

Developmental delay in a community setting: Role of a primary care physician

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Abstract

The early part of childhood especially the first 1000 days plays an essential role in the growth and development of the child. Various internal and external factors affect the child's development, including genetic factors, socioeconomic status, sociocultural environment, maternal mental health, and the parenting environment. There is a high prevalence of developmental delay 17.6% globally, whereas in India, it is around 6.6%. Numerous screening tools are available to detect developmental delay in the child early. Early identification and intervention are crucial because we can have a better outcome for the child if intervention is performed on time. The children can be identified during the postnatal follow-up period. Literature has shown that few parents take their children for regular developmental assessment after delivery. Identifying the developmental impairment early from a primary care physician's point of view is essential. In India under the Rashtriya Bal Swasthya Kariyakram (RBSK), the children are screened at home, Anganwadi centers, and schools to detect at-risk children under 4D's, so that early intervention can be planned by linking them to District Early Intervention Center.

Keywords: Child development, community, developmental delay, primary care, RBSK

Introduction

Development is a continuous process that affects the physical or quantitative components and refers to the qualitative or functional changes in physical, emotional, and social domains of life. According to Aristotle "Children are born like blank slates, the experiences, knowledge they acquire, will persist throughout their life." According to Jean Piaget, the father of "Developmental Psychology," child development is a process where the child transitions from a dependency phase to a phase of independence.^[1] Earlier development is more important than later life because maximum brain development happens within the first three years of life. Child development consists of

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several domains: cognitive, language (receptive and expressive), social and emotional, gross motor, and fine motor.^[2] Only 25% of the parents know the importance of the first five years of life. As school teachers also do not cover this phase of life, lack of stimulation and environment in this stage results in various developmental problems in the child. The first 1000 days of life, i.e., from birth till 2 years of age, is very vital in a child's life because rapid neuronal proliferation synaptogenesis happens in this period of life. The period is essential for optimal development of the brain of the child. The child who does not get proper nutrition during this time is 10 times more likely to overcome most of the life-threatening diseases and likely to earn 21% more wages and can lead a healthier life.^[3]

We coin the term developmental delay when the child cannot achieve the milestones compared with his/her peer of the same age range. There are three grades of developmental delay mild delay, i.e., functional age less than 33% of chronological

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age; moderate delay means functional age less than 34-66% of chronological age; and severe delay means functional age less than 66% of chronological age.^[4] The term significant delay is said when the development is less than two standard deviations of the age-appropriate standardized normal of reference testing, which is usually conducted in secondary and tertiary care settings.^[5] If only one developmental domain is involved, it is called "isolated developmental delay." But, if it involves two or more than two domains, then it is termed as "global developmental delay." But, there are certain reg flag signs for different age ranges, given by the American Academy of Pediatrics to diagnose developmental delay.^[6] One in six, or approximately 17%, of children who are in the age group of 3 to 17 years have one or more developmental disabilities.^[7] The prevalence of any developmental disability increased significantly by 9.5%, from 16.22% to 17.76%.[8] These delays get diagnosed in the developmental period, but they persist life-long. The prevalence of developmental delay in India is 6.6% from a study by Gupta et al.^[9] But, the prevalence of developmental delay increased significantly from the infant period, i.e., 5.7%, to 12-23 months of age (peak age), i.e., 20.3%; after that, there is a decreasing trend to 15.3% when the age of the child increased to more than 2 years.^[10]

Primary care provider gives a strong foundation for responsive parenting and interaction between a child and his or her caregiver.^[11] Primary care physician gives the opportunities for care providers to increase their knowledge of normal milestones of development.^[12]A primary care delivery system can identify the cultural connection of the child development to their families. The relationship between a caregiver and medical specialists, i.e. mental health, medical, and occupational therapists, is improved by primary health care workers who are involved with the children and their family members.^[13]

Current research globally suggests that the diagnosis of developmental delays and disabilities is lower than their actual prevalence, which means that measures undertaken to detect developmental delays are insufficient.^[14] Early identification of children with developmental delays is essential within three years of age, most of the major brain structures are mature, and it becomes more difficult to make significant changes in a child's "growth and development," so early intervention can be planned.^[15] In this study, we aim to see the need for assessment of developmental delay, factors affecting child development, especially in a community setting, the screening tools for the detection of developmental delay, and the role of a primary care physician in diagnosing as well as treating in collaboration with early intervention center and timely referral to the higher center.

Factors Affecting Child Development and Developmental Delay

There is a significant role of heredity or genetic factors in the development of the child. In extended family, the child may get all their love, affection, and attention, but the child's freedom is lost. Physical factors such as nutritional status and health conditions also affect child development. Social support, parenting behavior, domestic violence, and substance abuse influence children's cognitive, socioemotional, and language development.^[16] The gender of the child can also be a determining factor for child development. Female children are most likely to be neglected and left alone. The environment the child is brought up also affects the physical and functional development of the child.^[17]

There are various factors, leading to the developmental delay of the children. Prenatal factors such as genetic factors, chromosomal anomalies such as "Prader-Willi syndrome," "Angelman syndrome," "Fragile-X syndrome," and "Down syndrome"; environmental factors such as exposure to toxins, chemicals, alcohol, and drugs, antenatal factors such as toxoplasma CMV infections, varicella, malaria, HIV infections, and teenage pregnancy; perinatal factors such as IUGR, HIE, and periventricular leukomalacia; postnatal factors such as meningitis, inborn error of metabolism, maternal depression and anxiety, domestic violence, malnutrition, attention-deficit hyperactivity disorder (ADHD)," "cerebral palsy," "autism spectrum disorder," and severe psychological trauma can lead to developmental delay of the child.^[18,19] There are several signs and symptomatology for the detection of developmental delays such as learning or developing late than other children of the same age, rolling over, sitting up, crawling, or walking more slowly than developmentally appropriate, difficulty in language and expressive emotion or socializing with others, much lower than average scores on different IQ tests, not able to respond in an age-appropriate manner, and difficulty in naming the objects.[20]

Programs in India on Child Welfare and Development

Various flagship programs are running in India for protection of the rights of the child such as Integrated Child Development Services (ICDS), Rastriva Bal Swasthya Kariyakram (RBSK), Mission Vatshalya, and RMNCH+A. ICDS scheme was started in 1975 for early childhood development to provide preschool nonformal education to its children and nursing mothers. Mission Vatsalya provides a roadmap to achieve growth and child protection priorities to meet the Sustainable Development Goals (SDGs). It strengthens child rights, advocacy, and awareness and strengthens the juvenile justice care and protection system with the main motto of "leaving no child behind." RBSK program includes children from birth to 18 years of age. The children are screened under this program based on 4Ds-"Defects at birth," "Diseases of childhood," "Deficiencies," and "Development delays" including disabilities and early intervention of these conditions. It involves two types of screening; one is community-based based, and another is facility-based. Three different places for screening are used-birth to 6-week infants are screened at the health care facility of birth and at home by ASHA during the home-based newborn care, 6-week to 6-year children are screened at Anganwadi centers by the RBSK team in cooperation with Anganwadi worker (AWW), and children after 6 years to 18 years are screened in the schools by mobile health team. The RBSK program includes 32 common health conditions of the children. It provides early detection, free treatment, and rehabilitation, including surgeries at the tertiary level. If any of the children screened positive for any of the health conditions, they are provided early intervention and follow-up care at the district level at DEIC. As the services are provided free of cost, it decreases out-of-pocket expenditure for the treatment of poor families. There are two types of screening available by RBSK. First is facility-based screening, which involves screening of birth defects for institutional deliveries at various public health facilities by ANM, medical officers, or gynecologists. All health service providers at specified delivery points will be trained to detect, report, and refer birth defects to the "District Early Intervention Centers at District Hospitals" (DEIC). At the same time, another is community-based newborn screening, which is performed by Accredited Social Health Activists (ASHAs) during home visits for newborn care. They are trained with simple screening tools for detecting gross birth defects, diseases, and deficiency, and further, they mobilize caregivers of children to attend the local and developmental delay at Anganwadi centers for screening by the dedicated mobile health team. Three dedicated mobile teams in each block are usually involved in the screening for the children till 18 years in various government and government-aided schools quarterly in a year.^[21]

When and How to Detect Developmental Delay

Developmental delay is a condition where the child is delayed in attaining age-appropriate milestones in a particular domain. Temporarily or slightly lagging behind the age-specific milestones is not considered developmental delay. A child's development can be delayed in in one or more of the six domains such as "gross motor," "fine motor," "cognition," "social-emotional," "expressive language," and "self-help activities." If there is a delay in two or more than two domains, it is considered as "global developmental delay."[22] It has to be differentiated from "developmental deviation or dissociated development" and "developmental regression." Various neuromuscular disorders show the phenomenon of developmental regression. There is another entity, "developmental disorders," meaning that the child's development does not follow the usual pattern.^[23] Usually, the delays are first identified by parents or grandparents or caregivers. Developmental disability is relatively more severe and lifelong impairment in the domains of child development, and it affects not only learning of the child but also impacts on self-sufficiency and adaptive skills. Developmental delay can be transient and self-limiting also, and it can happen during a period of acute illness or any acute condition, which usually resolves spontaneously or it can be persistent.^[6] The American Academy of Pediatrics (AAP) recommends developmental and behavioral screening for all children during regular postnatal follow-up visits at ages: 9 months, 18 months, 24 months, and 30 months.^[24] The U.S. Preventive Services Task Force (USPSTF) specifically addresses screening for autism and speech and language delays but fails to address much broader spectrum developmental screening. The Canadian Task Force on Preventive Health Care and American Academy of Family Physicians usually recommend against the screening.^[25] Under the RBSK scheme, the mobile health team is visiting the AWC at 6-monthly intervals and the nonresidential schools yearly and the residential schools quarterly to detect the child with developmental delay. The AWW and the school teachers can be trained in identifying signs of developmental delay early and prompt linkage of the child with the RBSK team.

Role of a Primary Care Physician in Child Development Assessment

"Pediatric primary health care" (PPHC) is defined as continuous, comprehensive, and coordinated care that is accessible and affordable to fulfill the health needs of the infant, child, adolescent, and young adult by giving family-centered care. It consists of comprehensive care involving the life cycle, from infancy to young adulthood. PPHC incorporates health supervision focusing on preventing both physical and mental health conditions, promoting mental health wellness and age-appropriate screening for disease prevention. None of the public or private health systems can play a significant role in promoting children's physical, motor, social, and emotional development. Primary care is one of the greatest health care systems, which is the primary contact of the poor families. Primary care providers such as pediatricians and family physicians play the role of trusted guidance and information as well as its known for its excellence in various untouched domains of child health and neurocognitive development.^[26] Schroeder et al.^[27] in their study had found that around 20 percent of all children identified in primary care settings had significant developmental, emotional, or behavioural health problem. Most of the people often first seek help from a primary health care provider for their mental health issues as they find it less stigmatizing compared with other settings from a study by Kelleher et al.[28] A systematic review by Peacock Chambers et al. has shown that several interventions at the primary care level can cause improvement in early child development outcomes among children aged 0 to 3 years.^[29] There are different models to integrate mental and child health services in primary care: (a) Primary care physicians can be trained in child developmental issues and mental health problems to improve the provider expertise; (b) linkage between the primary care provider and mental health care provider or psychiatrist, and (c) availability of psychiatrist in the primary care setting.^[30] A study conducted in Singapore of parents of children aged 30-47 months indicated that only one in four parents took their child to the 2- to 3-year developmental monitoring visit. Another study by Kondaparthi et al.[31] conducted a study on 110 parents had found that 86% of the caregivers were mothers, and among them, only 36% of the mothers were able to answer correctly. There are different screening tools that can be used to detect the developmental delay. In the lower- and middle-income countries especially in India, "Trivandrum Developmental Screening Test," "Baroda Developmental Screening Tool," 'Malawi Developmental Assessment Test,"

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Tools			ng tools to assess developm		Time	Drawback
Tools	Domain	Age group	Administration	Use	Time	Drawback
ASQ.SE-2 Module ^[32]	Socioemotional development	2-60 months	It can be administered in homes, primary health care clinics, immunization clinics, mental health clinics, child care centers and preschools, baby groups, and school screenings Total score 120 and cutoff 85	With ASQ: SE-2, parents or other caregivers can fill a series of simple, understandable questions regarding their child's social-emotional development.	10-15 mins	Cannot measure other domains of development
ASQ-3 ^[33]	Gross and fine motor skills, communication, problem-solving, and personal-social development	1 month–5.5 years	Home visit, clinical setting, and center-based program Score ranges from 0-60. Higher the score, better the development.	It is a developmental screening tool that assesses the progress in the child's development. It is used to estimate if a child is able to satisfy her own self-help needs in an age-appropriate manner	15-30 mins	Cannot give a clear picture on the sociobehavioral development
SWYC (Survey of well-being of young children) ^[34]	Three domains— development, behavioral, and emotional and family risk factors	2 to 60 months	 It is a 10-item questionnaire. Cutoff will change according to age The Baby Pediatric Symptom Checklist (BPSC) for children up to 18 months (12 items) The Preschool Pediatric Symptom Checklist (PPSC) for children 18-60 months (18 items) Parents are also asked whether they have any concerns about their child's behavior, learning, or development (2 items) (POSI—Parent Observation on Social Interaction) 	MassHealth approves the SWYC for compliance with the Children's Behavioral Health Initiative screening guidelines. It is a screening tool to assess the development of children	10-15 mins	The administration is much more complicated
Bayley Scale of infant and toddler development— IV ^[35]	5 domains— cognition, motor, language, socioemotional, and adaptive behavior	16 days to 42 months	Scoring can be performed by paper and pencil; Q-global. An interval of approximately 3 months is recommended for children younger than 12 months; an interval of approximately 6 months is recommended for children older than 12 months. It can be administered by a psychologist, speech pathologist, occupational therapist, psychiatrists, neonatologist, and pediatricians	Subtest-level scaled scores, domain-level composite scores, percentile ranks, confidence intervals, developmental age equivalents, and growth scale values. It is the most comprehensive assessment tool for determining developmental delays in children. It is a diagnostic tool	30 to 70 minutes (depending on age of the child)	Intercurrent illness and distracting environment can affect the scoring
Child Development Inventory (CDI) ^[36]	Domains—social, self-help, motor, language, and letter and number skills, as well as the presence of symptoms and behavior problems. Scoring is performed by simply counting the number of YES responses for each of the scales using a single scoring template. The scores	15 months and 6 years.	300-item parent questionnaire	The Child Development Inventory (CDI) is a restandardized form of the Minnesota Child Development Inventory. The questionnaire consists of 300 items. The version includes 30 items to identify concerns of the parents about their child's health and growth, vision, and hearing, as well as development and behavior. The CDI is used mainly to assess	30–45 mins at home	Long administration time and multiple domains

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Table 1: Contd						
Tools	Domain	Age group	Administration	Use	Time	Drawback
	for the scales are then recorded on the Child Development Inventory Profile sheet. It can be completed by parents at home.			about children having impaired development. The CDI can even help professionally assess the child's functioning. Parent's CDI reports are finally integrated with professional's observation and test results at the end.		
Denver Development Screening Test II ^[37]	Four domains— gross motor, language, fine motor-adaptive, and personal-social.	from birth to	The American Academy of Pediatrics (AAP) has recommended developmental and behavioral screening for all children during regular well-child visits at 9, 18, and 30 months of age in the year 2021. It includes 125 items. It is administered by health care providers	biologically at-risk infants for	20-30 min	Low sensitivity and specificity. Lack of referrals who were in need
Parents' Evaluation of Developmental Status (PEDS) ^[38]	No separate division	Birth to seven years and 11 months	10-item simple questionnaire completed by the parent The Royal Children's Hospital Center for Community Child Health is licensed to distribute PEDS across Australia and New Zealand. PEDS materials are copyright. They cannot be photocopied, reused, or reproduced without permission from The Royal Children's Hospital Center for Community Child Health.	It is an evidence-based screening tool that elicits and addresses parental concerns about children's development, health, and wellbeing. It is a screening tool	5 mins	Not a diagnostic tool. Different domains cannot be assessed separately

and "Development Assessment Scale for Indian Infants" are used, whereas in Western countries, mostly used screening tools are" Bayley Scale of Infant and Toddler Development," "British Assessment Scale," "Denver Developmental Screening Tool," "Parents Evaluation of Developmental Screener," "Ages and Stages Questionnaire." PEDS and ASQ are based on parents' evaluation, whereas other tests are observational. DASII is the Indian version of Bayley scale [Table 1].

Discussion

Currently, there is no proper health care delivery system in India to identify the developmental milestones of children, despite recommendations from various government organizations. There is no screening of developmental milestones, which is performed routinely after the delivery.^[39] Literature has shown that there is need for assessing child development in low- and middle-income as well as in high-income countries for the normal and sick child especially during the sick child visit. Care for child development intervention was found to be very effective in supporting caregivers to provide a stimulating environment.^[40] A study had found that in the parents of the children who were more conscious, their children had good language development.^[41] Although various screening tools are available to detect developmental delay of the children, there is little use of the tools in the clinical setting.^[42] Most of the developmental delays resolve spontaneously, very few of them turn into developmental syndrome, which requires constant supervision and clinical monitoring.^[19] To provide treatment and improve the child's outcome, it is crucial to early identify the signs of developmental delay. The primary care provider can be trained for child development and can screen the children during the regular follow-up visit and provide appropriate referral to the higher center.^[43] Parent-implemented intervention on the children with developmental delay was found to be very effective in a multicenter clinical trial.^[44] Family-centered primary care by primary care provider was also found to be effective in the infant and toddlers with developmental disabilities.^[45]

Summary

The primary care physician can detect the children during the postpartum follow-up visit at risk of developmental delay and can send to the clinicians for further evaluation and management. It can cause early identification of the child in developmental delay. Furthermore, the child with a developmental disability can be linked with the DEIC and RBSK team. Despite its existence in the system, there are very few people who are aware of it. Community awareness regarding the same can play an important role in the management of such differently abled children with developmental delays.

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Conflicts of interest

There are no conflicts of interest.

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