatal, neurodevelopmental, injuries and sensory impairments.² Therefore, neurodevelopmental disorders (NDDs) comprise a significant subset of 'childhood developmental disabilities'; are due to an early disruption of brain development and are a heterogeneous group in terms of clinical characteristics,

aetiologies, outcomes and responses to treatment. Features which differentiate NDDs from other neuropsychiatric conditions include childhood onset, a steady clinical course, early onset of prominent neurocognitive deficits, male predominance, high heritability but often multifactorial aetiologies and overlap between conditions.³ NDDs included in both Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) and International Classification of Diseases, 11th Revision (ICD-11) are disorders of intellectual development, communication and language disorders, autism spectrum disorder (ASD), specific learning disorders, motor disorders (developmental co-ordination and tic disorders) and ADHD.^{2,4}

The Global Burden of Disease (GBD) 2019 study estimated that 11.3% of children under 20 years, or 317 million children, had mild to severe disabilities.⁵ UNICEF estimates differed in that they used household surveys of the child's functional status; evaluated children from 0 to 17 years and measured only moderate to severe disability. This yielded a prevalence of 10.1% (236.4 million).⁶ Olusanya *et al*⁷ have shown that despite their differences, the GBD and UNICEF estimates are complementary and comparable. In both databases, sub-Saharan Africa (SSA) and South Asia accounted for more than half of children with disabilities, and 94.5% of children with disabilities lived in low-income and middle-income countries.⁷ The GBD study reported an overall 11.6% prevalence of childhood disability in Africa.^{5,7}

During the past 20 years, there has been a steady decline in the neonatal, infant and under-5 mortality rates (U5MR) in Africa as a whole and in South Africa.⁸ Reduced mortality rates have resulted in more children surviving, with some of them presenting with NDDs. Globally, the risk of a child having a disability is at least 10 times that of dying before their fifth birthday.⁹ Early childhood is a period of rapid growth, neuroplasticity and heightened sensitivity to stimulation, nurturing, learning and to interventions which improve developmental outcomes. Scarcely resourced health systems in SSA focus primarily on infectious disease, resulting in underdiagnosis of NDDs. The child and affected family endure a high emotional and financial burden, missed opportunities and minimal support.¹⁰

The 2022 South African census revealed that of the 62 million population, 34% are children under 18 years and 11.3% are under 6 years of age.⁸ Although the overall national population numbers in this 0–6 age group have remained constant between 2011 and 2022, there have been changes in the distribution of young children across provinces. The child population of Gauteng is the highest in the country (22%; 4.5 million children) and has grown by 57% since 2002.⁸ There are limited data on the population prevalence of childhood disability, NDDs, screening and referrals to specialised health or educational services. However, the 2021 Thrive by Five Index, released in April 2022, gives reason for concern.¹¹ This initiative is the largest survey of preschool child

development undertaken in South Africa. It was the first in a series that will be repeated every 3 years to monitor the development of children aged 4–5 years attending Early Learning Programmes (ELPs). When both cognitive and growth parameters were combined, an alarming 57% of children had 'barriers to thriving'. 5.7% were stunted and suffering from chronic malnutrition. The authors reported that only 46% of children were developmentally appropriate, in key areas of cognitive development. As only children attending an ELP were included, it was likely that those from the poorest households were excluded and would fare even worse. The strong relationship between poverty, stunting and early learning was starkly emphasised in the differential cognitive performance between socioeconomic quintiles.¹¹

The neurodevelopmental clinic (NDC) at Chris Hani Baragwanath Academic Hospital (CHBAH) has expanded over the past 35 years and includes children with a wide range of NDDs. As this Soweto hospital is the largest on the African continent, referrals are far-reaching. This research is intended as a baseline description of the NDC population and the service offered over the past 4 years. It is hoped that this will enable a better understanding of diagnostic trends, obstacles to clinical and educational care, the burden of disease and need for developmental services. This knowledge may guide improvements in the referral pathways, waiting times and clinical practice and provide the foundation for future research.

METHODS

Study design

This was a retrospective, descriptive study, analysing the clinic database over a 4-year period (May 2020 to end December 2024).

Population

The population comprised all patients seen at NDC at least once from May 2020 to December 2024 (1877 patients). The University of the Witwatersrand REDCap data project, created in May 2020, was converted to an Excel workbook to facilitate analysis. Those attending the clinic for a follow-up visit, who were first seen prior to May 2020, were electronically entered with backdated information. Therefore, this database included all patients, whether new or old, who had attended the clinic since May 2020.

Setting

CHBAH is South Africa's largest tertiary referral hospital with 3400 beds and 20 000 births annually. It is situated in Soweto, which has a population of 2 million people, 413 311 of whom are children under 17 years, as measured in 2023. The CHBAH NDC began in the late 1980s and has expanded to include children with a wide range of NDDs. The high demand for services necessitated guidelines to define appropriate referrals. These include children below 14 years of age, with global developmental

delay (GDD) and intellectual disability (ID), regression of milestones, language delay, syndromic conditions, autism, attention and behavioural difficulties, visual and hearing impairment (HI). The service runs daily outpatient clinics with four permanent staff members—a developmental paediatrician, a developmental medical officer and two developmental fellows.

Outcome measures

Data were captured in the REDCap System Database and converted to an Excel workbook for further analysis.

► Current clinic statistics

- Number of patients (both new and follow-up) on the database, seen annually, to explore trends over a 4-year period (2020–2024).
 - In addition to the database, limited manual data from 2013 were available. This was captured prior to 2020, by administrative staff and included the monthly numbers of new and returning patients, for 2013, 2017, 2018, 2019. This allowed for the plotting of a basic 11-year trend.
 - An electronic list of referrals was created, from 2023 to 2024, to facilitate analysis of precise waiting times. Preliminary review of this provided age of referrals and waiting times from referral to the first clinic appointment date.
- #### ► Demographic characteristics of the cumulative clinic population: gender, age of first visit, referral source.
- #### ► Clinical disorder profile of all children:
- Primary diagnosis data.
 - Autism data—severity levels, specifiers, genetic diagnoses, medical comorbidity.
 - Genetic conditions—confirmed and suspected/likely.
 - ID and GDD (non-syndromic).
 - Intellectual functioning of all patients.
 - Comorbid medical conditions—epilepsy, visual impairment (VI), HI, cerebral palsy (CP)

- Comorbid behavioural disorders—ADHD, aggression and irritability, self-injurious, disruptive behaviour disorders and mood and anxiety disorders.
- #### ► The primary diagnosis was based on clinical assessment and results of investigations and included the following categories:
- Genetic disorders (confirmed on genetic testing or suspected based on the following criteria:
 - Two out of three characteristics: ASD/ID; congenital anomalies including dysmorphism, multisystem or neurological involvement; strong family history (FH)
 - ID and GDD (non-syndromic).
 - ASD (non-syndromic); ASD (genetic confirmed or likely genetic disorder).
 - Teratogen/environmental syndrome.
- #### ► In complex patients with many comorbidities and aetiological risk factors, it may be difficult to decipher the precise primary pathology. Therefore, a comprehensive, holistic assessment is used at this clinic, including consideration of all comorbid medical and behavioural conditions.
- #### ► Management intervention data
- Medication use.
 - School placement—type of school attended, age of placement in special school.

Data analysis

Descriptive statistics were conducted using Excel, including frequencies and proportions of categorical data; means, medians, SDs of continuous data.

RESULTS

There were 1877 patients attending the clinic at the end of December 2024. Of these, 557 were seen prior to 2020 but were captured on the database after May 2020, at the time of the follow-up visit. 20 patients had missing data

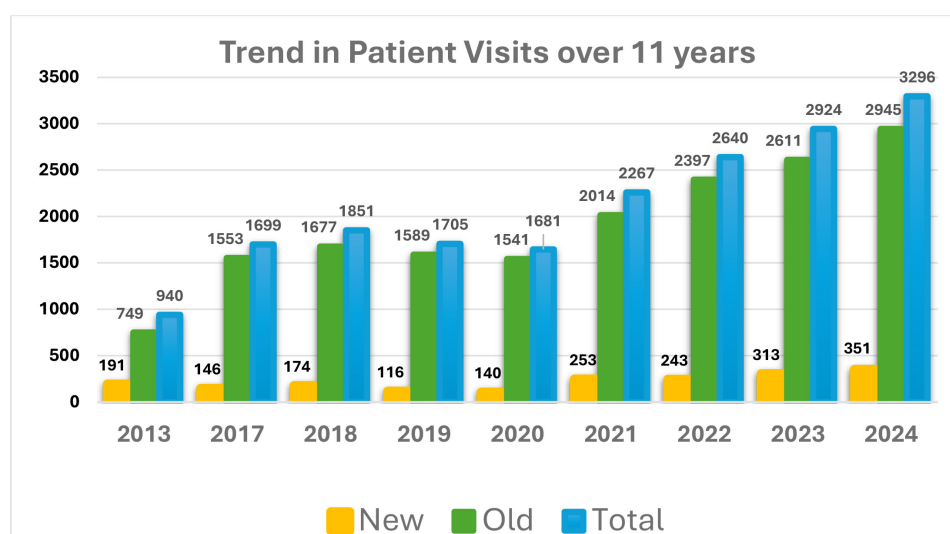


Figure 1 NDC patient visits 2013–2024. NDC, neurodevelopmental clinic.

Table 1 Demographic data of clinic attendees

	Number (%)	Age	Median (months)	Mean (months)	Age range
Gender	1877	Age at referral (2023/2024) (N=748)	48.8	54.2	1.6–189
Male	1412 (75.2)	Age at appointment date (2023/2024) (N=748)	62.8	66.2	9.4–201
Referral source (N=1822)		Waiting time (N=748)	12	12	
Specialist clinic	479 (26.3)	Age at diagnosis (N=1848)	60	66.1	5–192
Chris Hani Baragwanath Academic Hospital therapists	370 (20.3)	Pre-2020 (N=555)	56	60.9	5–168
Community health clinic	312 (17.1)	2020 (N=140)	66.5	71.5	15–192
Secondary hospital	184 (10.1)	2021 (N=253)	60	67	9–168
Schools/department of education	152 (8.3)	2022 (N=239)	63	69.3	12–190
Paediatric outpatients	133 (7.3)	2023 (N=310)	60	66.5	5–184
		2024 (n=351)	63	69.2	16–180

CHBH, Chris Hani Baragwanath Academic Hospital therapists.

for first visit date. 1300 new patients were assessed from 2020 to December 2024. [Figure 1](#) illustrates recordable clinic data from 2013 and shows the overall increase in patient numbers.

Demographic findings

Demographic findings are shown in detail in [table 1](#).

The median, mean and age range at diagnosis were 60 months, 66.1 months and 5–192 months, respectively. Annual variation of median age at first visit is shown in [table 1](#). The mean and median ages have increased from pre-2020 (median 56 months; mean 60.9 months) to 2024 (median 63 months, mean 69 months).

In addition, the 2023/2024 electronic referral list was analysed. The age at the time of referral was compared with the appointment date given (regardless of whether the patient attended or not). The average waiting time for appointment was 12 months, with a median age of 48.8 months at referral and 62.8 months at appointment date.

Clinical findings

The frequencies of primary diagnoses are shown in ([figure 2](#)). ASD was diagnosed in 37.1% (698) of the patients, 121 of whom were syndromic ([figures 2 and 3](#)). In patients with autism and GDD or ID, ASD was considered the primary disorder. Over half of autism patients had severe symptoms with level three support required, 37.1% were non-verbal and 51.7% had moderate or severe ID. 18.8% had mild autism and 7.4% appeared to have normal intellectual functioning ([table 2](#)).

A genetic disorder was considered the likely primary diagnosis in 560 (29.8%) children. Of these, a definitive genetic diagnosis was made in 222 patients (11.8% of the whole cohort), while 338 (18%) had ID with congenital anomalies or a positive FH, but no conclusive molecular

diagnosis ([figure 3](#)). Patients with confirmed disorders mostly had ID (88.3%), while a small proportion had ASD (11.7%). 98 different genetic conditions were identified, through available genetic testing. The most common conditions were Trisomy 21, tuberous sclerosis, neurofibromatosis 1, other RASopathies, overgrowth syndromes, Fragile X, Noonan, William, Angelman and Rett syndrome, 22q deletion, inherited metabolic disorders and 15q, 1p36, 16p11.2 mutations.

Isolated ID or GDD was the primary diagnosis in 16.6% (311) of the cohort. In these children, there were no features to suggest an underlying genetic or metabolic disorder. In addition, intellectual levels were documented for the whole clinic cohort where possible (1717 of 1877), as illustrated in [figure 4](#).

Teratogen or prenatal infectious exposure was classified as an ‘environmental syndrome’ in 3.2% (61) of children. Visual and HI as a primary diagnosis were rare, as most of these children had additional neurological pathology.

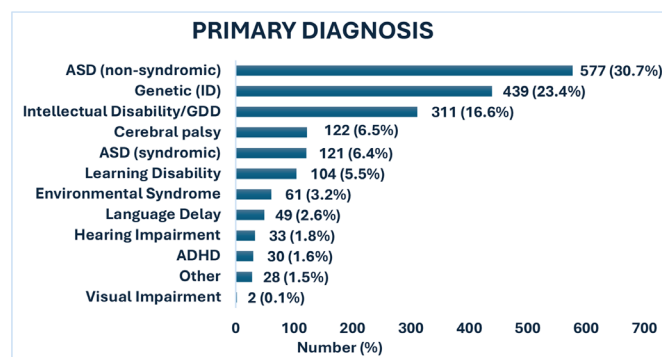


Figure 2 Distribution of primary diagnosis. ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; GDD, global developmental delay; ID, intellectual disability.

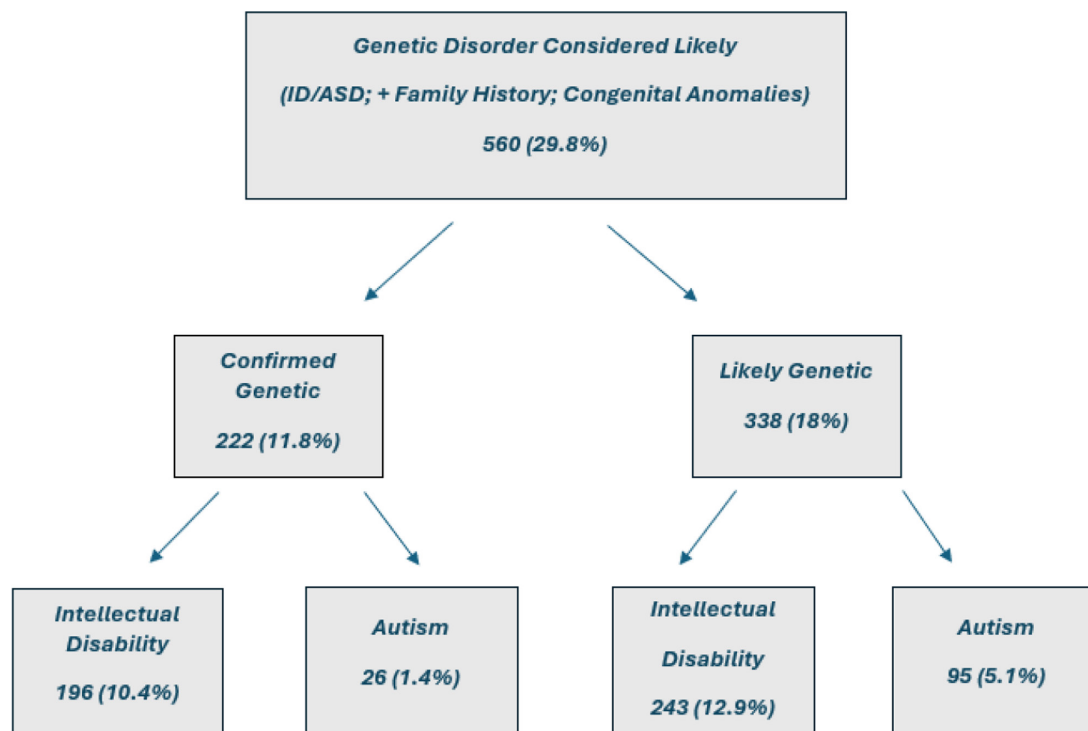


Figure 3 Genetic disorders. ASD, autism spectrum disorder; ID, intellectual disability.

Table 2 Autism severity, specifiers and confirmed genetic causes

Variable	Number (%)	Confirmed genetic diagnosis and autism	Number
Autism diagnosis	698 (100)	Autism (confirmed genetic)	26 (3.7%)
Autism (non-syndromic)	577 (82.7)	Fragile x syndrome	6
Autism (syndromic)	121 (17.3)	Tuberous sclerosis	3
Autism (confirmed genetic)	26 (3.7)	Trisomy 21	3
Severity (N=698)		Neurofibromatosis 1	2
Level 1	131 (18.8)	Rett syndrome	3
Level 2	210 (30.1)	22q deletion	2
Level 3	357 (51.1)	Bardet-Biedl	1
Language (N=698)		Simpson Golabi Behmel	1
Non-verbal	259 (37.1)	16p11.2 deletion	1
Single words	147 (21.1)	ADNP-related disorder	1
Phrases	139 (19.9)	15q11.2 triplication	2
Sentences	151 (21.6)	Albinism	1
No impairment	2 (0.3)		
Intellectual (N=698)			
Severe/profound	101 (14.5)		
Moderate	260 (37.2)		
Mild	116 (16.6)		
GDD	169 (24.2)		
Normal intelligence	52 (7.4)		

GDD, global developmental delay.

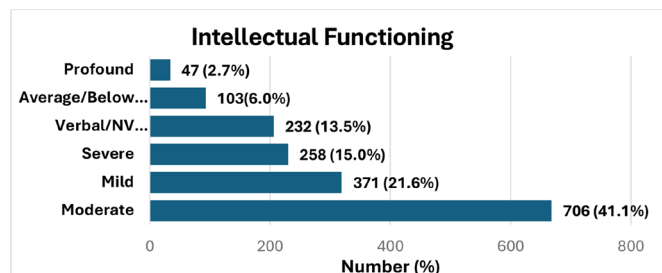


Figure 4 Distribution of intellectual levels of functioning. NV, non-verbal.

CP was the primary diagnosis in 6.5% (122) but mild CP (hemiplegia or spastic diplegia) was a comorbid finding in an additional 92 (4.9%) of children. Therefore, CP was diagnosed in 11.4% (214) of patients.

Comorbid medical and behavioural diagnosis

CP and epilepsy occurred in 11.4% and 16.1%, respectively. Rates of CP and epilepsy at this clinic do not reflect the regional burden as CHBAH has specific paediatric CP and epilepsy outpatient clinics. Hearing and VI were present in 5.2% and 5.5%, respectively. Over half of patients had an associated behavioural disorder, with ADHD the most common diagnosis, in 30% (table 3).

Medication

At least one medication was prescribed to 58.2% (1092) of children. Of these, most were treated with risperidone—41.9% (787), methylphenidate 18.5% (347) and antiepileptics 13.6% (256). Alternative atypical antipsychotics (aripiprazole/olanzapine), selective serotonin reuptake inhibitors and melatonin were only used in a small proportion of children.

Schooling

Most children were either attending a crèche (22.9%) in their local area or still at home with the primary caregiver (18.4%). 14.0% were enrolled in mainstream schools. Only 26.3% of the cohort attended a special needs school (for ID), 10.5% an autism school and 6.2% a remedial school. Of the 841 (44.8%) children attending a supportive alternative school, 6.3% (52) were placed between the ages of 3 and 5 years; 46.1% (378) between 5 and 7 years; 40.5% (332) between 7 and 10 years and 7.3% (60) after 10 years of age (figure 5).

DISCUSSION

There has been a steady increase in total patient numbers over the past 4 years and a tripling in the annual numbers since 2013. The dips in both new and follow-up visits in 2019 and 2020 are likely due to a staff shortage in 2019 and the covid pandemic in 2020. Regional demand for developmental health and educational services is high and growing.^{12–15} The capacity of this neurodevelopmental service has increased, with two additional paediatricians, an electronic data

Table 3 Comorbid medical and behavioural conditions

Associated medical condition	Number (%)
Cerebral palsy	214 (11.4)
Epilepsy	302 (16.1)
Dysmorphism	545 (29.0)
Cardiac involvement	128 (6.8)
Hearing impairment	97 (5.2)
Visual impairment	103 (5.5)
Macrocephaly	149 (7.9)
Microcephaly	267 (14.2)
Short stature	150 (8.0)
Tall stature	38 (2.0)
Failure to thrive	78 (4.2)
Overweight	45 (2.4)
Skin condition	103 (5.5)
Skeletal disorder	63 (3.4)
Renal disease	35 (1.9)
Gastrointestinal disease	27 (1.4)
Pulmonary disease	20 (1.1)
Associated behavioural disorder	Number (%)
ADHD	563 (30.0)
Aggression/irritability/tantrums	351 (18.7)
Disruptive behavioural disorder	89 (4.7)
Other	49 (2.8)
Anxiety/mood	39 (2.1)
Self-injurious behaviour	41 (2.2)
Enuresis/encopresis	10 (0.5)
Oppositional defiant disorder/conduct disorder	5 (0.3)
None	897 (47.8)

ADHD, attention deficit hyperactivity disorder.

system, a multidisciplinary autism clinic, community outreach, research involvement, and training and teaching of medical staff. Despite this growth, the demand continues to outpace capacity, as is evidenced by the 12-month delay from referral (median age 48.2 months) to diagnosis (median age 60 months) and the increased median age at first visit from the pre-2020 period (56 months) to 2024 (63 months). Delayed diagnosis, beyond the period of maximal neuroplasticity, results in missed opportunities for early intervention and later identification of associated medical, genetic and behavioural conditions. Though many referrals were from allied therapists in community, secondary and tertiary centres, others only access interventions following a diagnosis. This concerning trend clearly highlights the need for additional resources to reduce lengthy waiting lists and to promote early diagnosis and intervention.

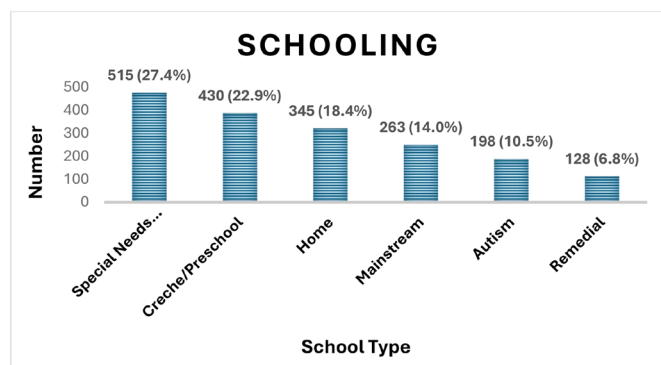


Figure 5 Schooling of NDC population. NDC, neurodevelopmental clinic.

The growing demand for neurodevelopmental services is also evident globally, regionally and within South Africa. International studies have shown that the number of children with developmental disabilities has been increasing, with UNICEF reporting that globally, 1 in 10 children has moderate to severe disability and in the USA, 1 in 6 children (17.76%) is diagnosed with an NDD.^{12 16} In SSA, Olusanya *et al*¹⁷ reported an increase in under-5 disabilities (epilepsy, ID, sensory impairments, ASD and ADHD), from 8.6 million in 1990 to 14.7 million in 2016. SSA had the highest years lived with disability for all disabilities except for ASD.^{5 17 18} In South Africa, Rasdien *et al*¹⁹ described a similar pattern at Tygerberg Hospital's NDC, with a threefold increase in patient numbers between 2008 and 2016.

The increase in NDDs in HICs is attributed to greater awareness, increased healthcare access and broadened diagnostic criteria.² However, there are more complex factors at play in SSA. First, this region has the world's highest fertility rates (though these are also declining) and greatest proportion of children. The United Nations projects that by 2050 more than a third of the world's children will live in Africa and this will increase to 50% by the end of the century.^{20–22} Second, this region has experienced significant reductions in U5MR, due to effective prevention and treatment of infectious diseases, with more children surviving but with developmental disability.^{8 21} Third, developmental risk factors such as poverty, malnutrition, stunting, HIV exposure and perinatal complications are common. Between 2013 and 2022, the proportion of children in SSA who lived in extreme poverty declined from 45% to 40%. However, the share of extremely poor children in the world has become dramatically more concentrated in Africa. Seven out of 10 of the world's children living in extreme poverty are in Africa.^{22 23} Despite South Africa's middle-income country status, a staggering 40% of children under 6 years live in households below the food poverty line and 70% below the upper-bound poverty line.⁹ Addressing these risk factors, which limit cognitive potential and disadvantage poor children from the beginning of their lives, should be a priority for all countries, especially in SSA.^{8 11}

The analysis of primary diagnoses at this clinic revealed that most children presented with ASD, genetic conditions and non-syndromic ID. ASD was diagnosed in 37.1% of the cohort. It is a growing global public health concern as the reported prevalence has increased markedly during the past three decades.^{24–26} The WHO estimates ASD prevalence at 1%, the US at 2.8%, the UK at 1.76% and Scandinavia at 1%–1.5%.²⁶ In South Africa, approximately 270 000 individuals live with autism, with around 5000 new cases diagnosed annually.²⁷ A disproportionate increase in ASD diagnosis, from 8.4% in 2009 to 35% in 2016, was reported at Tygerberg NDC.¹⁹ Large population-based ASD prevalence studies are urgently needed in South Africa. The rising rate of ASD has mostly been attributed to the broadening of diagnostic criteria, better screening, heightened awareness and diagnostic substitution. However, there remains concern about a perceived autism epidemic and potential environmental influences, particularly the effects of technology and screentime in infancy, pollutants and environmental chemicals.²⁸

Global research is uncovering the complex genetic nature of autism.^{28–30} Of the 698 children with ASD, 121 (6.4%) were considered to have a likely underlying genetic aetiology (syndromic autism) due to positive FH, dysmorphism or other physical findings, but only 26 (1.2%) had a confirmed genetic diagnosis. Over half of autism patients at this clinic had severe symptoms with level three support required, 37.1% were non-verbal and more than 50% had moderate or severe ID. A systematic review of SSA autism phenotype research reported that the majority had ID, were non-verbal and required substantial functional support for activities of daily living.²⁴ A South African study of 58 autistic children, in the Western Cape, revealed that 74% had comorbid moderate to severe ID, 72.4% were non-verbal, 10.3% had epilepsy and 34.5% had dysmorphism.³¹ While recent studies from the USA and Sweden have reported considerably lower rates of ID —33% and 25.6%, respectively.²⁶ In this clinic, it is postulated that the long waiting times for an appointment may result in a selection bias skewed towards greater severity. However, the proportion with ID is lower than previously reported in SSA.

Congenital anomalies are present in 1 in 15 South African births, of which 80.5% are expected to be of genetic, or partially genetic aetiology.³² Unsurprisingly, complex and rare genetic disorders represent a significant proportion of this clinic population. A specific genetic diagnosis was confirmed in 11.8% of clinic attendees. An additional 18% were suspected to have an underlying genetic disorder. 59 children attending the NDC were enrolled in the Deciphering Developmental Disorders study, which enabled access to Whole Exome Sequencing (WES).³³ A positive diagnosis was confirmed in 12 patients, to date, but most are still awaiting results. WES is not available in the public or private sector in South Africa, and a CGH array is usually performed for patients suspected to have a genetic disorder.³⁴ Patients with negative first and second line genetic testing would benefit from WES, NGS gene panels and Whole Genome

Sequencing. This would assist in ending the diagnostic odyssey for many families and would lead to greater knowledge of the population's genetic variants.

Primary diagnosis review at this clinic reveals that 16.6% of children have isolated ID but no other anomalies and often without an identifiable cause. Most of these have moderate ID with significant disability. Research shows that ID is likely to be of genetic origin in as many as 80% of cases.³⁵ ID syndromes are particularly difficult to diagnose, due to a high level of phenotypic and genetic heterogeneity. Genomic studies exploring the causes of ID and ASD are an active area of global research; however, the paucity of African dysmorphology and genomic data reflects a significant oversight in global research, given that African genomes contain the greatest genetic diversity of all populations. This not only exacerbates health disparities but hampers scientific discovery.^{29 30 36} Increasing large-scale genetic studies in Africa will benefit both patients and the global community.^{29 37}

Congenital infections and antenatal toxins were only documented in 3.2%. Teratogen exposures are possibly underreported in this area. While fetal alcohol syndrome was diagnosed in 2.7% (50), fetal alcohol spectrum disorder is more difficult to confirm. Antenatal HIV exposure is common in Gauteng, as 27.5% of women attending antenatal clinics are HIV-infected.⁸ HIV exposure is associated with poorer developmental outcomes, but the NDC data on this variable are currently incomplete. Prevention of Mother-to-Child Transmission has resulted in vertical transmission rates <1% and only 22 children at this clinic were HIV-infected on antiretroviral treatment. Antenatal valproate, retinoic acid and recreational drug exposure occurred in only 18 patients.

Appropriate school placement is vital to the well-being of both the child and the family but is fraught with obstacles. The research data on school attendance highlight some of the difficulties encountered in the public sector. First, many children remain at home (18.5%) or attend an informal crèche (22.3%). Perhaps the greatest area of need is for quality subsidised preschools, as these have been shown to have a lasting and positive effect on all children's developmental outcomes.^{11 38} Early childhood development (ECD) has been neglected under the Department of Social Development in South Africa, and quality state-funded preschools are scarce. ECD is mostly catered for by the informal sector and reliant on parent fees. This has resulted in the exclusion of the poorest children from any ECD facilities.^{8 11} Placement of 6–7 years, in all public schools in South Africa, including special needs schools, is under the jurisdiction of the Department of Basic Education (DBE). Appropriate school placement for children with NDDs is impeded by a dysfunctional inclusive education system and a scarcity of special needs schools.³⁹ Our anecdotal experience is that despite medical referrals to DBE and definitive developmental diagnoses, many children are placed in mainstream schools 'to see if they will cope', and often remain for years, making little academic progress. 14.4% of the cohort attended mainstream schools, often with no evidence of inclusive support, severe teacher shortages, huge class sizes, no facilitators or

therapists and poor infrastructure.^{38 39} Remedial schools, attended by 6.2% of patients, are for children with specific learning disabilities, high functioning autism or mild ID. Many of these children remain in mainstream schools. The demand for autism schools is high, with long waiting lists for placement. Of the 698 children with autism, only 198 were attending an autism school. Autism-specific classes have been added to many special needs schools, that previously only catered for ID, to address the overwhelming demand. Therefore, the 26.7% attending special needs schools comprise children with both ID and ASD. Of those that do attend remedial, autism or special needs schools (841), only 6.3% were placed prior to 5 years of age, 46.1% of children were placed acceptably, between 5 and 7 years of age, but for the remainder, the delays result in lost years of educational and therapeutic opportunity and have irreversible emotional effects on the child and family.

Strengths and weaknesses

CHBAH is a major regional referral centre for children with NDDs. This was a database analysis of outpatient clinic statistics, with the aim of describing the patient population and thereby facilitating future longitudinal and comparative studies. This study was the first to evaluate NDDs at this clinic, and it included a wide range of data on a large population. It highlighted the enormous need for health and educational services in this area. However, it was a retrospective, descriptive design, with basic statistical methods. It represented a convenience sample and did not provide prevalence data. The value of this study and the NDC database will be realised over time, for future researchers.

CONCLUSIONS

This study provided insights into the regional burden of NDDs and the need for services and additional resources. These include increased medical staff to improve diagnostic and therapeutic services; psychological support to patients and caregivers; improved diagnostic techniques, especially neuroimaging and advanced genetic testing; major upscaling of the educational system to provide additional special needs, autism and remedial schools, as well as better quality inclusive full-service schools and preschools. We hope that this research assists in motivating for these improvements. Developmental paediatrics is a growing field both globally and locally. It is an area of medicine at the confluence of genetics, paediatrics, psychology, economics, sociology and education. At its core are some of the most important issues and challenges affecting our country and the world. Principally, the well-being of the next generation, the effects of poverty and inequality and the vital need for all children to reach their cognitive potential.

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ORCID ID

Sarah Jane Lowick <http://orcid.org/0000-0001-9964-9448>

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