



Referral Pathway and Clinical Profile of Children Aged 0–12 Years under the 4Ds Framework of the Rashtriya Bal Swasthya Karyakram (RBSK) at a Tertiary Hospital District Early Intervention Centre in Ahmedabad, India: A Cross-Sectional Study

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Abstract

Introduction: Under India's Rashtriya Bal Swasthya Karyakram (RBSK), children with the "4Ds" (defects at birth) are referred from community screening to District Early Intervention Centres (DEICs). National referral compliance is only 46–50%, with no primary data on referral-pathway dynamics at a tertiary-level DEIC in Gujarat. This study aims to assess the referral pathways, time-lag, and clinical profile of children attending a tertiary DEIC. **Methods:** A hospital-based, descriptive cross-sectional study was conducted among 243 children aged 0–12 years attending the DEIC at a tertiary Civil Hospital in Ahmedabad (March–April 2026). Caregivers of consecutively enrolled, consenting children were interviewed. **Results:** Among children attending tertiary DEIC, self-referral was the leading pathway (40%), while formal RBSK Mobile Health Team (MHT) routes Anganwadi and school screening combined contributed only 9%. A referral (Sandarbh) card was documented in 59% of assessed low-income families. Only 55% of children reached the DEIC within three months of first detection (timely referral); 25% experienced delay exceeding one year. Developmental Delay and Disability (D4) was the dominant 4Ds category (56%). Low birth weight was significantly associated with Birth Defects ($p=.03$) and Deficiencies ($p=.02$). **Conclusion:** At this tertiary DEIC, community-based RBSK screening contributes only a small share of referrals, and one in four children arrives more than a year after first detection. Strengthening urban Mobile Health Team coverage, Sandarbh card issuance and tracking, and government scheme linkage at the point of DEIC registration are priority actions to close the referral gap.

Key Words: Child health screening, Developmental delay, Early intervention, India, Referral pathway

Introduction

Approximately 7.9 million children are born worldwide each year with a serious birth defect, and nearly 94% of this burden falls on low- and middle-income countries.^[1] India, with one of the world's largest annual birth cohorts, contributes disproportionately: modelled Global Burden of Disease estimates place the number of children with developmental disabilities in India at 11.5 million, the highest national total globally for intellectual disability, autism spectrum disorder and epilepsy combined.^[2] A maternal cohort study places the birth prevalence of congenital anomalies in India between 6 and 70 per 1,000 live births and birth-defect-related deaths in the early neonatal period in India represent an estimated 21% of the global burden of such deaths.^[3] Beyond structural birth defects, childhood morbidity in India is shaped by a wider constellation of preventable and manageable conditions severe and moderate acute malnutrition, anaemia, convulsive disorders, congenital hypothyroidism, and developmental delay spanning

language delay, global developmental delay, autism spectrum disorder and cerebral palsy. An estimated 270 million Indian children aged 0–18 years are at risk of at least one such condition at any given time.^[4]

To close this gap, the Ministry of Health and Family Welfare, India launched the Rashtriya Bal Swasthya Karyakram (RBSK) in 2013 under the National Health Mission. RBSK provides universal child health screening and early intervention services for children from birth to 18 years, organised around 30–32 conditions grouped under the "4Ds": Defects at birth, Diseases, Deficiencies, and Developmental delays including Disabilities.^[4] It is among the first national programmes globally to integrate systematic rare-disease and disability detection into routine primary care.^[5] Screening is delivered through delivery-point newborn screening, Anganwadi- and school-based Mobile Health Teams (MHTs), and facility-based case detection; children with a suspected 4Ds condition are referred, via a Sandarbh (referral) card, to a District Early Intervention Centre

(DEIC) for confirmatory diagnosis and management. Since inception, over 160 crore children have been cumulatively screened nationally, and more than 5.63 crore have availed secondary or tertiary care.^[6]

Despite this scale, the referral pathway linking community screening to the DEIC remains the programme's most persistent weak point. National formative research commissioned by the Ministry found that only 46–50% of children identified with a 4Ds condition through community screening actually reach the DEIC for management meaning that for every two children identified, only one is ever seen at the facility responsible for definitive care.^[7] Reported drivers include caregiver unawareness of entitlements, economic barriers such as lost daily wages and transport cost, geographic distance, non-issuance or loss of the Sandarbh card, and institutional bottlenecks at the DEIC itself.^[7,8] The time-lag between first detection of a condition and DEIC arrival is a particularly consequential but understudied dimension of this pathway: because early intervention windows for neurodevelopmental conditions are time-limited, delay itself represents a form of irreversible harm, independent of eventual diagnosis and treatment.^[2]

Evidence on DEIC functioning in India is accumulating but geographically uneven. Studies from Karnataka, Chhattisgarh and West Bengal have documented infrastructure and manpower shortfalls, poor referral documentation, and low caregiver awareness of entitlements as recurring barriers.^[8–10] The only published Ahmedabad-specific study to date examined RBSK-registered children at an urban primary health centre using retrospective secondary data, and does not capture the referral dynamics of a tertiary-level DEIC, which serves a larger, more clinically complex and geographically diverse catchment.^[11] No prospective, primary-data study has examined referral pathway dynamics, time-lags, or the clinical profile of 4Ds conditions at any tertiary DEIC in Gujarat.

This study was therefore designed to address that gap. Its aim was to assess the referral pathways, time-lag and clinical profile of children aged 0–12 years attending the DEIC at a tertiary Civil Hospital in Ahmedabad. The specific objectives were: (1) to identify the primary sources of referral and the time-lag between first detection and DEIC arrival, including the role of the Sandarbh card; (2) to describe the sociodemographic and clinical profile of children attending the DEIC; and (3) to examine the association between selected perinatal and clinical variables and 4Ds status, and to characterise co-occurrence among the 4Ds categories.

Methods

Study design and setting:

This was a hospital-based, descriptive, cross-sectional study conducted at the District Early Intervention Centre (DEIC) of a tertiary Civil Hospital in Ahmedabad, Gujarat, India, between March and April 2026, following institutional ethics approval. The study site was actively implementing the original 2014 RBSK operational framework during the data collection period.

Study population:

Children aged 0–12 years attending the DEIC during the study period were eligible, irrespective of referral channel (RBSK MHT, primary/community/district health facility, hospital department, self-referral or follow-up), including children from outside Ahmedabad district. Critically ill children requiring emergency care at presentation, and children whose parent or guardian did not provide written informed consent, were excluded.

Sample size and sampling:

Based on average daily DEIC attendance (10–12 children with a 4Ds condition) and an anticipated enrolment of 5–6 eligible cases per day, a minimum sample of 242 was calculated (5.5×44 study days). Children were enrolled consecutively as they presented until this target was reached. Total 243 consecutively enrolled cases were studied and analysed.

Data collection tool and procedure:

A pre-tested, semi-structured, bilingual/trilingual Case Record Form (CRF) was used, comprising seven sections: administrative details; sociodemographic profile (residence, housing, income, occupation, family type, primary referral source, time-lag from first detection to DEIC arrival); access and social support (distance from DEIC, government health scheme utilisation); medical examination (birth and current weight, birth asphyxia, convulsion history, NICU admission, developmental milestones, gestational age, mode of delivery, 4Ds assessment); services availed at DEIC; nutritional status (WHO Z-score based classification, including SAM/MAM for children under five); and immunisation status. In this study, "timely referral" was defined by authors as reaching the DEIC within 3 months of first detection; "moderate delay" as 3–12 months; and "prolonged delay" as greater than 1 year. "First detection" was defined as the earliest recognition of a sign or symptom by either a caregiver or a frontline healthcare provider. Nutritional status was assessed using appropriate WHO Z-score growth charts: weight-for-height was used for children under five years to identify severe/moderate acute malnutrition (SAM/MAM), and BMI-for-age was used for children

aged 5–12 years to identify severe/moderate thinness. Developmental milestones were assessed directly by the DEIC Medical Officer using the Denver II Developmental Screening Test, with "age-appropriate" development defined as the successful completion of standardized milestones for the child's chronological age according to this tool. After obtaining informed consent, caregivers of newly registered and follow-up children were interviewed; for follow-up children, clinical and birth-history data were supplemented from existing medical records. Both primary interview data and retrospective record review therefore contributed to the dataset.

Statistical analysis:

Data was entered in Microsoft Excel and analysed using Epi Info/SPSS. Categorical variables were summarized as frequencies and percentages; age was categorised per RBSK age brackets. Associations between selected clinical/perinatal variables (birth weight, age category, NICU admission, birth asphyxia, nutritional status) and each of the four 4Ds categories were tested using the chi-square test via cross-tabulation, with statistical significance set at $p < 0.05$.

Ethical considerations:

The study was approved by the Institutional Ethics Committee of the Indian Institute of Public Health Gandhinagar (No. IIPHGIEC/2025-26/40-37). Written informed consent was obtained in English, Hindi or Gujarati, as appropriate to the caregiver. No additional investigations were performed for research purposes. Data were stored using unique de-identified study codes (DEIC_001–243), and confidentiality was maintained throughout. Participation was voluntary, with the right to withdraw at any time without affecting care.

Results

Sociodemographic profile of 243 enrolled children, 63% were male. The largest age group was 6 weeks–3 years (37%), followed by 3–6 years (36%); newborns (0–6 weeks) comprised 7%. Eighty-five percent of families had a monthly household income below ₹20,000, and 54% of fathers were classified as unskilled workers. Just over half of families (51%) resided within Ahmedabad city, while 41% travelled from elsewhere in Gujarat (>100 km) and 8% from other states (Table 1).

One-third of children (33%) had a history of low birth weight, and 55% had a history of NICU admission. A history of delayed/absent cry at birth was recorded in 38%. Across the entire study population, combined acute malnutrition and thinness affected 40% of children (severe 17%, moderate 23%). Critically, only 30% of enrolled children had achieved age-appropriate developmental milestones at assessment (Table 2).

Table 1:
Sociodemographic profile of the study population. (N=243)

Variable	n (%)
Age group	
0–6 weeks (newborn)	17 (7%)
6 weeks–3 years	90 (37%)
3–6 years	88 (36%)
6–12 years	48 (20%)
Gender	
Male	153 (63%)
Female	90 (37%)
Household monthly income (INR)	
<₹10,000	63 (26%)
₹10,001–20,000	142 (59%)
₹20,001–30,000	31 (13%)
>₹30,000	7 (2%)
Type of housing	
Pucca	147 (60%)
Semi-pucca	77 (32%)
Kutcha/temporary	17 (7%)
Slum	2 (1%)
Family type	
Joint	138 (57%)
Nuclear	99 (41%)
Extended	6 (2%)
Father's occupation	
Unskilled	130 (54%)
Semi-skilled	74 (30%)
Skilled	39 (16%)
Place of residence	
Urban Ahmedabad (<20–100 km)	124 (51%)
Peri-urban/rural Gujarat (>100 km)	99 (41%)
Other state (>500 km)	20 (8%)

Referral pathway and time-lag Self-referral was the single largest route of entry to the DEIC (40%), followed by referral from a district or sub-district hospital (31%). Formal RBSK community screening Anganwadi and school-based MHTs combined accounted for only 9% of attendees, and delivery-point newborn screening for a further 6% (Table 3).

Regarding time-lag, 55% of children reached the DEIC within three months of first detection (timely referral). Overall, 45% experienced a delay: 20% waited 3–12 months and 25% waited more than one year. Caregiver recognition of the presenting sign or symptom was itself often delayed: only 28% of caregivers first noticed a problem at birth, while 31% first noticed a problem only after the child's first birthday (Table 3, lower panel). Among a subset of 97 low-income families (defined by possession of a Below Poverty Line card or reported monthly household income <₹10,000) assessed for government scheme utilisation, an RBSK Sandarbh (referral) card was documented in 59%; PMJAY coverage was present in 23%, JSSK in 9%, JSY in 7%, and only 2% held a disability certificate (Table 4).

Developmental Delay and Disability (D4) was the dominant 4Ds category, present in 136 children (56%),

Table 2:
Perinatal, birth and nutritional profile of study participants. (N=243)

Variable	n (%)
Birth weight	
Low birth weight (<2.5 kg)	81 (33%)
Normal birth weight	162 (67%)
Place of delivery	
Government facility	198 (81%)
Private facility	41 (17%)
Home	4 (2%)
Mode of delivery	
Normal vaginal delivery	148 (61%)
Caesarean section (LSCS)	93 (38%)
Assisted vaginal (forceps/vacuum)	2 (1%)
History of NICU Admission	
Yes	133 (55%)
No	110 (45%)
History of delayed/absent cry	
Present	93 (38%)
Absent	150 (62%)
Nutritional status	
Normal	130 (54%)
Moderate acute malnutrition (MAM) / Thinness	56 (23%)
Severe acute malnutrition (SAM) / Severe thinness	41 (17%)
Underweight	13 (5%)
Overweight/obese	3 (1%)
Developmental milestones	
Age-appropriate, achieved	72 (30%)
Not achieved	171 (70%)

Note. Nutritional status: WHO Z-scores: Weight-for-height <5 yrs; BMI-for-age >5 yrs

Table 3:
Primary source of referral to the DEIC and Time-lag from first detection to DEIC arrival. (N=243)

Variables	n (%)
Self-referral	97, 40%
District/Sub-district hospital (DH/SDH)	75, 31%
Private practitioner	22, 9%
Delivery-point (newborn) screening	15, 6%
Medical Officer, CHC/PHC/UHC	13, 5%
RBSK MHT – Anganwadi screening	12, 5%
RBSK MHT – school screening	9, 4%
First detection to DEIC arrival:	135, 55%
Within 3 months (timely)	
3–12 months (moderate delay)	48, 20%
>1 year (prolonged delay)	60, 25%
First sign/symptom noted at birth	68, 28%
First sign/symptom noted within 6 months	32, 13%
First sign/symptom noted 6 months–1 year	68, 28%
First sign/symptom noted after 1 year	75, 31%

led by neuro-motor impairment (n=80), language delay (n=73), cognitive delay (n=44), motor delay (n=40), behaviour disorder/autism (n=22), vision impairment (n=12), and ADHD (n=6). Deficiencies (D3) affected 68 children (28%), driven principally by severe acute malnutrition (n=41), severe anaemia (n=25), and vitamin D deficiency/rickets (n=12). Birth Defects (D1) and Diseases (D2) were less frequent, at 24 children (10%)

Table 4:
Referral card and government health scheme utilisation. (Assessed subset, N=97)

Scheme/document	n (%)
RBSK Sandarbh (referral) card	57, 59%
Pradhan Mantri Jan Arogya Yojana (PMJAY)	22, 23%
Janani Shishu Suraksha Karyakram (JSSK)	9, 9%
Janani Suraksha Yojana (JSY)	7, 7%
Disability certificate	2, 2%

Table 5:
Association between selected clinical variables and 4Ds categories

Clinical variable	4Ds category	p-value
Birth weight	Defects (D1)	.03
Birth weight	Deficiencies (D3)	.02
Nutritional status	Deficiencies (D3)	.05
Age category	Defects (D1)	.08
NICU admission	Defects (D1)	.51
Delayed/absent cry at birth	Defects (D1)	.89
NICU admission	Diseases (D2)	.08
Delayed/absent cry at birth	Developmental Delay (D4)	.17
Nutritional status	Developmental Delay (D4)	.26

Note. Chi-square test were used. Only significant and illustrative comparisons shown; full associations were tested for all five clinical variables against all four 4Ds categories, and remaining comparisons were not significant (p>.05).

and 15 children (6%) respectively; congenital heart disease (n=16) and Down syndrome (n=9) were the leading D1 diagnoses, while convulsive disorders (n=15) led the D2 diagnoses. Additional isolated diagnoses recorded included congenital hypothyroidism, sickle cell anaemia, beta-thalassemia, hemiparesis, anotia and Wilson's disease (n=1 each). Percentages are calculated on N=243 as denominator; because children could present with more than one 4Ds condition, the sum of category percentages exceeds 100%.

More than half of the enrolled children (n=137, 56%) presented with two or more co-occurring 4Ds categories, compared to 106 children (44%) with a single 4Ds category. The strongest co-occurrence pattern observed was between Deficiency and Developmental Delay (n=35 children), followed by Defect with Developmental Delay (n=16), Disease with Developmental Delay (n=13), Defect with Deficiency (n=11), Disease with Deficiency (n=2), and Defect with Disease (n=1).

Associations between clinical variables and 4Ds status On chi-square testing, birth weight was significantly associated with both Birth Defects (p=.03) and Deficiencies (p=.02), and nutritional status yield p value of .05 with Deficiencies. No statistically significant association was found between NICU admission history, history of delayed/absent cry at birth, or age category and any of the four 4Ds categories, including

Developmental Delay (Table 5).

Discussion

We did not identify a published primary-data study of referral pathway dynamics and 4Ds clinical profile at a tertiary-level DEIC in Gujarat, and it reveals a referral pattern markedly different from the community-screening model envisaged by RBSK.

Referral pathway and programme fidelity Self-referral accounted for 40% of DEIC attendance at this tertiary centre, while the formal RBSK MHT routes contributed only 9%. This pattern contrasts with community-based settings where the formal MHT screening pathway predominates^[8], and instead resembles the self-referral and hospital-referral dominance reported at other Indian medical-college-linked DEICs. Several supply-side explanations have been proposed in the literature, including weak DEIC-MHT linkage and documentation practices^[9,10], and staffing and awareness constraints among frontline screening teams.^[12] National formative research similarly attributed the broader 46% national referral-compliance gap to delayed Sandarbh card issuance and weak follow-up mechanisms.^[7] Consistent with this, only 59% of low-income families in the present study held a referral card confirming that card-issuance fidelity, rather than the concept of referral itself, is a key point of failure in the pathway.^[7,8]

Time-lag and the cost of delay Almost half of children (45%) experienced a delay of more than three months between first detection and DEIC arrival, and one in four waited over a year. Given that early intervention for neurodevelopmental conditions is most effective within the first three years of life, this delay represents a tangible and likely irreversible loss of developmental potential for a substantial share of this caseload.^[2] Delay was compounded by late caregiver recognition itself: 31% of caregivers first noticed a problem only after the child's first birthday, a pattern consistent with the insidious, easily normalised onset typical of D4 conditions and with well-documented cumulative risk-and-protective-factor pathways in early childhood development.^[2,13,14]

Clinical profile and co-occurrence Developmental Delay and Disability accounted for 56% of the 4Ds burden at this tertiary DEIC, considerably higher than the burden typically reported at primary-level screening points, and consistent with the expectation that tertiary DEICs receive a more complex, multidisciplinary-intervention-requiring caseload.^[15] High rates of NICU admission (55%) and history of delayed/absent cry at birth (38%) in this population are consistent with a facility that functions, in effect, as a high-risk perinatal follow-up service as well as a community-referral endpoint. The

strong co-occurrence between Deficiency and Developmental Delay (n=35) reinforces an established nutrition-neurodevelopment pathway; national survey data indicate that anaemia affects more than half of under-five children^[16], underscoring that this pathway is not unique to the DEIC caseload but reflects a broader national burden. This argues for combined nutritional and developmental screening at every DEIC visit, using a standardised tool such as the Denver II Developmental Screening Test^[17], rather than managing these two domains in parallel, separate service tracks.

Equity and entitlement realisation The DEIC population was predominantly low-income and drawn from unskilled-labour households, indicating that RBSK's mandate to reach marginalised families is broadly being met at this institution. However, uptake of linked government entitlements was low PMJAY coverage of 23%, and a disability certification rate of just 2% despite more than half the population presenting with a 4Ds condition of a severity warranting DEIC-level management. This mirrors earlier findings that caregiver unawareness of RBSK and allied scheme entitlements is a systemic, cross-setting barrier to full benefit realization.^[8,18]

Comparison with existing evidence Findings from this tertiary DEIC differ from the only previously published Ahmedabad-specific study, conducted at an urban health centre, which reported birth defects as the predominant 4Ds category and high (>80%) caregiver satisfaction using retrospective secondary data.^[11] The divergence in dominant 4Ds category (birth defects at the primary-care level versus developmental delay at the tertiary level) likely reflects case-mix referral upward along the health system a pattern also noted in DEIC evaluations elsewhere in India and underscores that tertiary and primary-level DEICs cannot be assumed to serve comparable populations for planning purposes.^[15,19,20]

Strengths and Limitations

This is among the first primary-data studies conducted at a tertiary-level DEIC in Gujarat, using a bilingual/trilingual case record form and consent process, with a comparatively large sample (N=243) relative to published DEIC studies from western India. The cross-sectional design precludes causal inference and does not capture long-term outcomes after DEIC management. Consecutive facility-based sampling at a single tertiary site may not represent rural DEICs or other districts/states, limiting generalizability. Time-lag and first-symptom-detection data relied on caregiver recall and are subject to recall bias. The two-month data collection window may not capture seasonal variation in

referral patterns or case-mix.

Conclusion

At this tertiary hospital DEIC in Ahmedabad, formal RBSK community screening contributes only a small fraction of referrals, self-referral and hospital-based pathways predominate, and one in four children arrives more than a year after a 4Ds condition is first detected despite a caseload in which developmental delay and disability, a category highly responsive to early intervention, is the leading diagnosis. Referral-card issuance and government scheme uptake remain low even among eligible low-income families. Strengthening urban Mobile Health Team coverage and tracking, ensuring universal and trackable Sandarbh card issuance, integrating nutritional and developmental screening at every visit, and linking DEIC registration directly to entitlement verification are priority, low-cost interventions to close the referral-to-management gap identified in this study.

Declarations

Conflicts of Interest: None declared.

Funding: No external funding received.

AI usage declaration: Grammarly AI was used only to assist with language refinement. The authors critically reviewed the AI-assisted content and take full responsibility for the accuracy, integrity, and final content of the manuscript.

Acknowledgement: We thank the Medical Superintendent, Head of Paediatrics Department and the Medical, Nursing and Allied-health staff of the District Early Intervention Centre (DEIC), Civil Hospital, Ahmedabad, and Dr. Falguni Pathak, Medical Officer, for facilitating this study, and the caregivers who consented to participate.

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