Children with developmental and behavioural concerns in Singapore

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INTRODUCTION Childhood developmental and behavioural disorders (CDABD) have been increasingly recognised in recent years. This study evaluated the profiles and outcomes of children referred for developmental and behavioural concerns to a tertiary child developmental centre in Singapore. This is the first such regional database.

METHODS Baseline information, obtained through a questionnaire, together with history at first consultation, provided information for referral, demographic and presentation profiles. Clinical formulations were then made. Definitive developmental and medical diagnoses, as well as outcomes based on clinical assessment and standardised testing, were recorded at one year post first consultation.

RESULTS Out of 1,304 referrals between January 1, 2003 and December 1, 2004, 45% were 2–4 years old and 74% were boys. The waiting time from referral to first consultation exceeded four months in 52% of children. Following clinical evaluation, 7% were found to be developmentally appropriate. The single most common presenting concern was speech and language (S&L) delay (29%). The most common clinical developmental diagnosis was autism spectrum disorder (ASD) (30%), followed by isolated S&L disorder, global developmental delay (GDD) and cognitive impairment (CI). Recommendations included S&L therapy (57%), occupational therapy (50%) and psychological/behavioural services (40%). At one year, ASD remained the most common definitive developmental diagnosis (31%), followed by S&L disorder, CI and GDD. Most were children with high-prevalence, low-moderate severity disorders who could potentially achieve fair-good prognosis with early intervention.

CONCLUSION Better appreciation of the profile and outcome of children with CDABD in Singapore could enable better resource planning for diagnosis and intervention.

Keywords: attention deficit hyperactivity disorder, autism, childhood developmental and behavioural disorders, early intervention, speech and language/ developmental delay

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INTRODUCTION

Childhood developmental and behavioural disorders (CDABD) have been extensively studied throughout the world, with about 15%-20% of children identified as having some form of developmental disability.⁽¹⁻³⁾ The United States Bureau has reported a 4.5% rate of developmental disability among children up to five years of age.⁽⁴⁻⁵⁾ In Singapore, demands for diagnostic and intervention services have thus risen dramatically in recent years, with about 1.5%–2.0% of the annual birth cohort requiring the services of the Child Development Unit (CDU) of KK Women's and Children's Hospital (KKH), Singapore. In studies involving preschool teachers, there was clearly a call for more resources and funding for children with CDABD.^(6,7) First established in 1991 at the Singapore General Hospital as the Developmental Assessment Clinic, the CDU, recently renamed as the Department of Child Development, was relocated to KKH in 1997.⁽⁸⁾ Now serviced by ten senior paediatricians, it serves as the larger of the two tertiary referral centres for preschool children with CDABD, receiving both local and foreign referrals.

About 1,000 pre-schoolers at risk for developmental outcome and adult functionality are referred annually for evaluation. The

CDABD database, funded by the SingHealth Cluster Research Funding 2003–2005, was therefore formulated to facilitate systematic and standardised data collection for children seen at the CDU. It would allow for an estimation of local prevalence and incidence of CDABD, track the progress of affected children as well as aid the understanding of resource utilisation and the impact of services on their outcome. To our knowledge, this is the first such reported database in the region.

METHODS

The study period extended from January 1, 2003 to December 31, 2004. All children referred for developmental concerns were identified at the point of first consultation at the CDU. This study was approved by the hospital ethics committee, and informed consent was obtained from all participants. The referred patients were screened through a parent questionnaire by the Programme Intake Coordinator so as to ensure that the referrals were for developmental concerns. After the first consultation with the paediatrician, baseline demographic data, including referral data, childcare practices, schooling, medical, birth and family history, were collected. Diagnostic evaluation data that were noted by

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Table I. Definitions for developmental disorders.

Type of development	Definition
Normal development	Normal history of milestones and development, with normal physical examination
Global developmental delay	Child < 4 years of age with delays in speech and language domain, and in at least 1 other developmental domain
Autism spectrum disorder	Qualitative impairments in social communication and interaction, together with presence of restricted, repetitive and stereotypic behaviour, interests and activities
Attention deficit hyperactivity disorder	Presence of hyperactivity, inattention and impulsivity, presenting prior to age 7, of sufficient degree to impair social, academic or occupational functioning, present for ≥ 6 months across ≥ 2 environments
Speech and language disorder/ motor delay	Delays/difficulties in these specific developmental domains (inappropriate for age level) not explained by any of the above diagnoses
Learning disability	Achievement substantially below expected given the child's age, intelligence and appropriate education
Dyspraxia/ developmental coordination disorder	Motor planning issues, with deficits in conceptualisation, organisation and execution of unfamiliar sequence of movement, often affecting attention and learning
Sensory integration disorder	Sensory defensiveness and modulation issues

the attending paediatrician included the following domains: motor, speech and language (S&L), social interaction, play, cognition and adaptive behaviour, and atypical developmental features. A clinical diagnosis (CD) was first formulated for each child, with appropriate recommendations for investigations and intervention. The definitive diagnosis (DD), formulated at one-year post first consultation, was a composite diagnosis based on the clinical information and results of standardised tests administered by different professionals and serial reviews over the one-year period. The progress and utilisation of resources, as well as the one-year outcome were tracked for each child. At one year post first consultation, improvement in outcome was deemed to have occurred if the therapist, psychologist, teacher or clinician reviewing the child assessed the child to have improved, either because the gap in developmental skills for age had narrowed in that one year or if the child had improved through maturity by age.

All information collected was entered into a specially customised database programme. Statistical analysis was carried out using the Statistical Package for the Social Sciences version 10.1 (SPSS Inc, Chicago, IL, USA). The means and medians for continuous data such as age and waiting times were calculated and explored for patterns of data distribution. Statistical significance for skewed continuous data between groups was explored using non-parametric tests (Mann-Whitney *U* test). Sensitivities and specificities were calculated using 2 × 2 tables. Statistical significance for categorical data was explored using the Pearson Chi-square test. Statistical significance was defined as p < 0.05. ANOVA was used to compare means among the groups. Developmental milestones were clinically assessed based on the Denver Developmental Screening Test, Singapore.^(9,10) Criteria for diagnoses were based on the Diagnostic Statistical Manual IV-revised version.⁽¹¹⁾ The definitions used for the purpose of this study are shown in Table I.

RESULTS

There were 1,304 new referrals in the two-year study period (Table II). Notably, the number of new referrals in the year 2003 (n = 542) was affected by the outbreak of the Severe Acute Respiratory Syndrome, during which time, referrals were rescheduled or cancelled. The majority of the referrals were Singaporeans. Fathers of the children were at least 20 years of age while mothers were at least 18 years of age, with the majority of parents being 30–40 years old. Most of the parents had at least a secondary education. Parental occupations varied widely, with 70% of fathers and 37% of mothers having professional or senior official posts, respectively.

The study population came predominantly from middleincome families, defined as a combined monthly income bracket of \$\$2,000–\$\$6,000. The majority (93%) had purchased their housing, with most owning at least a four-room Housing Development Board flat (public housing). Just over half (53%) of the patients were referred directly from government polyclinics that provided subsidised medical care, with another 32% being intra-hospital referrals. A total of 88% were subsidised cases. The waiting time from the point of initial referral to first medical consultation at the CDU exceeded four months for 52% of the cases. Private patients had a slightly shorter, although not statistically significant, waiting time compared to the subsidised patients.

At first consultation, 90% of the children were below six years of age (2–4 years 45%, 4–6 years 35%). The median age of the children was 44 (range 7–109) months. One-third of them were not in any form of educational set-up yet. The children were predominantly English-speaking (76%). About 54% were Mandarin-speaking (some of whom were bilingual), 12% were Malay-speaking and 5% Tamil-speaking. Only 10% of the children were born premature, which was defined as less than 37 weeks of gestation at birth. The median birth weight was 3,095 g (895–4,370 g).

About one-third of the cohort had parents who were not directly involved with their daily care, while another onethird had care provided entirely by parents (Fig. 1). The other caregivers included grandparents, domestic helpers and childcare centres. Concerns of CDABD were mainly raised by the child's parents (91%), doctor (14%) and the school (37%), many of whom were concerned with S&L delays (64%) in the child (Fig. 2).

Table II. Demographics of th	e study cohort (n = 1,304).
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*Data is missing for some participants.

S&L delay was the single most common presenting concern in 29% of referrals, and it also occurred in combination with concerns regarding social interaction (24%), motor issues (11%) and academic performance (7%). One-third of the children had behavioural issues (37%). Very few had purely motor (3%) or social interaction (1%) issues, while about 5% had purely academic

concerns. The clinical evaluation profile is demonstrated in Fig. 3. The most unperceived delay occurred in the domain of fine motor delay, which was found in a significant proportion of children for whom such concerns were not actually raised by the caregivers.

About 85% of patients in the cohort required further investigations or intervention at the first consult. About 10% were under observation only and 3.5% were discharged. The most frequent medical referral was to the otolaryngologist (16%) for further assessment of hearing status. Only one patient was started on stimulant medication at the first visit. About 4% of patients were given a direct referral to the Early Intervention Programme for Infants and Young Children, which was then sited at either the Rainbow School or AWWA Special School. About 5%-10% of the patients were referred to other out-ofhospital, centre-based early intervention services such as TOUCH Learning Support Centre or Autism Association (Singapore). More than half of the patients were recommended for S&L therapy, and about half were recommended for occupational therapy. One-third of the patients were referred for psychological services and slightly less than 10% were recommended for physiotherapy.

Based on the parental reports and clinical evaluations, the majority of patients were assessed to have a developmental disorder (Table III). The most common CD was cognitive impairment (Cl), which could be isolated or associated with other disorders. About 11% patients were deemed to have cognitive delay without concomitant autism spectrum disorder (ASD). Those with ASD belonged mainly to the moderate severity category. S&L disorder (unassociated with ASD) was also a predominant diagnosis (26%). Global developmental delay and attention deficit hyperactivity disorder (ADHD) were diagnosed in about 10% and 5.6% of patients, respectively. Physical disability such as cerebral palsy (CP) was not commonly referred to the CDU (3.2%). Less common diagnoses included learning disability (LD), developmental co-ordination disorder/dyspraxia and sensory integration disorder.

The CD made after the initial consult was compared with the DD made at one year after the initial consult (Table III). There were 542 patients in the 2003 cohort. The predominant primary diagnoses were ASD, S&L disorder unassociated with ASD and cognitive impairment, with about half of the latter being unrelated to ASD. Those who were clinically assessed to have ASD or cognitive delay, but did not receive a psychological assessment, were not included for analysis of sensitivity and specificity. The diagnoses appeared fairly stable across the clinical diagnoses made initially and the definitive diagnoses at one year post initial consultation.

According to the Ministry of Health guidelines, patients were categorised into four groups according to the prevalence and severity of disorders (Table IV).⁽⁸⁾ About 10% of patients were thought to have excellent prognosis with minimal intervention. About 20% were deemed to be having high-severity disorders with poorer outcomes, requiring long-term special school

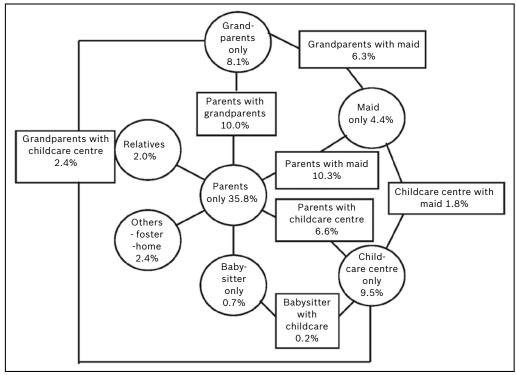


Fig. 1 Flowchart shows the childcare arrangement of the cohort.

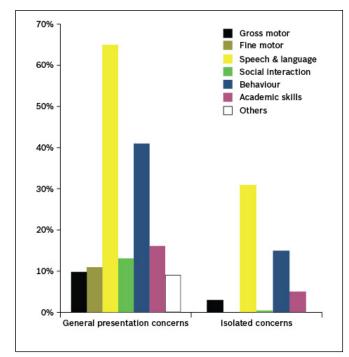


Fig. 2 Graph shows the presenting concerns of patients.

placement and intensive intervention. More than half (58.5%) were assessed to have made overall improvement at one year among the 542 patients in the 2003 cohort.

DISCUSSION

CDABD include delays in motor and S&L development, attainment of social skills, sensory deficits such as visual or hearing impairment, multisystem developmental disorders, CP and CI. Among some 5%–20% of children with developmental disabilities,⁽¹⁻³⁾ the most prevalent conditions in most

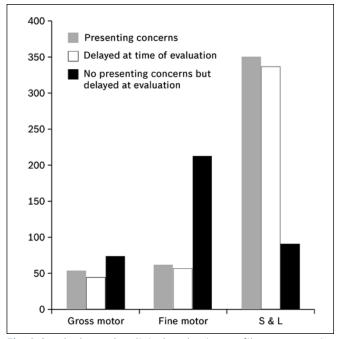


Fig. 3 Graph shows the clinical evaluation profile vs. presenting concerns of patients.

Western countries were LD, and emotional and behavioural problems, while the least prevalent disorder was CP. The prevalence of CP, which is a high-prevalence, low-severity disorder, has been reported to be around 1–3 cases per 1,000 live births or 6%–18%, while for Cl, a low-prevalence, high-severity disorder, it has been estimated at 3%.

In our local paediatric population, motor and S&L disorders are the two more recognised CDABD. However, LD, emotional and behavioural problems, as well as ADHD are increasingly recognised. The US Interagency Committee on Learning

Table III. Comparison of clinical vs. definitive diagnoses.

Developmental diagnosis	2003-4 cohort (n = 1,304)	2003 cohort (n = 542)			
	CD (%)	CD (%)	DD at 1 yr (%)	Sensitivity (%)	Specificity (%)
No developmental disorder	7.4	6.6	7.4	78	98
ASD as primary diagnosis	29.7	27.5	31.3 (24.1)	84	98
High functioning type/AS	3.9	3.5	4.4 (2.8)		
Moderate	19.9	16.4	12.7 (7.9)		
Severe	5.9	7.6	14.2 (13.3)		
S&L disorder unassociated with ASD*	26.2	26.4	30.1	-	-
Isolated S&L disorder	15.5	17.7	14.4		
Language without speech disorder	11.9	15.7	20.7 (9.0)		
Speech without language disorder	3.6	1.3	3.7 (2.6)		
Combination S&L disorder	-	-	5.7 (2.2)		
GDD as primary diagnosis	9.7	9.2	8.5	88	92
ADHD as primary diagnosis	5.6	6.6	7.8 (4.6)	64	98
Predominant inattention form	0.9	0.2	1.5 (0.9)		
Predominant hyperactive form	1.6	2.4	1.3 (0.4)		
Combined form	3.1	4.1	5.0 (3.3)		
Cognitive impairment	36.3	36.5	36.5 (21.6)	64	95
Cognitive impairment without ASD	10.6	12.5	12.9 (6.6)		
Isolated cognitive impairment	4.1	4.2	5.9		
Cerebral palsy	3.2	3.0	2.4	54	98
CP with cognitive impairment	0.8	1.3	1.3 (0.6)		
Hypotonic	1.7	1.8	0.7		
Spastic	1.4	0.9	1.5		
Mixed	0.2	0.2	0.2		
Learning disability	3.8	2.6	4.2	52	100
Dyspraxia/DCD	2.4	2.6	2.9	50	99
SID without ASD*	2.4	1.1	1.7	-	-
Mainly behavioural/environmental problems*	3.1	3.5	8.3	-	-

*Sensitivity and specificity are not calculated for these conditions due to the mutually non-exclusive nature of the diagnosis/numbers involved.

Note: Figures in parentheses denote patients who had definitive diagnosis by standardised testing.

CD: clinical diagnosis; DD: definitive diagnosis; ASD: autism spectrum disorder; AS: Asperger syndrome; S&L: speech and language; GDD: global developmental delay; ADHD: attention deficit hyperactivity disorder; CP: cerebral palsy; DCD: developmental co-ordination disorder; SID: sensory integration disorder

Table IV. Disorders categorise	d according to preva	lence and severity.
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Category	Definition	At initial consult (%)	At 1 year (%)
А	Low-prevalence, high-severity disorders	19.4	20.3
В	High-prevalence, moderate-severity disorders; fair prognosis with early intervention and therapy	32.5	30.4
С	High-prevalence, low-severity disorders; good prognosis with early intervention and therapy	37.8	39.4
D	Developmental delay and behavioural problems with no apparent biological basis; excellent prognosis with early intervention	9.8	9.4

Disabilities concluded that 5%–10% of children are affected by LD, with a reported prevalence of 2%–20%, and about 5% of American schoolchildren are currently receiving special services. Furthermore, disorders such as ADHD, which has a prevalence of about 3%–5% of school-aged children, could be accompanied by comorbid disorders in up to 65% of patients. There is also a growing population of young children presenting with compromised capacities in relating, communicating and thinking, such as in communication disorders like ASD.

Data on CDABD in Singapore is extremely limited. There is presently no consolidated database for local children or for children in the region. The most robust data available is that for the pre-school cohort (0–6 years old), with about 1,400 children being diagnosed annually to have patterns of developmental problems;⁽¹²⁾ this comprises about 3.2% of the annual local cohort. Despite these significant numbers, recent studies have indicated a lack of adequate knowledge on such disorders among the medical profession and care providers.^(6,7,13) The CDABD database would be a starting point to help provide relevant data, which could then aid in increasing awareness and planning of resources.

The CDABD database has indeed provided an insight into the profile of the child referred for evaluation of a developmental or behavioural concern. The referrals to a single-centre tertiary CDU generally average 750-1,000 new cases a year and have continued to increase over the years. Of these, the majority were clearly subsidised cases referred from polyclinics or intra-hospital professionals. It is interesting to note that these children hailed mainly from the average socio-economic background, as denoted by their parental educational and occupational status, as well as their combined monthly income and housing status. This is essentially seen due to the policy to service mainly subsidised patients at the hospital level. It has also been impacted upon by the waiting time from referral to first consultation, which prompts many parents to seek private consultation, something that only the higher-income families can afford. However, in recent years, there has been a rise in the number of private cases seen at CDU, possibly due to the expertise deemed to be available at this multidisciplinary centre. It is also important to note that families of a lower socio-economic status might be limited in terms of resources, access and knowledge to recognise irregularities in their children's development and to tap into the availability of services for them.

When a child with doubtful developmental progress is first referred, the clinician has to assess for genetically inherited conditions, syndromes, perinatal events, trauma, infections and other associated medical conditions such as seizures, visual or hearing impairment, as well as socio-environmental factors as possible aetiologies for the developmental or behavioural concerns.⁽¹⁴⁻¹⁷⁾ It is also important to search for possible comorbid conditions. For instance, ASD is known to be associated with Down Syndrome,^(18,19) Fragile X⁽²⁰⁻²²⁾ and tuberous sclerosis.^(23,24) ADHD is often comorbid with LD,^(25,26) and other psychiatric disorders such as oppositional defiant disorder.^(27,28) A multi-disciplinary team assessment is often needed to establish a definitive diagnosis and make appropriate recommendations for intervention and educational placement.

The most common triggering concern resulting in a referral was related to S&L development. S&L skills impact upon communication and play as well as interaction. As such, parents start to get concerned when their children cannot speak, generally at around the two-year-old mark. Consistent with this, our data showed that most of the children seen at first consultation were around the 2-4 year range. The most common primary diagnosis made in our cohort was ASD, followed by S&L disorder. ASD, a neurodevelopmental disorder involving impairments in communication, interaction and play, in the presence of stereotypic behaviours,^(11,29) has been recently reported to occur in as many as one per 167 children.⁽³⁰⁻³³⁾ It commonly presents at the 2–3-year age group,⁽³¹⁾ when S&L delays alert parents to potential problems. S&L delay in the preschooler may also be a red alert for subsequent LD, which is often diagnosed through achievement testing closer to school-going age and hence is under-represented in this cohort.

Delays in motor development can span a wide variety of diagnoses, with the most easily identified being CP. Gross motor concerns usually present as delays in walking or frequent falls. However, fine motor difficulties, frequently accompanying many developmental disorders, were often under-estimated by caregivers in the younger age group.^(34,35) It goes to show that a full multidisciplinary evaluation of children with any developmental concerns would be needed to fully appreciate their difficulties on a wider scope. Not all developmental centres provide multidisciplinary assessment at the first consultation. In our centre, the CD is first made, followed by the DD, the latter being based on a combination of clinical evaluation and standardised testing, and the two may not always coincide. Nevertheless, the similar patterns of rates of the various diagnoses between the two in this study were encouraging.

Such developmental diagnoses continue to demand significant intervention resources, particularly for S&L as well as occupational therapy services. The one-third of the study cohort that required psychological services is likely to be an underrepresentation, often largely limited by departmental resource constraints, with priority given to those who required urgent educational placement. Child development work has always been challenging and labour-intensive, as can be seen by the fact that just over 50% of the cohort were deemed to have improved after one year of intervention and follow-up. Manpower, time, resources and money are critical to improve this area of paediatric care. The formation of this database has allowed systematic data collection and patient tracking. This has, to some extent, permitted mapping of diagnostic patterns and the examination of service utilisation and patient needs. It has allowed shortterm analysis of the outcomes and impact of services on these children.

Resource utilisation, in natural resource-scarce Singapore, can be subsequently evaluated and the availability be recruited, consolidated and re-distributed among those who need it the most. Organisations involved in resource and programme planning, such as the Ministry of Health, Ministry of Community Development, Youth and Sports and Ministry of Education, might be able to tap into this available data to aid in making evidencebased changes in preschool as well as grade school structure and form. This would lead, in turn, to healthier and more functional adults who are better equipped and able to contribute to society in real terms, an objective that is crucial to Singapore in the years to come.

The formation of the CDABD database would put Singapore onto the international map, establishing a definitive base for regional referrals, and for diagnosis and evaluation of childhood developmental and behavioural disorders. This would additionally serve as a form of revenue, although services in government-aided and subsidised organisations should remain purely allocated for Singaporeans. This would permit collaboration for research not only in the regional area, but also in the international field of developmental paediatrics. A significant challenge would be to maintain this database, which requires significant manpower and funding. It warrants partnership from parties with vested interest in the availability of this valuable knowledge, without which many of the above goals would be limited.

In conclusion, this is the first study in developmental paediatrics in the region. There is presently no known existing database for childhood developmental and behavioural disorders. Yet, it is recognised that there is inadequate reporting of all cases within the nation, as there are cases referred to other smaller centres as well as private centres. It would be ideal for a national database, as that would aid with epidemiological studies, planning for resource allocation and training and research collaboration. Much needs to be done to represent this under-reported group of patients. It is hoped that with this study, changes can occur to aid better identification, diagnosis, intervention and outcomes for these children.

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