



## Review article

# Missed opportunities in surveillance and screening systems to detect developmental delay: A developing country perspective

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Received 30 January 2009; received in revised form 19 May 2009; accepted 13 June 2009

## Abstract

The future of human societies depends on children being able to achieve their optimal physical and psychological development. Developmental delay is failure to acquire age-appropriate functionality. It may involve one or more streams of development. Responsive parenting has potential to promote better development. Primary health physicians are in the best arrangement to provide this assistance as they can monitor child's development longitudinally and understand the child's developmental trajectory better. Current strategy employed by majority of primary-care providers to monitor the trajectory is termed 'developmental surveillance'. It is "a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care". Age-appropriate developmental checklists are also used to record milestones as part of surveillance. Both, the American Academy of Pediatrics and the British Joint Working Party on Child Health Services, recommend developmental surveillance by physicians as a method of identification of developmental delays. Developmental screening, however, improves the accuracy of identifying children with delay, compared with surveillance. Primary health physicians should consider using developmental screening tools that are standardized, reliable, valid and practical in the office setting, be familiar with screening techniques which should be incorporated into ongoing care, and keep abreast of current literature. Pakistan, as a developing country, needs specific strategies to ensure that we seize all the chances to detect this delay at an earlier age and introduce intervention, in order to lessen the burden of the disability on child, family and society.

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**Keywords:** Developmental delay; Primary health care; Surveillance; Developmental disability; Development; Screening

## 1. Introduction

The progress of societies is based upon appropriate physical and mental maturation of its individuals. In the past decades, the relationships among health, physical growth, psychological development and parental

care giving have become clearer [1]. Combined growth and development interventions that help families practice "responsive parenting" have shown the potential to promote better psychological development, as well as physical growth [2]. Never before has there been so much knowledge to assist families and societies in their desire to raise children to meet their maximum potential.

An estimated 5–10% of the global pediatric population has some form of developmental disability [3]. In United States, seventeen percent of children have a developmental or behavioral disability such as autism, mental retardation, or attention-deficit/hyperactivity disorder (ADHD) [4]. Majority of children with

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developmental disabilities and mental health problems are not identified [5]. In addition, many children have delays in language or other areas but, less than half are identified before starting school [6]. In Great Britain, only 45–55% of children with developmental disabilities are detected before school entrance [7]. This denotes the high proportion of children that are missed out during screening, even in developed countries, and who could have received help at an early stage.

The primary physicians are in the best arrangement to provide this assistance. Their regular contact with the child from birth to adolescence provides them the opportunity to monitor the child's development longitudinally and understand of the child's immediate developmental trajectory better [8,9]. They are usually familiar with underlying social and familial factors at work in the child's immediate environment, hence they can play a crucial role in monitoring the developmental progress and early identification of children with developmental delay. However, a vast majority of primary health care physicians miss opportunities for early identification, referral and intervention. [7,10] Pediatricians use developmental screening tests infrequently and, probably, only after evidence of developmental delay has been established by other criteria. These missed opportunities increase the level of dependence and disability of an individual and decrease the productivity of the community at large. The emotional, psychological and social impact of these missed opportunities, not only incapacitates the child with developmental delay but the whole family is subjected to agonizing debilitation.

## 2. Understanding developmental delay

Development of a child is an assortment of few intangible domains. A single stream of human development constitutes a particular domain of development. These streams are measured in terms of developmental milestones. Developmental delay is the inability of a child to acquire developmental milestones at the expected age, 'age-appropriate' functionality, even after allowing for the broad variation of normality [11]. It may be restricted to one (single domain) or involve more streams of development (global developmental delay) [3]. These streams do not have continuous and/or constant flow. Therefore, the spurts and pauses of child's development make the whole process devious and its assessment a challenge.

The domains of development can be conceptually categorized into four major areas:

### 2.1. Motor development: [5]

It is the attainment of muscle power and coordination along with cerebral networks that relate motor action of the limbs to sensory (vision and proprioception) percep-

tion. In all motor activities, systematic adjustment of muscle tone and coordination of movement require the functions of the basal ganglia and cerebellum. The actions involving vision and upper or lower limbs require coordination between the occipital and frontal lobes of the brain. Therefore, acquisition of eye-limb coordination indicates the establishment of structural networks that serve both the sensory-linked (vision and position – occipital and parietal lobes) action and the structures initiating movement (frontal lobe) and coordination of tone (basal ganglia and cerebellum) and their inter-connections at various levels in the nervous system. Repeated observation of actions is required to determine the age when neural connections serving those actions have occurred. However, children progress through motor milestones in an orderly fashion, attaining these functions in a clear and sequential process.

### 2.2. Cognitive development: [5,11,12]

Cognition is learning from sensory perception. It is a measure of the child's ability to solve problem through intuition, perception, and verbal and nonverbal reasoning. It includes the ability to learn, understand, retain and apply information as needed. Recognition and meaning (reasoning) of symbols (words, objects, images, letters, numbers etc.) are indicators of such learning. Curiosity and creativity are two key features of this developmental domain. Creativity is a basic driving force leading to exploration, which provides sensory inputs and the opportunity to learn from sensory perception. Creativity reflects imagination which is a prominent feature of a normal child. It is a manifestation of manipulation of thought, which is based on sensory experience; therefore, observation of its absence or paucity should lead to a search for disabling features of the social environment. Intense imagination is evident from the age of 1–5 years and beyond, at least to the age of 10 years, with less time devoted to it with increasing age and the engagement of thought and activity in social activities, play and planned learning introduced into the social environment.

### 2.3. Language performance or development: [13]

It consists of articulation, receptive and expressive language skills, and the use of nonverbal symbols. It is a major stream of development, arising from the interaction between innate communication abilities and environmental influences. Child begins to understand spoken language (receptive language skills) very early (0–6 months). At an early stage (1–2 years) the ability to understand can be assessed by performance of a set of actions in accordance with instruction. The ability to express thought without words is evident very early (from 2 to 3 months). The ability to speak (expressive language skills) begins with syllables or single words at

about one year and progresses rapidly, with increasing vocabulary and expression in sentences (articulation) by the age of 2–3 years. Written language begins later (1.5–2 years) with recognition of letters and their phonated sounds or words beginning with those letters, the age depending upon parental stimulation and exposure to learning resources. The ability to write familiar words, such as the child's name, depends upon demonstration and encouragement to write, as well as opportunity to play with writing instruments and paper.

#### 2.4. Personal or social development: [5,12]

Personal development involves the formation of self-help skills in various activities of daily living, such as feeding, dressing, and toileting. Social development encompasses the child's interactions, as shown by the formation and maintenance of relationships and responsiveness to the presence of others. It presents itself over time as behavioral abnormalities that differ from normal behavioral responses by their quantity, severity, nature and duration. It includes:

(a) Self-confidence [5,12]: evidence includes the performance of a new activity (the ability to perform rather than the accuracy of performance); independent thought and action, such as feeding oneself; social interaction with unfamiliar persons, after establishing trust in the individuals and initial shyness; expression of thought, by verbal and nonverbal methods; spontaneous repetition of effort.

(b) Behavior [5,12]: the ability to modulate impulsive action by the cerebral cortex, especially the pre-frontal, the development of which is apparently the latest, might be a crucial attainment affecting learning and behavior in adolescence and beyond and one that develops during a critical period in early childhood. It is heavily conditioned by conformity with social norms.

(c) Affect [5,12]: emotion influences memory, curiosity and interest, exploration, association of new sensory experience with concepts developed from past experience, learning, and behavior. Therefore, observation of affect in order to track changes is important; trends might reveal that patterns of affect are established early and continue to adolescence and adulthood.

### 3. Monitoring developmental progress

A comprehensive developmental evaluation of a child should lead to either a definitive diagnosis, development of an interdisciplinary comprehensive plan of remediation, realization that there is no significant problem or decision that additional observation is warranted [14]. The current strategy employed by majority of primary-care providers to monitor a child's developmental trajectory or progress is termed as “developmental

surveillance” [9]. It is a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care [15]. The components of developmental surveillance include eliciting and attending to parental concerns, obtaining a relevant developmental history, making accurate and informative observations of children, and sharing opinions and concerns with other relevant professionals [5]. Age-appropriate developmental checklists are also used to record milestones as part of developmental surveillance [14]. In successful surveillance, development is viewed in the context of the child's overall well-being and is not isolated from other domains pertaining to child health and well-being. Both the American Academy of Pediatrics and the British Joint Working Party on Child Health Services recommend developmental surveillance as an effective means to identify children with delay. Both committees suggest that developmental monitoring be performed by the process of surveillance. With developmental surveillance, the importance of eliciting parents' opinions and concerns, obtaining a relevant developmental history, and performing skilled, longitudinal observations of children is emphasized. The success of surveillance depends on the extent to which its implementation is enhanced through clinical practice, professional training, and research [16].

However, clinical impressions are not entirely effective in assessing development [15]. Using only clinical judgment, fewer than 30% of children who have mental retardation, language disabilities, or other developmental problems are detected [17]. Similarly, fewer than 50% of those with serious emotional and behavioral problems are detected before the age of 5 years. Another study even compared pediatricians' intuition against a complete standardized assessment for behavioral problems, demonstrating that pediatricians' sensitivity was low (~20%) [18]. Thus, developmental surveillance is an important method of detecting delays but it lacks the sensitivity required at the primary-care level.

Other factors which hamper full implementation of developmental surveillance in the context of medical practice at primary health care level include:

(a) Time: perhaps most importantly, time constraints often do not allow the primary practitioner to implement surveillance. It might be omitted altogether when dealing with more “acute” health problems [17]. In clinics in which visits have been trimmed, the primary-care physician will simply not have enough time to perform all of the necessary steps for comprehensive developmental surveillance [19].

(b) Infrequent care: success in developmental surveillance is dependent on a continuous and ongoing process; [16] it is not likely to work well for those infants receiving infrequent care by different care providers at different times.

(c) Inadequate training: the efficacy of developmental surveillance is dependent on the practitioner's knowledge, training and experience. Inadequate training regarding developmental issues compromises the practitioner's skills in early identification; [20] for instance, not eliciting parental concern properly can be a significant factor leading to missed opportunities of early identification [21,22].

(d) The central dilemma for the pediatricians and physicians who screen these children is that identification must precede services and the act of identifying a child who needs further assessment for developmental disabilities provokes anxiety in parents. This concern may create a tendency to identify only markedly delayed children, denying other children potential access to needed care [15]. This specifically holds true from a developmental country perspective as services for children with disabilities are available at a very basic level. This raises concerns on part of the primary-care physician as to the importance of surveillance and screening for disability.

The process of proactively testing every child to identify those at high risk of clinically significant but, as yet, unsuspected deviations or delay from normality is termed as "Developmental Screening". It is a brief assessment procedure designed to identify children who need more comprehensive and intensive diagnosis and evaluation [15,23]. Standardized screening tests have been developed that help remind practitioners to dedicate time to developmental assessment and also provide a standardized structured format to assist clinicians in making skilled observations [15]. Developmental screening does not give a definite diagnosis but improves the accuracy with which children are identified when compared with decisions based only on clinical judgment. It also indicates the physician's interest in the child's development, not just his or her physical health [24]. A number of tools are available for the physician's use. Table 1 describes the major available screening tools and has been adapted from a previous publication to include those validated in Pakistan [3,25,26].

There has been increasing pressure to identify these children with developmental delay at an earlier age, with the focus being on infants (birth to 2 years of age). Identification of children with developmental delays or disabilities at an early age can lead to treatment of, or intervention for, a disability and lessen its impact on the functioning of the child and family [14]. This has been spurred by the theory that the brain's development is dependent on environmental influences, suggesting that a favorable environment could enhance and optimize development. For children with developmental delay, intervention programs have been shown to be beneficial, maximizing developmental attainment. In US the Education of the Handicapped Act Amendments calls for state-wide, comprehensive, coordinated multidisciplinary,

interagency programs of early intervention services for all handicapped children and their families. It is believed that gains will be greatest if the child participates in intervention services as early as possible. Also professional organizations such as the American Academy of Pediatrics are strongly endorsing the early identification of delayed children by health practitioners [14,27,28]. This law emphasizes the screening to take place at a younger age with the focus being on children from birth to 2 years of age. At this age the pediatrician is closely involved with the children and their families and is in an important position to have an impact on the future of the child. American law requires the pediatrician to refer those children suspected of delay early on, so that appropriate interventions can start at the earliest [14]. In Pakistan there is a special law called the Disabled Persons (Employment and Rehabilitation) Ordinance, 1981. This law seeks to deal with the employment, rehabilitation and welfare of disabled persons but no specific law, to deal with children with disability and their interventions are so far in place (personal communication).

#### 4. The challenge: adapting global recommendations to the local scenario

Data from developing world regarding developmental delay is scarce. However, it has been shown that the prevalence of mental health problems among children is higher in a developing country than developed countries [29]. In a study conducted in the Philippines, showed that periodic developmental assessments ensures quality follow up [30]. Disorders of mental and motor development (34.8%) are the leading neurological problem in Pakistani children [31]. In a study conducted in 2002, in Pakistan, prevalence of mild mental retardation among 6- to 10-year-old children was found to be 6.2% with additional impairments in 75%, of which speech impairment was the most common. Socio-economic status parental education and occupation [32] also correlated with mental retardation [33–35]. In another study conducted in 1998, lack of maternal education was strongly associated with the prevalence of mental retardation (MR). Other factors that were independently associated with MR, included histories of perinatal difficulties, neonatal infections, postnatal brain infections, and traumatic brain injury, as well as concurrent malnutrition [34].

In many countries like Pakistan, there is social stigma attached to persons with developmental disabilities. What adds fuel to the fire is the rampant prevalence of consanguineous marriages in our society which further leads to mental retardation [36–38]. Generally, there is no provision for the management of childhood disabilities in healthcare services [39]. Families have to suffer increase demands on their resources for taking care of the disabled member [35]. Available social and educational services are also rudimentary and tend to alienate rather than integrate disabled children into the larger society.

Table 1  
Screening tools.

Instrument	Age	Time (min)	Description
<i>General screening instruments</i>			
Battelle developmental inventory screening test	6–96 m	10–30	96 items divided into seven subtests: personal-social, adaptation, gross and fine motor skills, communication, and cognition.
Bayley infant neurodevelopmental screener	3–24 mo	15–20	Composed of six sets of 11–13 items; screens four areas: basic neurologic, expressive, receptive, and cognitive functions
Brigance screens	0–96 mo	10–15	Screens for fine and gross motor skills, receptive and expressive language, self-help skills, and social-emotional domains; assesses reading and math at older ages
Early screening inventory	48–72 mo	20	Composed of three sections of 30 items that assess language, cognition, visual-motor/adaptive skills, gross motor/body awareness
First STEP	32–72 mo	15–20	Assesses five domains: cognition, communication, physical functioning, and emotional and social status; composed of 12 subsets in the form of games
Denver developmental screening test, 2nd edition	0–72 mo	20–30	125 items divided into four sections: gross motor skills, fine motor/adaptive skills, personal/social, or language skills; similar to a growth chart
10 questions	2–9 yrs	10	Uses 10 basic questions with various parts of the questions to assess serious cognitive and other developmental disability. It is validated and used for mass screening in the community to identify disability of various kinds.
Griffiths mental developmental scale	2–8 yrs	50–60	A kit of standardised equipment (example drawing book, puzzles) is required to administer the items in the Griffiths scales. Consists of six subscales designed to test locomotor, personal-social, language, eye and hand coordination, performance and practical reasoning skills.
<i>Cognitive screening instruments</i>			
Cognitive adaptive test (CAT)/clinical linguistic and auditory milestone scale (CLAMS)	1–36 mo	10	CAT assesses visual-motor problem-solving skills, and CLAMS assesses receptive and expressive language parental interview; the two scores produce a quotient for cognitive function
Slosson intelligence test	2 wk–26 yr	30	Assesses cognitive abilities by measuring language skills, verbal problem solving, and general information
<i>Language screening instruments</i>			
Early language milestone scale, 2nd edition	0–36 mo	2–10	43 items arranged into three categories assessing auditory expressive, auditory receptive, and visual categories
Peabody picture vocabulary test, 3rd edition	2.5–40 yr	10–15	17 sets of 12 questions arranged in increasing difficulty offering an index of child's receptive vocabulary skills and verbal ability
Token test for children	3–12.5 yr	10–20	61 items assessing functional receptive language
<i>Neuromotor screening instruments</i>			
Alberta infant motor scales	0–~24 mo	10–15	58 items grouped into four subscales (prone, supine, sitting, and standing) focusing on three key descriptors (weight bearing, postural alignment, and antigravity movements); based on dynamic systems theory
Milani–Comparetti developmental test-revised	1–16 mo	10–15	27 items assessing primitive reflexes, tilting, righting, spontaneous posture, and movement through attainment of independent posture; based on neurodevelopmental theory
Toddler and infant motor evaluation	4–42 mo	10–15	Composed of five subscales: mobility, motor organization, stability, functional performance, social/emotional; based on dynamic systems theory
<i>Behavioral screening instruments</i>			
Eyberg child behavior checklist	2.5–11 yr	~7	Assesses behavior through 36 statements of common behavioral problems
Pediatric symptom checklist	4–16 yr	~7	35 items assessing both externalized behavior problems such as conduct and internalized behavior problems (depression, anxiety, and adjustments); parent-completed assessment
Vineland adaptive behavior scales (survey form)	0–19 yr	20–60	Assesses communication, daily living skills, socialization, and motor skills; the maladaptive section also identifies the number of maladaptive behaviors present

(continued on next page)

**Table 1** (continued)

Instrument	Age	Time (min)	Description
<i>Parent-completed screening instruments</i>			
Ages and stages questionnaire	4–60 mo	10–15	30 questions testing five domains (fine motor skills, gross motor skills, communication, problem-solving, and personal-social skills); questionnaire intervals are 4, 6, 8, 10, 12, 14, 16, 18, 20, 22, 24, 27, 30, 33, 36, 42, 48, 54, 60 months.
Minnesota child development inventory (MCDI)	0–72 mo	15–20	300 questions testing 7 domains (social, self-help, fine and gross motor skills, communication, letters, and numbers); score can also be calculated for general development
Parents' evaluations of developmental status	0–9 yr	2	10 questions eliciting parental concern; no score, but determines when to refer, provide a second screen, provide patient education, or monitor development more carefully

A child in a developing country may never undergo developmental assessment in the first three crucial years for early childhood development [35,40]. Routine newborn or childhood screening does not exist among high risk groups for the lower socioeconomic group or for the 49.1% of child births which take place at home [41] or for the 600,000 babies born with congenital deafness annually in developing countries [42]. Current evidence [43] suggests that if these babies are detected within three months of birth and provided with amplification within six months of life, they are likely to have linguistic, speech, and cognitive development comparable to their normal hearing peers [44]. In developing countries parents should be counseled about the potential benefit of seeking help for early identification and intervention.

Very few studies have been done to test the validity of the available screening tools in the developing country especially South-East Asia. One study conducted in 1994 showed that the 10 questions for identifying disability in underserved populations has a diagnostic value in screening large populations and necessitates other professional resources to be efficiently directed toward those at high risk [25,45]. In an attempt to validate local language versions of the screening tools a study was carried out in Pakistan for validation of Strengths and Difficulties Questionnaire (SDQ), which was able to discriminate between the study groups [46]. The study population consisted of 212 children aged 4–16 years. Parents of these children were interviewed using the extended version of the SDQ. Adequate sensitivity ( $>$  or  $=$  61%) was obtained for each type of psychiatric disorder in the case group using the abnormal category of the SDQ symptom scores as a cut-off. Children in need of intervention were also identified.

## 5. Conclusion and recommendations

- Primary health care providers should realize that their role is crucial in relation to early detection and referral of children with developmental disabilities.

- With the increasing availability of appropriate intervention programs and the growing acknowledgment of the efficacy of these programs, there is a concomitant growing responsibility for primary health care professionals to monitor developmental trajectory through proactive, appropriate and effective services.
- In surveillance paradigm, developmental screening can be a valuable adjunct. All infants and children should be screened for developmental delays, incorporated into the ongoing health care of the child including every well-baby visit [47].
- Primary health care physicians should acquire skills in the administration and interpretation of reliable and valid developmental screening techniques appropriate for the population [15], dedicate time to developmental assessment and follow a structured format to make skilled observations using a culturally sensitive and family-centered approach.
- The emphasis of detecting developmental delay should shift to identifying disabilities at a younger age, with the focus being on infants and children from birth through 2 years of age.
- Primary health care physicians especially in an underdeveloped area should maintain and update their knowledge about developmental issues, risk factors, screening techniques, and community resources, such as early intervention, school and other community-based programs, for consultation, referral, and intervention.
- Physicians in all levels should work at promoting the health and welfare of children with disability and be the voice to bring about a change in the government policies.
- Primary health care physicians should develop a strategy to provide periodic screening in the context of office-based primary care, including the following:
  - Recognizing abnormal appearance and function during health care maintenance examinations.
  - Recognizing medical, genetic, and environmental risk factors while taking routine medical, family, and social histories.

- Listening carefully to parental concerns and observations about the child's development during all encounters.
  - Recognizing troubled parent–child interaction by reviewing history or by observation [2,48].
  - With parental agreement, refer children with developmental delays in a timely fashion to the appropriate early intervention to enable families to develop the strategies and obtain the resources for successful family functioning [15].
- Investment in the health of mothers and children is an investment in the labor force of the future by preventing the wasted physical, mental, and social potential of stunted growth [49]. Preventive measures with provision of obstetric and health services, services for genetic information and risk evaluation, vaccination programmes and identification of children with retarded development for specific stimulation and habilitation measures, e.g. organized play activities, are important in developing and low-income countries [38].
  - The global situation can be controlled by improving the basic life and fundamental factors to improve the hygiene and general health status of mothers and their children.
  - Development of rehabilitation of services for early intervention remains an important part of early screening process and cannot be overemphasized.

### Competing interests

None.

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