Original Research Paper

Volume - 16 | Issue - 08 | August - 2026 | PRINT ISSN No. 2249 - 555X | DOI : 10.36106/ijar

Psychiatry

TIME-TO-CLINIC GAP IN NEURODEVELOPMENTAL DISORDERS: CARE-SEEKING PATHWAYS, DIAGNOSTIC DELAY AND INTERVENTION LAG IN A CHILD PSYCHIATRY COHORT FROM CENTRAL INDIA

Dr Vivek Rai*	Senior resident SAMC, PGI Indore *Corresponding Author
Dr Hiral Kotadia	Professor SAMC & PGI, Indore
Dr Srikanth Reddy	Hod & Professor SAMC, PGI Indore
Dr Libnus B Varghese	Junior resident SAMC PGI Indore

ABSTRACT **Background:** Neurodevelopmental disorders are usually recognizable in early childhood, yet many children reach specialist services only after a clinically meaningful delay.**Objective:** To estimate the time lapse from caregiver recognition of symptoms to first consultation, diagnosis and intervention among children with neurodevelopmental disorders.**Methods:** This single-centre cross-sectional analytical study included children aged 0-18 years diagnosed with a neurodevelopmental disorder according to DSM-5-TR criteria in a tertiary child psychiatry service in Central India. Clinical age milestones were recorded in months. The primary outcome was the recognition-to-first consultation gap; a gap longer than 12 months was considered prolonged. Continuous variables were summarized as median and interquartile range. Kruskal-Wallis and Fisher exact tests were used for group comparisons.**Results:** The study included 51 children; 40 (78.4%) were male. ASD-spectrum presentations formed the largest group (21/51, 41.2%). Median age at symptom recognition was 36 months, first consultation 42 months, diagnosis 60 months and intervention 60 months. The median recognition-to-first consultation gap was 6 months, and 11/50 children (22.0%) crossed the >12-month threshold. Recognition-to-diagnosis lag differed across diagnostic presentations (p=0.002), being longest in ID/GDD-predominant presentations. Prolonged time-to-clinic gap was associated with first consultation setting (p=0.007).**Conclusion:** Most children entered clinical care after a measurable post-recognition delay, with further diagnostic lag in complex developmental presentations. Strengthening early developmental surveillance and referral linkage may reduce loss of intervention time.

KEYWORDS : Neurodevelopmental disorders; autism spectrum disorder; ADHD; developmental delay; diagnostic delay; pathway to care; early intervention

INTRODUCTION

Neurodevelopmental disorders (NDDs), including autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), intellectual disability/global developmental delay (ID/GDD) and specific learning disorder (SLD), begin during the developmental period and often affect communication, learning, behaviour and adaptive functioning [1]. Early developmental surveillance and screening are recommended because delayed identification can postpone developmental, educational and family-level support [2-4].

Although the value of early intervention is well established, diagnostic pathways remain slow in many health systems. Recent work has shown substantial delays between first parental concern and developmental assessment, with additional complexity when autism and ADHD co-occur [5-7]. Indian data have also highlighted delayed pathways to autism care and later age at diagnosis, particularly outside highly resourced settings [8,9]. However, most available studies have focused on ASD alone. The present study examined the recognition-to-clinic gap across a mixed NDD cohort attending a tertiary child psychiatry service in Central India.

MATERIALS AND METHODS

This cross-sectional analytical study was conducted in the Department of Psychiatry at a tertiary care institute of central India. Children aged 0-18 years who received a DSM-5-TR diagnosis of an NDD and whose parent/caregiver provided consent were included. Children whose parents did not consent were excluded.

Data were collected using a semi-structured proforma and entered in a master chart. The variables analysed for this manuscript were age at symptom recognition, age at first consultation, first consultation setting, age at diagnosis, number of consultations before diagnosis, age at first intervention, socioeconomic status, family history and consanguinity. Ages were converted to completed months. The recognition-to-first consultation gap was calculated as the interval between caregiver recognition of symptoms and first consultation. Values below zero due to a prior medical contact before symptom recognition were conservatively set to zero for post-recognition delay analysis.

Predominant diagnostic presentation was assigned using a consistent hierarchy to avoid double-counting overlapping diagnoses: ASD spectrum, followed by ID/GDD, SLD/academic and ADHD/behavioural presentations. Descriptive statistics were reported as n (%) or median (IQR). Between-group comparisons of continuous variables used the Kruskal-Wallis test. Categorical associations with prolonged time-to-clinic gap (>12 months) were tested using Fisher exact test because of small cell counts. A two-sided p value <0.05 was considered statistically significant.

RESULTS

The analysis included 51 children. The median age at assessment was 85 (66-110) months. The cohort was predominantly male (40/51, 78.4%). ASD-spectrum presentations constituted the largest subgroup (21/51, 41.2%), followed by ADHD/behavioural, ID/GDD and SLD/academic presentations. Pediatric or developmental services were the first point of consultation for 36 children (70.6%).

Table 1. Baseline profile and first point of clinical contact of the study cohort

Factor	Category	n (%)
Age at assessment	0-5 years	16 (31.4)
	6-11 years	28 (54.9)
	12-18 years	7 (13.7)
Gender	Male	40 (78.4)
	Female	11 (21.6)
Socioeconomic status	Upper middle	22 (43.1)
	Lower middle	14 (27.5)
	Upper lower	15 (29.4)
Predominant diagnostic presentation	ASD spectrum	21 (41.2)
	ADHD/behavioural	15 (29.4)
	ID/GDD	12 (23.5)
	SLD/academic	3 (5.9)
First consultation setting	Pediatric/developmental services	36 (70.6)
	Psychiatry/child psychiatry	13 (25.5)
	Other specialty	2 (3.9)

Symptoms were recognized at a median age of 36 months and first consultation occurred at a median age of 42 months. The median recognition-to-first consultation gap was 6 months. Diagnosis and first intervention occurred at a median age of 60 months each. A prolonged recognition-to-first consultation gap was present in 11/50 children (22.0%).

Absolute milestone ages differed significantly across diagnostic presentations. SLD/academic presentations were identified at the latest age, whereas ID/GDD-predominant presentations had the longest recognition-to-diagnosis and consultation-to-diagnosis lag. The recognition-to-first consultation gap itself did not differ significantly across diagnostic groups.

Table 2. Clinical milestones and delay intervals by predominant diagnostic presentation

Variable	n	Overall	ADHD /behav.	ASD spectrum	ID/GDD	SLD/academic	p value
Age at symptom recognition	50	36 (24-48)	36 (27-46)	30 (24-36)	36 (24-48)	108 (96-114)	0.025
Age at first consultation	51	42 (30-60)	54 (36-69)	36 (30-48)	48 (28-51)	108 (108-120)	0.014
Age at diagnosis	51	60 (45-72)	60 (44-69)	48 (36-60)	72 (57-111)	120 (114-126)	0.003
Age at first intervention	50	60 (42-72)	60 (42-72)	48 (39-66)	60 (57-96)	120 (114-126)	0.020
Recognition-to-first consultation gap	50	6 (0-12)	6 (0-22)	6 (0-12)	0 (0-8)	12 (6-18)	0.622
Recognition-to-diagnosis lag	50	23 (12-30)	23 (12-28)	12 (12-24)	39 (34-60)	12 (12-18)	0.002
Consultation-to-diagnosis lag	51	6 (0-24)	0 (0-12)	6 (0-12)	36 (9-60)	0 (0-6)	0.020
Recognition-to-intervention lag	49	18 (12-30)	15 (6-27)	12 (12-24)	30 (27-36)	12 (12-18)	0.033

Values are median (IQR) in months. Between-group comparisons used the Kruskal-Wallis test. ADHD, attention-deficit/hyperactivity disorder; ASD, autism spectrum disorder; GDD, global developmental delay; ID, intellectual disability; SLD, specific *learning disorder.*

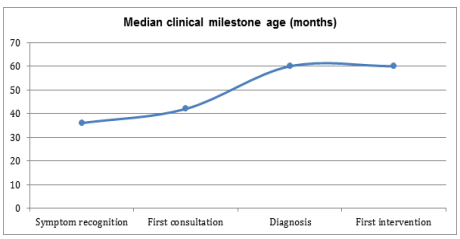

Figure 1. Median age at key clinical milestones in the care pathway

Median age increased from symptom recognition at 36 months to diagnosis and intervention at 60 months.

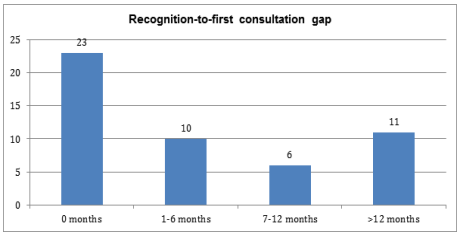

Figure 2. Distribution of recognition-to-first consultation gap

The >12-month category represents the prolonged time-to-clinic gap and included 11/50 children (22.0%).

On categorical analysis, prolonged time-to-clinic gap was significantly associated with the first consultation setting (p=0.007). Children first reaching psychiatry/child psychiatry had a higher proportion of prolonged delay than those first seen in pediatric or developmental services. Age group, gender, socioeconomic status, predominant diagnostic presentation, family history and consanguinity were not significantly associated with the prolonged-gap threshold. When all observed categories were retained, the number of consultations before diagnosis showed a trend but was not statistically significant (p=0.073).

Table 3. Factors associated with prolonged recognition-to-first consultation gap (>12 months)

Factor	Category	Category n (%)	Prolonged gap n/N (%)	p value
Age group at assessment	0-5 years	16 (32.0)	3/16 (18.8)	0.899
	6-11 years	27 (54.0)	7/27 (25.9)	
	12-18 years	7 (14.0)	1/7 (14.3)	
Gender	Male	39 (78.0)	10/39 (25.6)	0.416
	Female	11 (22.0)	1/11 (9.1)	
Socioeconomic status	Upper middle	22 (44.0)	6/22 (27.3)	0.622
	Lower middle	13 (26.0)	3/13 (23.1)	
	Upper lower	15 (30.0)	2/15 (13.3)	
First consultation setting	Pediatric/developmental services	35 (70.0)	4/35 (11.4)	0.007
	Psychiatry/child psychiatry	13 (26.0)	7/13 (53.8)	
	Other specialty	2 (4.0)	0/2 (0.0)	
Predominant diagnostic presentation	ADHD/behavioural	14 (28.0)	5/14 (35.7)	0.406
	ASD spectrum	21 (42.0)	3/21 (14.3)	
	ID/GDD	12 (24.0)	2/12 (16.7)	
	SLD/academic	3 (6.0)	1/3 (33.3)	
Consultations before diagnosis	0 consultations	1 (2.0)	1/1 (100.0)	0.073
	1 consultation	14 (28.0)	6/14 (42.9)	
	2 consultations	25 (50.0)	4/25 (16.0)	
	3 consultations	7 (14.0)	0/7 (0.0)	
	4 consultations	2 (4.0)	0/2 (0.0)	
	5 consultations	1 (2.0)	0/1 (0.0)	
Family history of psychiatric illness	Absent	36 (72.0)	9/36 (25.0)	0.705
	Present	14 (28.0)	2/14 (14.3)	
Consanguineous marriage	No	47 (94.0)	11/47 (23.4)	1.000
	Yes	3 (6.0)	0/3 (0.0)	

Percentages in the category column use the analyzable recognition-to-consultation cohort as denominator (n=50). Percentages in the prolonged-gap column are calculated within each category. Fisher exact test was used for 2 x 2 comparisons and the Fisher-Freeman-Halton exact extension for larger R x 2 tables.

DISCUSSION

This study shows that the care pathway for children with NDDs contained two distinct losses of time: an initial post-recognition gap before first consultation and a further diagnostic lag after entry into clinical care. The median recognition-to-first consultation gap was 6 months, but more than one-fifth of children waited beyond 12 months. This is clinically important because early intervention may modify developmental trajectories, particularly when support begins soon after atypical development emerges [10-12].

The pattern is consistent with international literature showing that caregiver concerns often precede diagnostic assessment by months or years [5,6]. The findings also align with studies done in India on autism pathway, where recognition, referral and diagnostic closure may occur later than the age at which developmental screening is feasible [8,9]. Our study extends this discussion beyond ASD by including ADHD/behavioural, ID/GDD and SLD/academic presentations in the same clinical cohort.

The longest diagnostic lag was observed in ID/GDD-predominant presentations. This may reflect the need for repeated developmental assessment, exclusion of sensory and neurological contributors, and coordination between pediatric, rehabilitation and mental health services. Conversely, children with SLD/academic presentations were recognized late in absolute age because difficulties often become evident only after formal schooling begins.

First consultation setting was the only variable significantly associated with prolonged time-to-clinic gap. The higher delay among children first presenting to psychiatry/child psychiatry should not be interpreted as delay caused by psychiatry; rather, it likely indicates that these children reached specialist psychiatric care after concerns had persisted and become behaviourally or academically disruptive. Strengthening linkage between pediatric, developmental and child psychiatry services may therefore be more useful than relying on late referral after functional impairment becomes obvious.

Gender and socioeconomic status were not significantly associated with prolonged delay in this cohort. This finding should be interpreted cautiously because the sample size was modest and the study was hospital-based. Larger multicentre studies are required to identify equity-related determinants of delay in Central Indian settings.

LIMITATIONS

The study was single-centre and cross-sectional in design, Age at recognition was based on caregiver recall, which may introduce recall bias. Diagnostic overlap was common; therefore, a hierarchy was used to assign predominant presentation for analysis. The study quantified pathway timing but did not measure treatment response or long-term developmental outcomes.

CONCLUSION

Children with NDDs in this tertiary child psychiatry cohort experienced a measurable time-to-clinic gap after symptom recognition, followed by additional diagnostic lag in complex developmental presentations. Early developmental surveillance, timely referral and shared care between pediatric/developmental services and child psychiatry may reduce avoidable loss of intervention time.

DECLARATIONS

Ethical approval: Institutional Ethics Committee approval was obtained before starting the study.

Conflict of interest: Nil.
Source of funding: Nil.
Acknowledgement: Nil.

REFERENCES

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed, text rev. Washington, DC: American Psychiatric Association; 2022.
2. Lipkin PH, Macias MM; Council on Children With Disabilities, Section on Developmental and Behavioral Pediatrics. Promoting optimal development: identifying infants and young children with developmental disorders through developmental surveillance and screening. Pediatrics. 2020;145(1):e20193449. doi:10.1542/peds.2019-3449.
3. Hyman SL, Levy SE, Myers SM; Council on Children With Disabilities, Section on Developmental and Behavioral Pediatrics. Identification, evaluation, and management of children with autism spectrum disorder. Pediatrics. 2020;145(1):e20193447. doi:10.1542/peds.2019-3447.
4. Wolraich ML, Hagan JF Jr, Allan C, Chan E, Davison D, Earls M, et al. Clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. Pediatrics. 2019;144(4):e20192528. doi:10.1542/peds.2019-2528.
5. Boulton KA, Hodge MA, Jewell A, Ong N, Silove N, Guastella AJ. Diagnostic delay in children with neurodevelopmental conditions attending a publicly funded developmental assessment service: findings from the Sydney Child Neurodevelopment Research Registry. BMJ Open. 2023;13(2):e069500. doi:10.1136/bmjopen-2022-069500.
6. Knott R, Mellahn OJ, Tiego J, Johnson BP, et al. Age at diagnosis and diagnostic delay across attention-deficit hyperactivity and autism spectrums. Aust N Z J Psychiatry. 2024;58(2):142-151. doi:10.1177/00048674231206997.
7. Sainsbury WJ, Carrasco K, Whitehouse AJO, McNeil L, Waddington H. Age of diagnosis for co-occurring autism and attention deficit hyperactivity disorder during childhood and adolescence: a systematic review. Rev J Autism Dev Disord. 2023;10(3):563-575. doi:10.1007/s40489-022-00309-7.
8. Patra S, Patro BK, Padhy SK. Symptom recognition to diagnosis: pathway to care for autism in a tertiary care medical centre. J Neurosci Rural Pract. 2020;11(1):164-169. doi:10.1055/s-0040-1701778.
9. Malhi P, Singhi P. Age at diagnosis for autism spectrum disorders: does it differ by place of residence? Indian J Public Health. 2022;66(2):166-170. doi:10.4103/ijph.ijph_1801_21.
10. Whitehouse AJO, Varcin KJ, Pillar S, Billingham W, Alvares GA, Barbaro J, et al. Effect of preemptive intervention on developmental outcomes among infants showing early signs of autism: a randomized clinical trial of outcomes to diagnosis. JAMA Pediatr. 2021;175(11):e213298. doi:10.1001/jamapediatrics.2021.3298.
11. Franz L, Goodwin CD, Rieder A, Matheis M, Damiano DL. Early intervention for very young children with or at high likelihood for autism spectrum disorder: an overview of reviews. Dev Med Child Neurol. 2022;64(9):1063-1076. doi:10.1111/dmcn.15258.
12. Muthiga M, Mbwayo A, Kangethe R, Horn N. Pathways and delays in the diagnosis of autism spectrum disorder in Kenya: a cross-sectional study from tertiary hospitals in Nairobi. Child Adolesc Psychiatry Ment Health. 2025;19(1):114. doi:10.1186/s13034-025-00916-2.