

Chapter 13

Early Childhood Intervention Services in India



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Abstract Early childhood development is determined by intrinsic and environmental factors. Development is variable and rapid in early childhood and influenced by many factors. Delay in achievement of milestones beyond a certain age indicates underlying health complications. Early intervention is a set of coordinated services and support systems that are available to infants and young children with developmental delays and disabilities and their families that aim at maximizing the developmental and health outcomes of children. Early intervention may be in the form of physical and occupational therapy, speech therapy, behavioural education and play therapy. Early intervention is more beneficial and cost-effective if provided early than at a later stage in life. In India, policies for early intervention are disconnected, with services being offered through the District Early Intervention Centres of the Rashtriya Bal Swasthya Karyakram, and programmes of the National Trust. This article describes early intervention services in India. Considering the magnitude of childhood disability in the country, the article identifies that there is a need to focus on developing integrated services for children needing these services.

Keywords Early intervention · Developmental disabilities · Child development · India

Early Child Growth and Development

Child growth and development are a result of constant interplay of genetics and environmental influences [54]. Growth is increase in size of the body, body organs, and increase in height and weight that are visible physically. Overall, growth is compatible with the established standards of a given population, although there are individual, ethnic and geographic variations among the human population. For example, European children have different growth parameters than children of Indian

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or Asian origin. The World Health Organization (WHO) has developed the WHO Child Growth Standards that provides an international standard that gives description of physiological growth for all children from birth to five years of age [55]. The WHO Multicentre Growth Reference Study (MGRS) conducted across varied ethnic and cultural backgrounds across the world is the foundation of these growth curves [34].

Human growth and development go hand in hand. Development is different than growth, being the physical, language, cognitive, social and emotional development that initiates from birth [49]. Physical development refers to the development of the capability to skillfully conduct complicated activities. Motor development refers to muscular coordination that enables the infant to hold the neck, roll over on the side, crawl and walk. Gross motor development refers to co-ordination of major muscles of the body such as those of the arms, forearms, thighs and legs, so that the child can perform functions like throwing a ball, riding a tricycle or climbing stairs. Fine motor development refers to co-ordination of minor or smaller muscles of the body such as those of fingers or toes. Examples of fine motor functions include ability to pick up a peanut from the ground or scribble on a piece of paper [42]. Physical development that is acquisition of motor skills progresses from general to specific. The control of major muscles and gross motor skills such as walking or running, are acquired first followed by minor muscle and fine motor skills, such as picking up a pencil.

Language development is the ability to communicate. Infants initially communicate their needs through crying, followed later on with single words, followed by small sentences. By the age of three years, children are able to communicate through larger number of words. Cognitive development relates to the mental development of a child. Cognition refers to the process of gaining knowledge through thoughts, experiences and senses. A baby is not born with cognitive abilities at birth. During the course of development, cognitive skill-sets are acquired by children through surrounding experiences, own senses and own thoughts. Social-emotional development is another important area of human development. Social development refers to behaviour of a child with respect to accepted social culture. During infancy and early childhood, children do not form stable relationship bonds. But as age advances they can make friends, understand socially acceptable behaviours and etiquettes. Emotional development of an infant also evolves. For example, an infant can express basic emotions such as distress and delight. Gradually, other emotions such as joy, happiness, fear, anger, and sorrow develop, as well as ways of expressing emotions. All these areas of development are interrelated and interdependent on each other. A deviation in any one area can hamper overall development of a child.

Development occurs at variable rates and over a variable period of time, but is governed by some underlying principles. The rate of development is most rapid during early childhood [49]. Human physical development is cephalocaudal, that is development proceeds from the head downward. That means babies gain head control first, i.e. ability to lift up the head followed by coordination of upper extremities and finally the coordination of lower extremities. At the same time, development is proximodistal, that is the baby gains coordination of arms first and later of the hands

and the fingers. Similarly, legs develop first then the feet and the toes. The spinal cord develops first before the peripheral structures. Development is largely dependent on biological maturation and learning new abilities. These are determined by the changes in the brain and the nervous system over a period of time. The rate of synaptogenesis determines the rate of maturation. The child must mature to a certain point before progressing to a new level. A stimulating environment, and positive experiences during early childhood enable the child to achieve optimal developmental potential.

Human development proceeds from simple to more complex. The ability to classify and find relationship between two objects is the most essential and primitive state in development. Children find simpler relationships between two objects initially and as age advances, they are able to proceed to find more complex relationships. Children utilize their cognitive skills for reasoning and problem solving. For example, younger children can identify the similarity in shape between an apple and an orange, and distinguish between them on the basis of colour. After attaining next maturation level, children achieve the ability to categorize items such as food and fruit.

In addition to being a continuous process, development is a sequential process, with the first level of maturation laying the foundation for other levels of maturation. Thus, children go through a continuous process of acquiring and adding sets of skills. Despite these general rules, every child is unique and the rate of growth and development is different for each child. However, the sequence and pattern remain the same. Hence, there is no fixed age at which a particular skill set is acquired, but there are age ranges for a particular developmental task [1, 20, 44].

Milestones of Development

“Developmental milestones are a set of behaviours, skills or abilities that are demonstrated at specified ages during infancy and early childhood in typical development” [5]. Table 13.1 summarizes the age at development of gross and fine motor, social/emotional, language and cognitive milestones [8, 20]. The achievement of milestones is influenced by a number of factors. For example, the achievement of milestones remains more or less the same among boys and girls in the first year of life, but thereafter, gender based differences in development emerge. Cultural, environmental and parental factors play an important role in achievement of milestones like independence, walking or climbing stairs [15]. A protective environment, where the child is not allowed to do things independently, delays the achievement of milestones. It is essential to understand these differences or else a child, without any delay may be at a risk of receiving early intervention services without need [50].

Figure 13.1 summarizes the early warning signs of developmental delay. These are, lack of response to sound, does not smile and cannot hold head by the second month of life; trouble moving eyes, inability to raise hand to mouth, does not make sounds by four months of age; appears floppy/stiff, does not roll and does not reach for objects by six months of age; does not sit, does not recognize familiar faces, does not babble, does not play by nine months of age; and does not crawl, stand, point to

Table 13.1 Milestones of development

Age	Gross motor	Fine motor	Social/emotional	Language/communication	Cognitive
2–3 months	Can hold up head, pushes up when lying in prone position	Movement of hands	Social smile, recognizes mother, anticipates feeds, can briefly calm herself	Alert to sound, coos, gurgling sounds	Begins to follow objects with eyes, pays attention to faces
4 months	Holds head steady, can roll over	Bidextrous reach	Smiles spontaneously, copies facial expressions	Begins to babble, laughs aloud	Hand eye coordination—sees and reaches for a toy with one hand, responds to affection
6 months	Sits with support, rolls in both directions	Unidextrous reach	Stranger anxiety	Monosyllables (ba, pa, da), responds to sound by making sounds	Shows curiosity to things around, tries to reach at them, transfers object from one hand to other
9 months	Sits without support, crawls, pulls to stand	Immature pincer grasp	Waves bye-bye	Bisyllables (baba, papa, dada), copies sounds	Transfers object from one hand to other
12 months	Stands without support, walks with support	Mature pincer grasp	Responds when called by name, cooperates in dressing, shows fear in some situations	One to two words with meaning	Explores objects by banging, shaking, throwing, follows simple directions
18 months	Walks alone, climbs stairs, explores, drinks from a cup	Scribbles, builds tower of 2–3 blocks	Copies caregivers in task, clings to caregivers in new surrounding or situations, may have temper tantrums, plays	8–10 single words, says “no” and shakes head “no”	Points to one body part, knows what common things are for; e.g. spoon, brush, phone

(continued)

Table 13.1 (continued)

Age	Gross motor	Fine motor	Social/emotional	Language/communication	Cognitive
2 years	Walks upstairs, jumps, runs, kicks and throws ball, stands on tiptoe	Builds tower of 6 blocks, makes and copies circular and vertical strokes	Copies others, excited in company of other children, shows independence, defiant behaviour, asks for food, expresses toilet need	2–3 word sentences, uses pronouns, repeats words, follows simple instructions, points to things	Sorts shapes and colours, finds things hidden under 2 or 3 covers, might use one hand more than other, names items in books
3 years	Runs, climbs well, walks upstairs with alternate feet, rides tricycle	Builds tower of 9 blocks, copies circle	Shares toys, knows name, gender, understands mine, his/her, shows concern and wide range of emotions	Can name familiar things, says first name, understands words like in, on, under, converses with 2 or 3 sentences	Can work with buttons, moving parts, does puzzle with 3–4 pieces, understands concept of two
4 years	Hops on one foot, walks downstairs (alternate feet)	Copies cross, bridges with blocks, uses scissors, plays card game	Enjoys company of other children, doing new things, plays cooperatively, attends toilet	Says songs or stories, correctly uses he/she	Understands concept of counting, understands time, same/different, remembers parts of a story
5 years	Hops, may be able to skip, summersault, swings, climbs	Copies triangle, and other shapes, able to draw a person with minimum 6 body parts	Wants to be like friends, wants to please them, likes to dance, act, sing, knows gender, shows more independence, helps in household tasks	Clear speech, tells simple story, uses full sentences, uses future tenses	Counts 10 or more things, knows about things used daily like food, money



Fig. 13.1 Warning signs of delayed development

things and does not say single words by one year of age. The warning signs after this age are inability to walk, say at least six words, and unable to imitate at 18 months of life. Losing skills at any point is a major warning sign. Inability to follow instructions, lack of verbal abilities, communication, mobility issues, and extreme behaviour, or appearing withdrawn and distracted are all early signs of developmental delay and disabilities.

Factors Affecting Growth and Development of a Child

Early childhood development is determined by both intrinsic and environmental factors (Fig. 13.2) [47, 48, 50]. Brain development initiates from conception, with

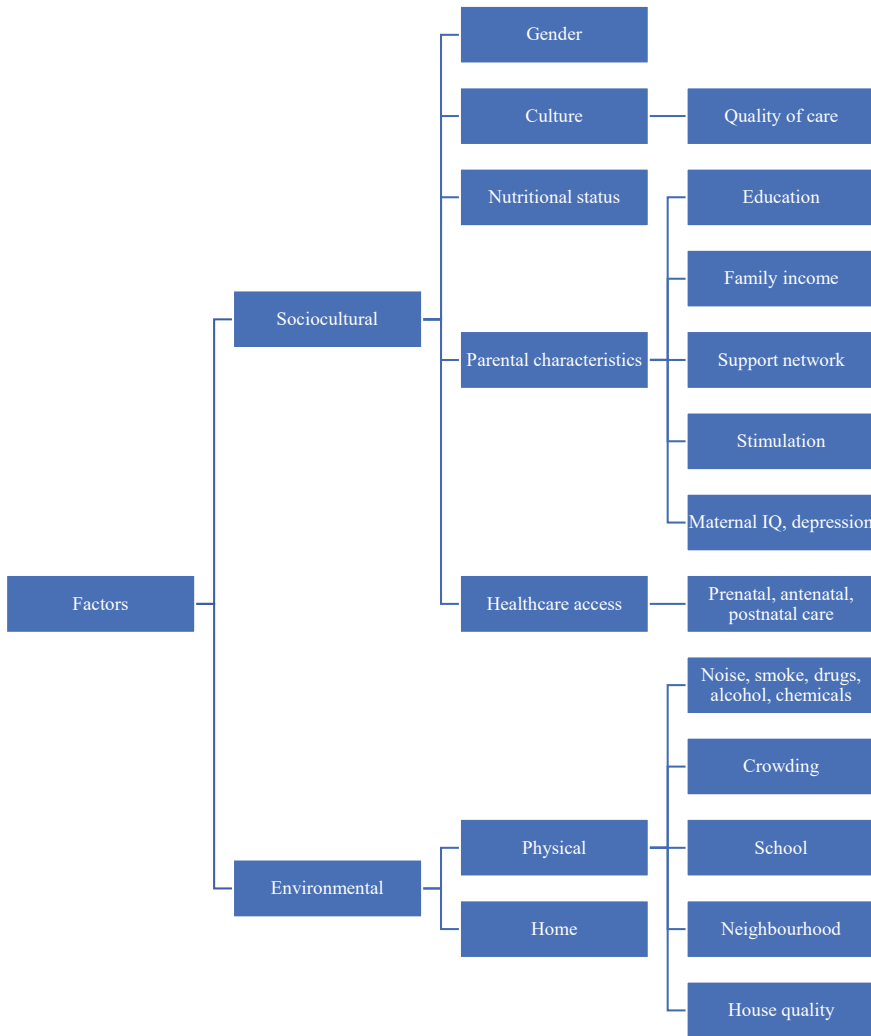


Fig. 13.2 Factors affecting growth and development

synaptogenesis (that is the establishment of synapses, the structure that facilitates communication between neurons) accelerating till the age of three years [22]. Synaptogenesis has a pivotal role in child development, determining language skills and cognitive abilities [7]. Positive and stimulating experiences and nurturing care received during this period lay the foundation for healthy child development. Socio-economic factors are important influencers of child development, as education, occupation and family income determine the ability to provide quality education, stimulating environment and nutritious food which are basic needs for optimum child development. Engagement of children in income generating activities among the

lower socio-economic strata adversely influences healthy child development. As primary caregivers, parental characteristics are equally important. During early years, children need love and care from parents. The amount and quality of time parents spend with children is determined by parents education, occupation and emotional status.

Environmental factors are influencers of child development. Residence in urban areas where there are more facilities in terms of hospitals, schools and recreational areas makes a difference in a child's development, as compared to rural areas where access to healthcare facilities and schools is difficult. Growing up in unhygienic environments influences child development with chances of repeated infections leading to bouts of morbidity and malnutrition. In the environment of urban slums, overcrowding, noise, lack of adequate space for children to play affects development in a negative way. Other factors also influence development. For example, gender is often a determinant, as in many countries including India, different attitudes prevail towards raising a girl child. There are evidences of girl children being neglected and deprived of opportunities for better education, food and clothing. Cultural and religious factors also determine child development. Different religions have different values and ways of living. Children usually follow the customs which their family follows and make own beliefs regarding many day-to-day living activities.

These factors are of utmost importance in a country with as much linguistic and cultural diversity as that of India. Intra-state differences in language and vocabulary may be very different, and language acquisition may be different at different ages. Similarly, an urban-rural difference is an important influencer. For example, urban children may have better cognitive abilities, whereas rural children may have better motor abilities. This implies that though belonging to a common country, there are different factors such as religion, cultural sub-groups, economic class, neighbourhood qualities which have direct or indirect impact on the growth and development of a child [14].

Early Childhood Intervention

Delayed developmental milestones are indicators of underlying health complications. Early intervention is a set of coordinated services and support systems that are available to infants and young children with developmental delays and disabilities, that aim at maximising the developmental and health outcomes [13]. Early intervention is required for newborns and children with developmental disabilities such as intellectual, visual, hearing, speech, locomotor, behavioural, social and learning difficulties. Very premature and low birth weight infants, whose survival has improved with advanced technologies, are at a higher risk of developmental difficulties. These children are another target group for early intervention. Early intervention basically helps these children and their families in learning basic life skills. Studies have shown that early intervention produces moderate to large effects on cognitive and social development [41]. Early behavioural intervention normalizes brain activity

of autistic children, which improves social behaviour and has positive long term outcome [9].

Based on the need of the child, early intervention may be in the form of physical and occupational therapy, speech therapy, behavioural education and play therapy (Fig. 13.3). Early intervention services work closely with medical, nursing and psychological services, audiology and vision services and nutritional services. One of the key features of early intervention services is counselling and empowering families on caregiving. Parent-focussed programs are found to be effective not only for the child with developmental delay but also for other siblings as there are changes in the family environment due to new caregiving needs [4]. Children are linked up to appropriate assistive technology, and frequently, transportation issues are also addressed. The goal of early intervention can be restorative, i.e. restoring existing developmental issues, and preventive, i.e. preventing occurrence of developmental issues.

Primary prevention in early intervention activities aims at reduction in the risk factors that are responsible for developmental delay and disabilities. Examples include addressing malnutrition related to low birth weight and prematurity. Secondary prevention aims at reducing the impact of disability and shortening its duration. Stimulation, therapies and various forms of strategies and interventions are

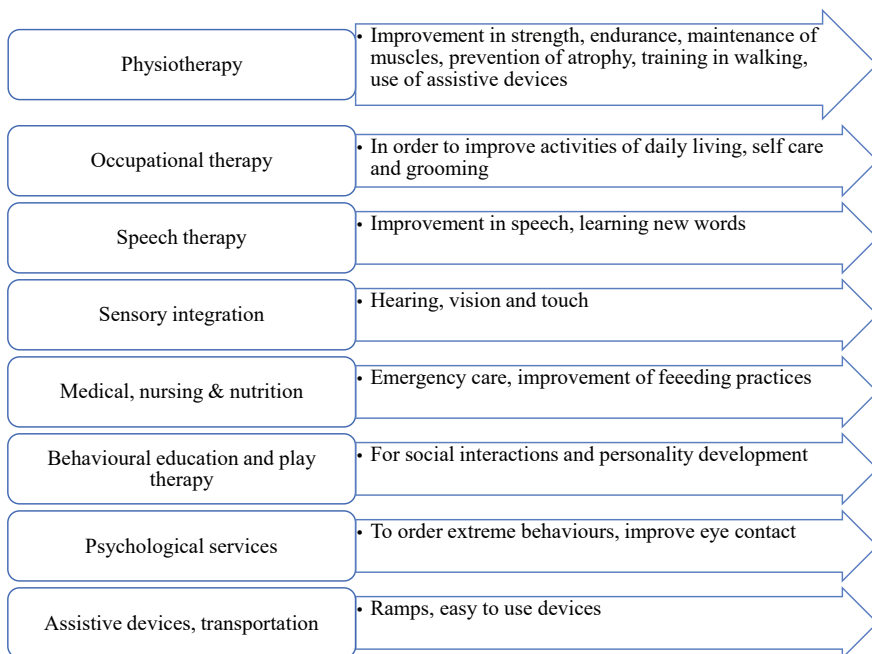


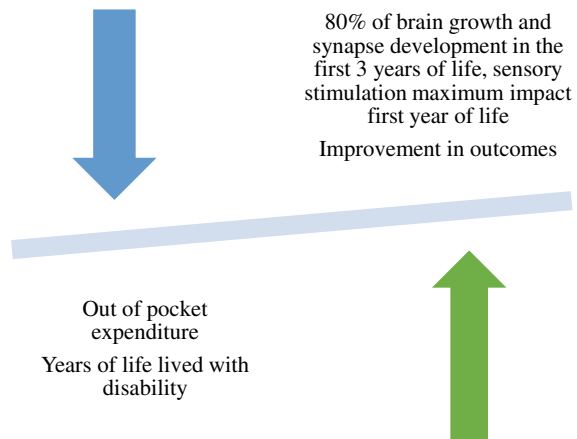
Fig. 13.3 Early intervention services

applicable at this stage of prevention. Tertiary prevention aims at preventing deterioration of the condition that may result in complications and hospitalization or immobilization.

Early intervention services initiated in the 1960s, focusing on children with developmental difficulties. Initially, care for children with disabilities was institutional. Emerging evidences, however, indicated that children staying at institutions or orphanages or in single parent families showed poor cognitive development, neurobiological and behavioural problems. They also experienced poor sensory and linguistic stimulation thus leading to poor attachment and socio-emotional development [16]. Studies indicated improvement in cognitive development if children living at institutions were moved earlier to foster care or parent support. With these emerging evidences, in the 1980s and 1990s, programs became family centred as the importance of family on child development was realized. Currently, early intervention has shifted in focus from school-based to home-based programs, with parents sharing a major responsibility in providing appropriate and recommended interventions to the child [21]. Additionally, early intervention also reduced the costs incurred by parents (Fig. 13.4) [17, 19].

Early intervention begins with an evaluation that helps in identifying the areas in which the child requires assistance and therapy. The child is further provided with tailored services relevant for his or her further development. Services are family oriented, so that the concerns of the family are addressed and the parents are counselled to help them understand the needs of the child, and the role of early intervention in the child's development. Early intervention is more beneficial and cost-effective

Fig. 13.4 Benefits of early intervention



if provided early than at a later stage in life, with studies suggesting that the impact of early intervention for a child with developmental disability is highest at 18 months of age [2, 6, 21].

Early Intervention Strategies

While designing early intervention strategies, it is essential to focus on components of intervention and mode of delivery for better compliance. Early intervention can be provided at home, day care, institutions, schools, play groups or centres specifically meant for providing early intervention. Other options are parent-child groups or family support groups. Group development interventions may also be given, where the child is provided intervention in a group of two or more children. Providing intervention in the natural environment and targeting everyday experiences are more effective. A review of early intervention in autism shows that interventions that are delivered for more than 20 hours per week and those that are individualized increase the development of children. Few points that need to be considered while designing any intervention program are as follows [3, 40].

- Developmental timing: interventions that begin at an earlier age and last longer are more effective than those that start later.
- Program intensity: intensive programs with more number of hours produce larger positive effects.
- Direct provision of learning experiences: direct contact and combination of centre-based and home-based treatment.
- Program breadth and flexibility: interventions that are comprehensive and multidisciplinary are more effective.
- Individual difference in program/Individualized care: are essential and beneficial.
- Environment: children's environment before and after intervention plays an important role in development.
- Child and parent needs have to be the focus of the programme.
- Evidence based practice has to be the centre of all intervention activities.
- Most importantly, the programme has to be embedded within local delivery systems in order to ensure sustainability.

The goals of early intervention are shown in Fig. 13.5. Cost of early intervention varies from setting to setting. It depends on the services offered and availed and also the competency of the staff. The higher qualified and trained the staff, the higher is the cost.

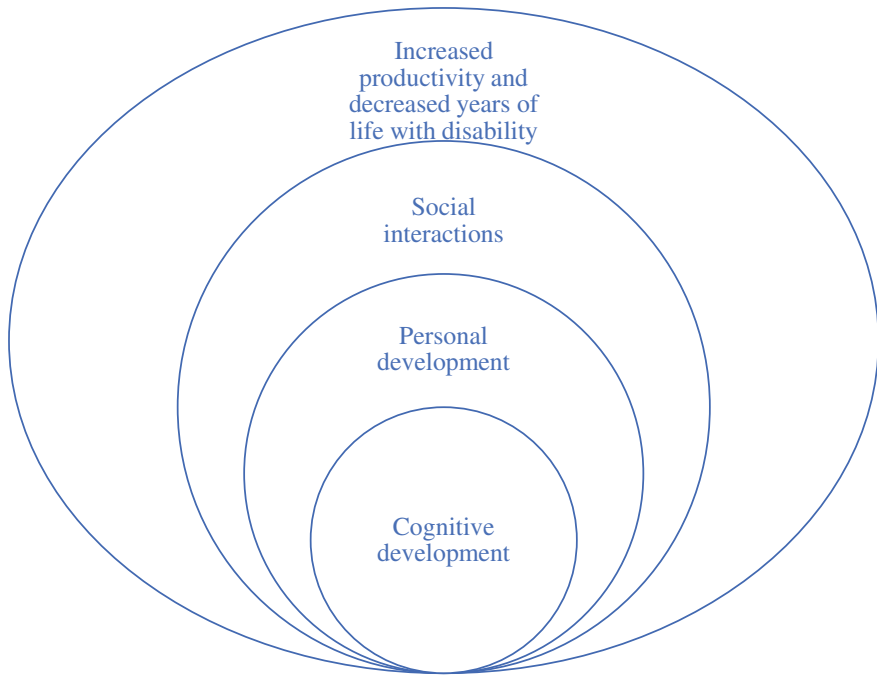


Fig. 13.5 Impact of early intervention

Early Intervention Services in India

In India, early intervention is mentioned under several policies. These include policies of the Ministry of Social Justice and Empowerment, which is the key ministry entrusted with the welfare of persons with disabilities [11], the Ministry of Health and Family Welfare, which has a screening and early intervention programme, and the Education Ministry, which calls for early intervention in its policies. Figure 13.6 enlists the various policies to promote early childhood development in India [26–32].

District Early Intervention Centres (DEICs) have been established by the Ministry of Health and Family Welfare for providing referral support to children with predetermined health conditions. The plan intends a team consisting of a paediatrician, physiotherapist, audiologist and speech therapist, psychologist, optometrist, lab technician, special educator, social worker and dentist for providing services. A programme manager has the responsibility of coordinating multiple therapies and guiding parents to required hospital departments. All newborns delivered at government hospitals, including those admitted in Special New-born Care Units, children in postnatal wards and paediatric wards, are to be screened for hearing, vision and congenital heart disease before discharge. Children born sick or preterm or with low birth weight or any birth defect are followed up. Records are maintained and are followed for all

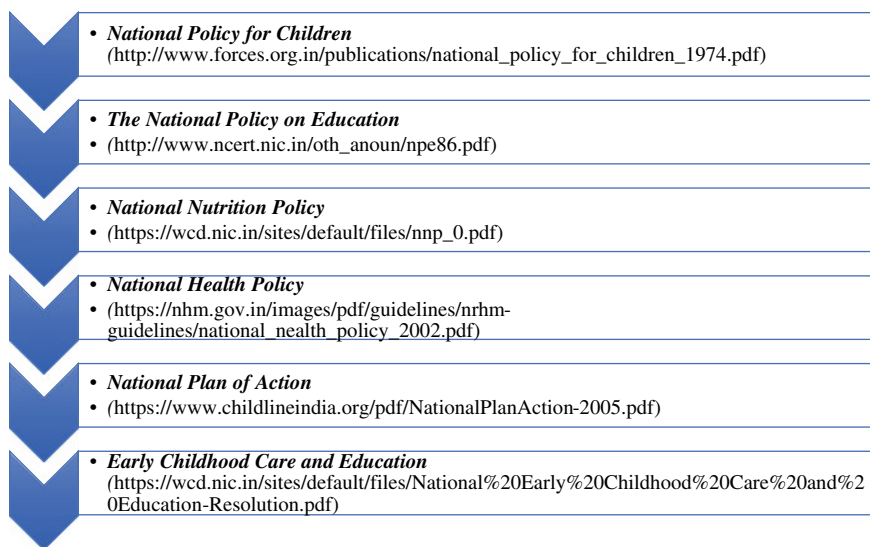


Fig. 13.6 Policies supporting early childhood development in India

children with developmental delay [46]. DEICs have been established in over 90 districts across the country (Chap. 12).

A rapid assessment of two DEICs in Chhattisgarh showed that beneficiary feedback was poor for one, due to lack of staff and required infrastructure. The other DEIC was well equipped, and recommendations for developing it as a model DEIC for Chhattisgarh were given [39]. A case study from Vishakhapatnam identified similar factors, that is the need to improve infrastructure and replace damaged equipments. Shortage of staff was another concern [35]. These findings were similar to the study from Odisha [37]. A study from Madhya Pradesh also reported dissatisfaction among beneficiaries, primarily as only few cases could be managed by the DEIC [38, 53]. A study from Pune identified that service uptake was poor because these were provided at district centres [18]. Non-compliance attributed to loss of wages, lack of time due to competing family issues, long travelling time, difficulty in transporting child with disability, failure to identify the health issue and belief that it will be resolved as the child grows old. Reasons attributed to health services were irregular time of visits by specialists, poor communication with healthcare professionals, inability to comprehend what is being told and where to go [18]. A long-term multi-sectored engagement is required for addressing the issue of disabilities in children. Caregivers, health personnel, government bodies are important stakeholders. Caregiver's role has been considered as pivotal. However, parental understanding of the nature of health issue, available treatment options, effectively following the treatment regimens, financial constraints, quality of counselling provided by health professionals are some of the important factors which determine the adherence of caregivers to medical advice/intervention/services [45]. Maternal education and proximity to intervention

facility are also some determining factors [10]. Frequent monitoring and evaluation of DEIC, availability and working condition of the screening/evaluation equipments, screening tools, lab equipments, strengthening infrastructure and referral system, capacity building, awareness and training of staff, availability of specialists, and regular follow-up will improve DEIC functioning [37]. Use of social media as a tool to provide information on the DEIC will help in creating awareness and thus influence the use of services [43]. The use of telemedicine in delivering services should be considered for underserved districts [39].

In addition to the DEICs under the RBSK programme, early intervention centres have been established by the National Trust for Welfare of Persons with Autism, Cerebral palsy, Mental Retardation and Multiple Disabilities, a body established under the Ministry of Social Justice and Empowerment [51]. This Ministry is empowered with social welfare of persons with disabilities. The Rights of Persons with Disability Act 2016 aims at ensuring protection of rights, equal opportunities and full participation for persons with disabilities. Chapter III (Education) of the Act mentions the need for early intervention and early detection of disabilities [52].

One of the programmes offered by the National Trust is Disha, which is an early intervention and school readiness programme for children aged 0–10 years. The objectives of the programme are to provide therapies, training and support to families along with day care facilities to children up to 4 hours per day. The programme is for children in the age group 0–10 years with four disabilities (mental retardation, autism, cerebral palsy and multiple disabilities). The programme is implemented through registered voluntary organizations, and mandates qualified personnel, that is an Early Intervention Therapist or a special educator, physiotherapist or occupational therapist, counsellor and speech therapist. Vikaas is a day care programme for enhancing interpersonal and vocational skills for persons with disabilities. Vikaas centres also provide respite care, that is it helps family members of children with disabilities to have some time off to carry out other responsibilities.

District-Based Model for Early Intervention for Children with disabilities

Although available, early intervention services in India are limited, under-developed with little coordination among services and the ministries offering these services. At the community level, access to early intervention in India is plagued by both parent- and provider-related factors. Firstly, the lack of awareness about early intervention for childhood disability is apparent from a paucity of literature in the area. Studies identify parent-related factors to include beliefs about disability, lack of awareness about care for children with disabilities, lower education, family customs and traditions, transportation, financial constraints, early intervention centres being concentrated in urban areas thus missing target population, and parents perception that these centres lack trained professionals [33, 36].

There are several provider-related factors. A study conducted in Gujarat, India, to understand the perspective of paediatrician on early intervention showed that paediatricians referred the child mainly for three reasons, viz. sensory impairment (hearing or vision), abnormal muscle tone or loss of developmental milestones. The barriers to referral encountered by providers included lack of knowledge about referral services, and limited knowledge about options for treatment at affordable costs. Among providers, 28% reported that they were not confident about screening for a disability. Also referred parents do not report at the centre early, and only visit when the condition has become severe, showing lack of awareness among the parents [12]. These factors, that are observed globally, identify the need to create awareness among both providers, parents and other family members regarding the danger signs of a developmental disability, and the benefits of early interventions.

The feasibility of bringing health and early intervention services closer to communities was demonstrated in a district-based model by Nair and colleagues [24]. In this study, community-based health workers, Accredited Social Health Activists (ASHA), were trained in screening children, using two validated tools developed by this research group. These two tools were the Trivandrum Developmental Screening Chart [23] and the Language Evaluation Scale Trivandrum [25]. Both these tools were validated against the Denver Developmental Screening Test and Receptive Expressive Emergent Language Scale. Following training of the ASHAs, 101,438 children less than 6 years of age were screened, of which 1329 children were further evaluated by specialists at Developmental Evaluation Camps organized at Community Health Centres. Among screened children, 57% were identified with either developmental delay (49.89%), speech and language delay (24.98%), multiple disabilities (22.95%), intellectual disability (16.85%), cerebral palsy (8.43%), hearing impairment (5.12%), seizure disorders (3.99%), visual impairment (3.31%), neuromuscular disorders (1.35%) and autism (1.28%). Individualized treatment plans were offered to children by multidisciplinary teams. The project developed and offered education materials not only for mothers, but also for healthcare providers in the district.

Conclusion

Children with disabilities can be identified through delayed developmental milestones. Early intervention services provide the opportunity for maximizing the health and developmental potential of children with developmental delays or disabilities. In India, policies for early intervention are not coherent. Services are also not coordinated. Considering the magnitude of childhood disability in the country (Chap. 8), there is a need to focus on developing integrated services for children and their families. The available literature shows that there is a paucity of evidence, and there are still many unanswered questions on developing the most cost-effective system for providing early intervention. Research to understand how to identify those that

require early intervention, the duration of early intervention, approaches and their benefits are needed to inform the development of a model for early intervention in resource-limited settings.

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