Chapter 7
Magnitude of Developmental Disabilities in India

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Abstract Developmental disabilities are a group of conditions responsible for physical, social, emotional, behavioral, cognitive, and motor impairments in children. This article reviews available data on the magnitude of developmental disabilities in India. Estimation of these conditions is challenged by the lack of validated, culturally adapted screening tools in low- and middle-income countries. There is a paucity of good quality studies, so that prevalence estimates vary between studies. Nevertheless, data from selected studies identify a notable magnitude of developmental disabilities in India. Comparison between an Indian study with data from a US surveillance for autism and selected developmental disabilities identified that the magnitude of autism and attention-deficit/hyperactivity disorders were similar, learning disabilities were lower in prevalence, but other developmental disabilities such as intellectual disabilities, epilepsy, and hearing and vision impairment were markedly higher in India. The Global Burden of Disease study estimates that developmental disabilities may affect more than 11 million children under the age of five years in India. The article identifies the need for well-designed studies using validated screening tools so that the data could yield better estimates of the magnitude of the problem in India. The high numbers suggested by existing studies indicate the need to urgently expand services for prevention, care and rehabilitation of children with developmental disabilities.

Keywords Prevalence · Developmental disabilities · India · Low and middle income countries

Childhood Development

Early childhood, that is the first five years of life, form the critical period of growth and development of children. Growth is increase in physical size. Development refers to functioning and capability, which increase with the development of motor, cognitive, emotional, and social functions. Development is a continuous process, correlated with the change and maturation of the central nervous system [35]. Although development

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has been divided into specific domains of gross motor, fine motor, language, cognition and social/emotional growth, substantial overlaps exist. Studies have established specific ages when certain milestones are achieved, and there is a range of variation observed among children [67]. Failure to achieve a set of skills by a specific age is indicative of a developmental delay. Crossing the window of achievement without achievement of milestones is strongly indicative of the need for interventions.

Table 13.1 (Chap. 13) summarizes the developmental milestones. Early development is marked by primitive reflexes, such as the Moro (startle) reflex, palmar grasp reflex and rooting and suck reflex. As the child grows, these reflexes are integrated. Development is reflected in improvement of gross motor and fine motor skills, cognitive and language development and personal social interaction. The child holds its neck by three months, sits with support by six months and without support by eight to nine months, stands with support by eight months, walks with support by 10 months. Crawling is seen at 11 months and walking without support by 12 months. The child runs by 18 months and climbs stairs by 24 months.

Fine motor skills are those involving small muscle groups. By four months, the child grasps objects placed in the hand, by five months reaches out to an object, by seven months palmar grasp and by nine months pincer grasp develops. Language development is evident at one month of age, when the newborn turns its head toward a sound, starts cooing by three months, and starts producing monosyllables by six months, bi-syllables by nine months and two words with meaning by 12 months. By 18 months, the child speaks ten words and can communicate with simple sentences by two years of age. Personal social development includes smiling by two months, recognizing mother by three months, smiling at mirror image by six months and waving goodbye by nine months. Parallel play develops by 18–24 months. These milestones are seen in all normally developing infants.

Developmental Delays and Disabilities

Development is a multifactorial process. Environmental factors such as nutrition and stimulation, disease and psychological factors interact with the genetic predisposition of the child to determine the developmental pattern. Studies have identified many factors that affect development. These include genetic factors (hereditary conditions, consanguineous marriages), maternal complications (prolonged labor, eclampsia/pre-eclampsia), nutritional deficiencies, poverty, infection, illness and injury (including febrile illness, injury or trauma, damage to the central nervous system), prematurity, low birth weight, exposure to environmental toxins such as smoke and psychosocial stress [4, 56]. Motor development is determined by family patterns, prolonged illness, or pathophysiological conditions such as cerebral palsy and intellectual disability. Delay in language development is commonly linked to hearing loss. Cognitive development, that is the intellectual maturation of the child, is associated with nurturing care and strong relationships. Emotional and behavioural developments are more individual-specific.

Delayed milestones, that is not achieving skills within a specific time frame, or persistence of primitive reflexes is termed as developmental delay. Modifiable risk factors like poor nutrition, poverty, and infections are more common in the low- and low-middle income countries (LMICs). The higher prevalence of these factors can be attributed to the high prevalence of developmental delays in these countries [14, 44]. These risk factors form targets of public health programmes, in order to improve growth and development in the early years. Specific medical conditions may be a cause for delayed or disordered development. Developmental disability refers to a childhood intellectual, physical or behavioral impairment or combination of these impairments that cause substantial functional limitations in major life activities.

Developmental Disabilities

A developmental disability (neuro-developmental disability, neuro-developmental disorders, NDD) arises when age-specific skills are not achieved within a specific time frame, affecting the functioning and skill performance of the child. Developmental disabilities are a group of conditions where the child has an impairment in physical, learning, language, sensory, motor, cognitive, social, emotional skills and behavior [12]. The most common developmental disabilities are epilepsy or seizures, sensory impairments (hearing or vision loss), cerebral palsy, attention-deficit/hyperactivity disorders (ADHDs), autism spectrum disorders (ASDs), and intellectual disability (ID). Developmental disabilities may affect several functions. For example, in children with epilepsy, 22% also report ASD, 33% have ADHD, and 30–50% have behavioral and emotional problems [4]. This raises issues not only on the disabling nature of these conditions, but also regarding measurement of the magnitude of the conditions, as there is a risk of over-counting.

Epilepsy is a neurological condition, characterized by two unprovoked seizures more than 24 hours apart [62]. Epileptic seizures are caused by abnormal signaling of neurons, causing involuntary movements, loss of awareness, sensations, behaviors and emotions. Intractable epilepsy (i.e., epilepsy that cannot be controlled with medications) accounts for 30–40% of all epilepsy. A European study on the quality of life (QoL) of people with epilepsy identified that achieving better seizure control and reducing the side-effects of medications were related to improved quality of life [3]. An Indian study identified that the QoL was impaired in all patients, but more so among women, older patients, those with simple partial seizures and those with recent seizures [61]. Hearing loss present at birth (congenital hearing loss) is caused by genetic factors, and by other factors such as prematurity and low birth weight. Congenital infections, especially congenital cytomegalovirus infections, are associated with congenital hearing loss [37]. Childhood blindness and vision impairment constitutes only 4% of blindness [36], but both these congenital sensory organ impairments (hearing loss and blindness) can severely affect the QoL, education, and employability of individuals. Cerebral palsy is a heterogeneous group of non-progressive neuro-motor disorders that affects balance and movement. It is one of the

most common causes of childhood locomotor disability [55]. ASDs are characterized by impairments in social interactions, repetitive behaviors, and restricted interests. Pervasive developmental disorders (PDDs) are disorders that include a broad range of social communication deficits. Appropriate interventions can improve the behavior and language achievement, but most people with ASD are dependent on caregivers throughout life [40]. ADHD is another common disabling neuro-developmental disorder that is marked by inattentiveness, hyperactivity and impulsiveness [18]. Intellectual disabilities are one of the largest group of disabling conditions, characterized by below-average intellectual function and limitations in adaptive functioning [46]. Developmental disabilities impact activities of daily living, causing participation restriction and affecting the educational and employment potential of the individual. Within families, developmental disabilities affect family functioning and QoL of the child, parents and siblings. Chapter 2 provides a further overview of the disabling nature of these conditions.

Table 7.1 shows the exposures/factors associated with some common developmental disabilities [15, 18, 25, 33, 37, 38, 40, 59]. These include genetic factors, gene-environmental factors, environmental factors, maternal health status and health service factors. The prevalence of these factors are higher in LMICs, which might account for the higher prevalence of developmental disabilities in these countries. The factors associated with developmental disabilities form the targets of maternal health services during the prenatal and perinatal periods. Increasing institutional deliveries in LMICs, for example, can reduce some of the adverse complications for developmental disabilities like epilepsy and cerebral palsy.

Tools for Measuring Developmental Disabilities

Developmental disabilities are diagnosed through a step-wise process, with screening followed by diagnosis [7]. Screening tools examine early child development and can detect a developmental delay and disability. A screening test is meant to identify a child with a developmental delay, but further evaluation is required to confirm the presence or absence of a developmental difficulty. Screening tests are therefore followed by specific diagnostic tests. For example, after screening for hearing loss, further evaluation and diagnosis is done using audiometry. For children with intellectual impairment, the Vineland Social Maturity Scale (VSMS) is a diagnostic instrument to determine social maturity.

Over 100 screening tools have been developed, which have been reviewed comprehensively and are available as the World Bank's Toolkit for Measuring Early Child Development (ECD) in low-income and middle-income countries [19]. An ECD measurement inventory which summarizes and lists a total of 147 tools for children up to 8 years of age is also available [16]. The tools may be for population-level, or individual-level screening. The tools may or may not screen for the nine developmental domains listed in the World Bank Toolkit (cognitive, language, motor, socioemotional/temperament, attention/executive function,

Table 7.1 Risk factors for common developmental disabilities

Condition	Risk/associated factors
Epilepsy	Structural etiology (stroke, trauma, infection, congenital), genetic etiology (familial syndromes, mutation), infectious etiology (malaria, tuberculosis, HIV, toxoplasmosis, congenital Zika, cytomegalovirus, etc.), metabolic etiology (disorders such aminoacidopathies, uremia, etc.) immune etiology (autoimmune mediated central nervous system inflammation), unknown etiologies
Cerebral palsy	Birth complications (neonatal encephalopathy, birth asphyxia, trauma), breech position, preterm birth, mechanical ventilation, post-natal administration of steroids for lung maturation, systemic inflation in premature born infants, low birth weight, fetal hypothyroxinemia, genetic factors, multiple births, disadvantaged populations, prepregnancy obesity, maternal pre-eclampsia, fetal growth restriction, maternal infections, cerebral malformations, perinatal stroke, kernicterus
Congenital hearing loss	Admission to a neonatal intensive care unit, low gestational age and birth weight, medical interventions (assisted ventilation, venous access and aminoglycoside use), genetic factors, autosomal recessive genetic factors, congenital infections, primarily cytomegalovirus infection, socioeconomic factors, access to prevention services such as rubella immunization
Congenital vision impairment (VI) and blindness	Congenital anomalies (uveal coloboma, anophthalmos, microphthalmos), infantile glaucoma, retinal dystrophies, Leber's congenital amaurosis, congenital cataract, retinoblastoma, ophthalmia neonatorum, retinopathy of prematurity, optic nerve lesions, cerebral visual impairment
ASD	Genetic factors (approximately 40–90% heritability). Environmental risk factors (neonatal hypoxia, maternal obesity, gestational diabetes mellitus, short interval between pregnancies, older sibling with ASD, paternal age >50, maternal age >40, valproate use during pregnancy) Not associated with vaccination, prolonged labor, cesarean section or assisted vaginal delivery, use of assisted reproductive technologies and premature rupture of membranes

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Table 7.1 (continued)

Condition	Risk/associated factors
ADHD	Gene-environmental genetic (70–80% heritability) Male sex, ethnicity and low socioeconomic status, prenatal and perinatal factors, including maternal smoking and alcohol use, low birth weight, premature birth and exposure to environmental toxins, like organophosphate pesticides, zinc, lead, and polychlorinated biphenyls
Intellectual disability	Genetic (chromosomal abnormalities, single-gene disorders, inherited conditions), non-genetic (advanced maternal age, maternal black race, low maternal education, third or more parity, maternal alcohol use or tobacco use, maternal diabetes, hypertension, epilepsy and asthma, preterm birth, male sex and low birth weight)

personal-social/adaptive, academic/pre-academic, approaches to learning, disability screener) [19]. Table 7.2 enlists some of the widely used screening and diagnostic tools.

There are several reviews on these developmental tools [21, 43]. A recent review of ECD instruments identified the limited numbers of population level screening tools (five) [5]. The review noted that the tools did not cover all domains, or did not rate high on accuracy and feasibility. Cognitive, language, and motor domains were measured frequently, with gaps across other domains. Vision, hearing, and disability screeners were missing or absent in all population-level tools. Most of the widely used screening tools (Table 7.2) have been developed in high-income countries, but several culturally adapted and validated tools have been developed in LMICs. These include a number of tools from India (Table 7.3). The reliability and validity of the tools are important, as they would influence prevalence estimates.

Among the tools developed in India, both the Baroda Developmental Screening Test and the Trivandrum Developmental Screening Chart (which are derived from Bayley Scales of Infant Development), as well as the ICMR Psychosocial Developmental Screening Test have not been re-validated since their inception [47, 48]. The INCLEN Neurodevelopmental Screening Test is a recently developed and validated tool [29] that has been used to report data on the prevalence of developmental disabilities from five settings across the country [2].

Sources of Data

Data on developmental disabilities can be obtained from surveillance systems, national surveys and from ad hoc studies. Estimates are also available from the Global Burden of Disease (GBD) analyses.

Table 7.2 Routinely used screening tools

Tool	Domains and time required	Age group
Bayley Scales of Infant Development (BSID-I, 1st edition; BSID-II, 2nd edition; BSID-III, 3rd edition)	Used to assess development across domains such as cognition, language, motor skills, socioemotional and personal/social adaptive skills. Useful in diagnosing and planning interventions for developmental delay. Requires specialist training and 30–90 min for administration	One month–3.5 years
British Ability Scales (BAS)	Includes domains such as cognition, language and pre-academic and academic screening. The main purpose is to develop and support interventions. Requires specialist training and 30–45 min for administration	Three years–17.9 years
Denver Developmental Materials II (formerly DDST)	It includes cognition, language, motor, and personal-social/adaptive domains. It is used for screening and not diagnosis. Requires specialist training and time required is 10–20 min	One month–6 years
Stanford Binet Intelligence Scale	Used for studying cognitive skills, language, and attention/executive functioning. It includes 15 sub-tests. Requires specialist training. Time required for each subset is 5 min	Two years–85 years
Ages and Stages Questionnaire (ASQ)	Used to screen for domains such as: communication, gross motor, fine motor, problem solving, and personal-social skill. Requires minimal training and 10–20 min for administration	One month–5.5 years
Vineland Adaptive Behavior Scales II	Includes domains such as language, motor skills, socioemotional skills, personal/social and pre-academic and academic skills. Requires moderate training for use. Time required for administration is 20–90 min	Birth–90 years

Table 7.3 Tools validated for use in India

Name of tool	Age range	Description (domains measured)	Sensitivity	Specificity	Time required	Special training required	Country used	Cost
Trivandrum screening chart (TDST)	0–2 years, 3–6 years	Mental, motor, hearing, and vision	66.7%	78.8%	5–10 min	No	India	Free
Development Assessment Tool for Anganwadi's (DATA) DATA II	1.6–3 years 3–4 years	Gross and fine motor, language, social skills	Not available	Not available	Not available	Limited training	India	Free/low cost
Lucknow development screen (LDSC)	6 months–2 years	Gross and fine motor, language, social skills	95.9%	73.1%	10–15 min	Limited training	India	Free/low cost
Baroda Development Screening Test (BDST)	0–30 months	Gross and fine motor, language, social skills	95%	65%	10–15 min	Moderate training	India	Free/low cost
Rashtriya Bal Swasthya Karyakram (RBSK) screening tool	0–6 years	Gross and fine motor, language, social skills	Not available	Not available	30 min	Minimal	India	Free
Guide for monitoring child development (GMCD)	0–3.5 years	Communication, gross and fine motor, socioemotional, self-help skills	88%	93%	7–10 min	Minimal	Turkey, India, South Africa	Free/low cost

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Table 7.3 (continued)

Name of tool	Age range	Description (domains measured)	Sensitivity	Specificity	Time required	Special training required	Country used	Cost
Development Assessment Scale for Indian Infants (DASII)	1–30 months	Gross and fine motor, cognitive, personal, social	Not available	Not available	60 min	Yes, specialist	India	Copyright
Disability Screening Schedule (DSS)	0–83 months	Physical, motor, sensory, cognitive	89%	98%	5 min	Minimal	India	Free/low cost
Screening test battery for assessment of psychosocial development (STBAPD)	0–6 years	Gross and fine motor, language, vision, hearing, concept development, self-help skills, social skills	Not available	Not available	30 min	Yes	India	Inexpensive
Language Evaluation Scale Trivandrum (LEST)	0–6 years	Language	66.7%	94.8%	10 min	Minimal	India	Expensive
WHO Ten Question Screen	2–9 years	Cognitive disability, movement disability, seizures, vision, hearing impairment	100%	Not available	10–15 min	Minimal	Multiple	Free

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Table 7.3 (continued)

Name of tool	Age range	Description (domains measured)	Sensitivity	Specificity	Time required	Special training required	Country used	Cost
Developmental Milestones Checklist (DMC, DMC-II)	1 month–8 years	Language, motor, personal-social	Not available	Not available	10–20 min	Minimal	Multiple (Cambodia, Kenya, Burkina Faso)	Free/low cost
ICMR Psychosocial Development Screening Test	0–6 years	Cognition, language, motor, social, personal	Not available	Not available	10–20 min	Minimal	India	Free
Caregiver-Reported Early Child Development Index (CREDI)	0–3 years	Cognition, language, motor, social, attention	Not available	Not available	5–15 min	Minimal	Multiple	Free
Intergrowth 21st Neurodevelopment Assessment (INTER-NDA)	1.8–2.2 years	Cognition, language, motor, social	66.7%	98.6%	35–45 min	Moderate	Brazil, Kenya, India, Italy, UK	Free
Profile of Socio-Emotional Development (PSED)	5 months–3 years	Social	Not available	Not available	15–20 min	Moderate	Multiple	Free
12 month screener	0–12 months	Cognition, language, motor, social	79%	85%	Not available	Yes	India, Pakistan, Zambia	Free/low cost

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Table 7.3 (continued)

Name of tool	Age range	Description (domains measured)	Sensitivity	Specificity	Time required	Special training required	Country used	Cost
East Asia Pacific Early Child Developmental Scales	3–5 years	Cognition, language, motor, social, academics, learning	Not available	Not available	45–60 min	Moderate	East-Asia Pacific	Free
Engle Scale and Survey	24–59 months	Cognition, language, motor	Not available	Not available	30–40 min	Not available	East-Asia Pacific	Free
Rapid Pre-Screening Denver Questionnaire	0–6 years	Gross motor, fine motor, language, personal-social	100%	7.8%	20 min	Yes	India	Not available
Woodside Screening Technique	6 weeks–24 months	Social, hearing, language, vision, gross and fine motor	88%	83%	Not available	Yes	India	Free/low cost
INCLEN Neurodevelopmental Screening Test	2–9 years	Vision, speech, hearing, language, cognition, gross, and fine motor	75%	87%	Not available	Yes	India	Free/low cost

Developmental Disability Surveillance

Several surveillance programs for specific developmental disabilities have been established. For example, there are 27 surveillance programs for cerebral palsy, located in Europe, Australia, and North America, that provide data on these conditions [26]. The Autism and Developmental Disabilities Surveillance System in the USA collects data on the prevalence and trends of intellectual disability, cerebral palsy, hearing loss, vision impairment, and epilepsy. The data are collected from the health and special education records of 8-year-old children who live in one of 11 surveillance sites across the USA. This surveillance program emerged from the Metropolitan Atlanta Developmental Disabilities Study (MADDS) that was established in 1984. The goal of the Autism and Developmental Disabilities Monitoring (ADDM) Network is to provide prevalence data among 8-year-old children, describe the characteristics of affected children, and identify risk factors for these conditions. The surveillance system forms the basis for further research, such as characterizing these conditions, identifying risk factors for these conditions, and improving diagnostic tools.

The utility of a surveillance system for developmental disabilities is evident from the data reported by the ADDM Network. In 2016, the prevalence of ASD among 8-year-old children was 18.5%, with ASD being four times more likely to affect boys than girls. There was no difference in ASD prevalence between black and white children, but autism prevalence among Hispanic children was lower. One-third of children with ASD also had intellectual disability. Nearly 84% of children had been diagnosed by the age of 4 years [41]. Due to methodological issues, ASD prevalence varied between 1.5 and 3.1% between different reporting sites. The utility of such surveillance data is that it can identify the needed services and support for children and adults with ASD. The data forms the background knowledge for conducting further research to understand the etiology of autism and other developmental disabilities.

Data on developmental delays and disabilities in India are collected by the Rashtriya Bal Swasthya Karyakram [60], a screening and early intervention programme. Under this programme, children are screened in community settings, for common childhood diseases, nutritional deficiencies, birth defects and developmental delays and disabilities [60]. As developmental delays are included with disabilities, the numbers are not specific for developmental disabilities. For example, in 2015–16, this programmes screened 187 million children across the country, of whom 83 million had a diagnosis of common childhood diseases, 26 had nutritional deficiencies, 3 million had birth defects, and 19 million had developmental delays and disabilities [28]. The RBSK data is, however, infrequently reported, and not representative as it is restricted to users of the RBSK service. Furthermore, the data is an over-estimate, as it includes both developmental delays and disabilities.

National Surveys

The magnitude and trends of developmental disabilities have been reported through several national level surveys in different countries. In the USA, for example, the National Health Interview Survey (NHIS) is a source of data for reporting the prevalence and trends of specific developmental disabilities (ADHD, cerebral palsy, ASD, ID, seizures, hearing loss, blindness, learning disorders (LDs), stuttering or stammering, and other developmental delay) among children aged 3–17 years [6, 71]. Data are collected from randomly sampled households through personal interviews conducted by trained interviewers. Data are collected on selected demographic and broad health measures, following which one adult and one child is randomly selected and interviewed using a more detailed health questionnaire. The most recent data included 88,530 children aged 3–17 years [71].

The study reported that the prevalence of any developmental disability in the USA between 2009 and 2017 was 16.93%. It was 9% for ADHD, 1.74% for ASD, 0.16% for visual impairment, 0.31% for cerebral palsy, 0.63% for hearing loss, 7.7% for learning disabilities, 1.1% for intellectual disabilities, 0.77% for seizure disorders, 2% stuttering/stammering and 4% for other developmental delay. For some conditions such as cerebral palsy, there were small differences in prevalence by age group, but some conditions like learning disability and ADHD had higher prevalence in the school years, when they are likely to be recognized.

The data indicated that the prevalence of children diagnosed with any developmental disability had increased in the USA from 5.76% in 2014, to 6.99% in 2016. The prevalence of children with ADHD, ASD, and ID had increased (ADHD increased from 8.47 to 9.54%, an increase of 12.6%; ASD increased from 1.12 to 2.49%, an increase of 122.3%, and ID increased from 0.93 to 1.17%; an increase of 25.8%). The diagnosis of autism was higher at older (8–12 years) than younger ages (3–7 years). As noted earlier, the prevalence of developmental disabilities was higher in boys than girls, and among white children.

In India, there is no nation-wide survey equivalent to the NHIS for measurement of the prevalence of developmental disabilities. The Census of India collects data on disability prevalence, through a single question that records data on impairment of vision, hearing speech, movement, cognition, and multiple disabilities. Two national disability surveys have been conducted by the National Sample Survey Organization (NSSO) [53], one in 2002 and another recently in 2018. (The findings from these surveys have been described in Chap. 8.) In 2002 survey, data on household, sociodemographic, and disability characteristics were collected from a random sample of 396,943 individuals from across the country.

Prevalence data reported by the Census 2011 and the NSSO 2002 for children and young adults less than 20 years of age identified that the disability prevalence was 2.2% and 1.8% of the total Indian population respectively. The proportion of children with disabilities below five years of age was estimated to be between 0.5 and 1%, that is 0.54–1.29 million. The National Sample Survey 2002 reported that among the 4.63 million children under 18 years of age, 58% were reported to have

been born with disability (2.70 million children, prevalence 64 per 10,000), while the remaining 42% (1.93 million children, prevalence 49 per 10,000) had acquired disability (Chap. 8). The data indicated that 88% of speech disability, 85% of multiple disability, 78% of cognitive disability, 63% of visual disability were reported to have been present since birth.

Ad Hoc Studies

Most of the data on the prevalence of developmental disabilities are available from independent studies. Systematic reviews and meta-analysis have been conducted for most of the common developmental disabilities, so that global prevalence estimates are available. However, majority of studies are available from industrialized countries. Nearly, all systematic reviews identify the paucity and poor quality of studies from LMICs. Maulik and Darmstadt [44] identified that the poor quality of research was responsible for a significant knowledge gap and frequently questionable data.

For example, from a systematic review and meta-analysis of 51 studies of selected NDDs (epilepsy, hearing and vision impairment, ADHD, cerebral palsy, ASD, behavioral disorders, motor impairment, and other neurological impairments), the authors estimated that the prevalence of NDDs was 7.6 per 1000. Majority of studies were on epilepsy. The prevalence was highest for behavioral problems, i.e. 362 per 1000, followed by mental disorders 232 per 1000, ADHD was 61 per 1000, epilepsy 8 and ASD 0.6 per 1000, respectively. Most of the studies were from the Asia Pacific region. The highest pooled prevalence was from Latin America. There were very wide variations in prevalence, which led to conclusions such as epilepsy being more common in Asia and Africa, whereas ADHD and hearing impairment were common in South America. Conditions like ASD appeared to have a very low prevalence in LMICs. The paucity of good quality studies in LMICs identified the challenge of estimating the true prevalence of developmental disabilities in these countries [4].

Prevalence of Developmental Disabilities in India

A multicentric study by Arora et al. is perhaps the strongest study to report the prevalence of developmental disabilities from India [2]. The study recruited 3977 children from five sites across the country, using cluster sampling method. The children were in the 2–<6 and 6–9-year age groups. The neuro-developmental disabilities that were included in the study were vision impairment, epilepsy, cerebral palsy, hearing impairment, speech and language disorders, autism spectrum disorders, and intellectual disability. Children aged between 6 and 9 years were additionally assessed for ADHD and learning disorders.

All children were assessed using a validated version of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (Diagnostic and Statistical Manual),

Text Revision (DSM-IV-TR) guidelines. Culturally relevant tools, that were feasible for community-based use were developed and validated for epilepsy [58], cerebral palsy [29], ASD [34] and ADHD [48]. Specific diagnostic instruments were used for confirming diagnosis [2].

The prevalence of neuro-developmental disorders was 12% (95% CI 11.0–13.0%) (475 out of 3964). Among children with neuro-developmental disorders, nearly 22% had more than two disorders. ASD, cerebral palsy, and epilepsy were most frequently associated with comorbidities. Hearing impairment, intellectual disability, speech and language disorders, epilepsy, and learning disorders (LD) were the most common types of developmental disabilities identified across all sites. Site-specific variations in prevalence were observed. The survey did not find difference in prevalence of developmental disabilities among boys and girls, urban and rural residence and by religion. The study identified several modifiable risk factors associated with developmental disabilities. These were home delivery, history of perinatal asphyxia and neonatal illness, post-natal brain infections, stunting, low birth weight/prematurity. The population attributable fraction was nearly 37% for these factors (Table 7.4).

A large body of work on developmental disabilities has been contributed by Nair and colleagues from the Child Development Centre, Kerala [11, 51]. Several culturally adapted, valid tools that could be used by community health workers have been developed. Using two such validated tools, the Trivandrum Developmental Screening Chart (TDSC) 0–3 and Language Evaluation Scale Trivandrum (LEST) 0–3, a survey of 32,664 children less than three years of age across the state of Kerala was conducted [49, 50]. Screened children were referred to pediatricians for re-evaluation. In this age group, the prevalence of developmental disability was 2.5%. Among 1110 children who were clinically evaluated, 69% had developmental delay, 14% had speech delay, 6% had global delay, 5% had gross motor delay, and 4% had hearing impairment.

Table 7.4 Prevalence of developmental disabilities (%) [2]

Description	Age group (years)	
	2-<6	6–9
Any neuro-developmental disorder	9.2	13.6
>1 neuro-developmental disorder	2.3	2.6
Visual impairment	0.7	0.6
Epilepsy	1.1	2.2
Neuro-motor impairment (NMI)-cerebral palsy	2.1	1.3
Hearing impairment	3.3	2.6
Speech/language	1.6	1.6
Autism spectrum disorder	1	1.4
Intellectual disability	3.1	5.2
Attention-deficit/hyperactivity disorder		1
Learning disabilities		1.6

Selected Conditions

Epilepsy

A recent systematic review and meta-analysis of 222 studies examined the prevalence and incidence of epilepsy globally. The point prevalence of active epilepsy was 6.38 per 1000 persons (95% CI 5.57–7.30), the lifetime prevalence was 7.60 per 1000 persons (95% CI 6.17–9.38). The incidence rate was 61.44 per 100,000 person-years (95% CI 50.75–74.38). The prevalence of epilepsy did not differ significantly by age group, sex, or study quality. Epilepsy prevalence was higher in low- to middle-income countries [20].

A systematic review of epilepsy prevalence in Europe identified that population-based epidemiological studies on epilepsy were available mainly from the UK and the Nordic, Baltic, and western Mediterranean countries. The study estimated 0.9 million cases (prevalence 4.5–5.0 per 1000) among children and adolescents, 1.9 million in ages 20–64 years (prevalence 6 per 1000), and 0.6 million in ages 65 years and older (prevalence 7 per 1000). The study reported that 20–30% of patients would have more than one seizure per month. The estimated number of new cases per year among European children and adolescents was 130,000 (incidence rate 70 per 100,000), 96,000 in adults 20–64 years (incidence rate 30 per 100,000), and 85,000 in the elderly 65 years and older (incidence 100 per 100,000) [22].

Several studies to estimate the prevalence of epilepsy in India have been conducted, but data quality are affected by issues of case definitions, sample size, data collection tools, research setting (i.e., urban versus rural), and the inclusion of acute symptomatic seizures (which is not epilepsy) [1]. A systematic review and meta-analysis of 20 studies estimated a prevalence of 5.34 per 1000 (4.25–6.41 per 1000) [64]. The estimated rural rate was 5.5 per 1000, and the urban rate was 5.1 per 1000. These estimates were similar to prevalence reports of other studies (Table 7.5). Incidence rates of epilepsy have varied between 0.2 and 0.6 per 1000 population. Although earlier studies had reported a higher prevalence of epilepsy among males, this gender difference has narrowed due to better care seeking among women [1].

Cerebral Palsy

Analysis of 49 global cerebral palsy prevalence studies conducted among children born between 1985 and 2011 reported a pooled prevalence of 2.11 per 1000 live births (95% CI 1.98–2.25) [55]. The pooled prevalence of cerebral palsy was associated with birth timing and weight, being highest in children weighing 1000–1499 g at birth (59.18 per 1000 live births, 95% CI 53.06–66.01), and among children born before 28 weeks of gestation (111.80 per 1000 live births, 95% CI 69.53–179.78). The study reported that the overall prevalence of cerebral palsy appeared to have remained constant, despite the increased survival of preterm and low or very low

Table 7.5 Selected Indian epilepsy prevalence studies

Studies	Prevalence	Region	Sample	Tool used
Mani et al. [42]	5.4 per 1000 (lifetime prevalence); 4.63/1000 active epilepsy prevalence	Rural population, Yelundar, Karnataka	64,963 individuals, house to house survey	Modified ICEBERG (International Community Based Epilepsy Research Group) screening instrument
Radhakrishnan et al. [57]	4.9 per 1000	Urban population, belonging to 10 panchayats of Thrissur, Palakkad and Malappuram districts, Kerala	238,102 population	Modified WHO screening questionnaire
Bangalore Urban Rural Neuro-Epidemiological Survey (BURNs) [27]	Overall—8.82 per 1000 5.8 per 1000 for urban 11.9 per 1000 for rural	Bangalore, Karnataka	102,572	Modified WHO protocol
Das and Biswas [13]	5.7 per 1000 for the	Urban population, Kolkata	52,377	NIMHANS screening questionnaire

birth weight infants. Himpens et al. [30] reported a prevalence of 1.13 per 1000 live births (95% CI 0.93–0.14) per 1000 in term born infants, and an increased cerebral palsy prevalence among infants born at 22–26 weeks of gestation (146 per 1000 live births , 95% CI 125–170). Hirtz et al. [31] reported the prevalence of cerebral palsy at 2.4 per 1000 live births. The prevalence in preterm births and in children with low birth weight (11.2 per 1000 live births) and very low birth weight (63.5 per 1000 live births) was higher than term born infants. Winter et al. [70] estimated the prevalence of cerebral palsy from the MADDS data. For the period between 1975 and 1991, the reported prevalence of cerebral palsy was 2.0 per 1000, showing a modest increase from 1.7 per 1000 in 1971, primarily among infants of normal birth weight. No change in prevalence was seen among low birth weight or very low birth weight infants. The prevalence was higher in boys, African-American children with normal birth weight and in white children with low birth weight. Spastic cerebral palsy was the most common subtype of cerebral palsy identified [70].

The challenge of estimating the prevalence of cerebral palsy in resource limited settings was reported in a systematic review of 20 studies. These studies were published between 1990 and 2009. The authors of the systematic review reported lack of appropriate study designs, case classifications and definitions. Most studies

were hospital, rather than population-based. Such methodological issues resulted in skewed prevalence rates of 31–160 per 1000. Pooled prevalence rates for India (2–2.8/1000) were however similar to data from Western countries [23].

An identical paucity of quality studies was observed by Chauhan et al. [8] in a systematic review and meta-analysis of studies on cerebral palsy in India. Globally, the prevalence of cerebral palsy ranges from 1.5 to 4 per 1000 births. The systematic review extracted eight community based studies of cerebral palsy prevalence in children aged 1–18 years in India. The studies were located in either rural or urban areas, or in both geographical locations, and included children of different ages . The studies used several different screening and diagnostic tools (INCLEN Diagnostic Tool for Neuro-Motor Impairments, Trivandrum Developmental Screening Chart (TDSC), Denver Developmental Screening Test (DDST), pre-tested Performa for Disabled Children, Lucknow Neurodevelopmental Screen (LNDS) and WHO questionnaire). The overall pooled prevalence was 2.95 (95% CI 2.03–3.88), with lower prevalence in rural areas (1.83; 95% CI 0.41–3.25) than urban areas (2.29; 95% CI 1.43–3.16).

Intellectual Disabilities

A systematic review of 52 studies conducted between 1980 and 2009 reported that the prevalence of IDs was 10.37 per 1000 [45]. The prevalence was higher among low- and middle-income countries and among children rather than adults. The estimates varied by country, income group, age group of the study population and the study design adopted. The authors noted the importance of using appropriate tools for measuring prevalence, as using psychological assessment tools yielded higher estimates when compared to those using standard diagnostic systems or disability assessment instruments. A more recent systematic review and meta-analysis of twenty two studies conducted between 2010 and 2015 identified the prevalence of ID between 0.05 and 1.55%. The authors reiterated that different methodological approaches, age groups and different case definitions were the key reason for differences in prevalence data [46].

The prevalence of intellectual disabilities in Indian studies is very heterogeneous. Studies have reported that the prevalence of intellectual disability varies by age, gender, urban versus rural residence, but study quality issues are associated with these findings [39]. Using national disability data published by the National Sample Survey 2002, the disability prevalence was 10.5 per 1000 population. ID prevalence was higher in urban than rural areas.

Autism Spectrum Disorders

Prevalence estimates of ASD are also challenged by methodological issues. Williams et al. [69] estimated that the prevalence of typical autism was 7.1 per 10,000 (95%

CI 1.6–30.6). The prevalence estimates varied by the diagnostic criteria used (ICD-10 or DSM-IV or others), age of children and study location. Elsabbagh et al. [17] reported the prevalence of ASD from a review of studies that spanned over a period of 50 years. The studies varied in terms of diagnostic category, criteria, age at prevalence evaluation, and geographical setting. These factors led to a large variation in prevalence, ranging from 0.19/1000 (for autistic disorder) to 11.6/1000 for PDD. Tsai [66] updated these data, finding nearly no difference in prevalence estimates (1.32/1000 for AD and 6.19/1000 for PDD/ASD). These estimates were further updated after 2014 [10]. This study concluded that there appeared to be increasing prevalence within regions, but methodological differences in case detection and study designs could have influenced the data. A systematic review of studies published from South Asia between 1962 and 2016 showed that the prevalence ranged from 0.09% in India to 1.07% in Sri Lanka. Three percent prevalence was reported from Dhaka. Prevalence studies from Pakistan, Nepal, Bhutan, Maldives, and Afghanistan were either unavailable, or not eligible for inclusion in the review [32].

A systematic review and meta-analysis of studies on ASD in India identified 195 records, of which four studies were included for determining the prevalence of ASD. However, the prevalence data were limited by study quality, especially the diagnostic tools used, and the sample size of the studies [9].

Attention-Deficit/Hyperactive Disorders

ADHD is difficult to diagnose, which influences prevalence estimates. A systematic review of 39 eligible studies conducted between 1992 and 2006 reported wide variation in prevalence from 2.2 to 17.8% [63]. The review identified a higher prevalence in boys as compared to girls, reduction in prevalence of ADHD by age, and lower prevalence among Asian children as compared to non-Hispanic, white children. The type of study tool, and the type of respondent that is parents or teachers, influenced prevalence data. A meta-analysis of 86 studies conducted between 1994 and 2010, all of which used DSM-IV reported that the pooled prevalence of ADHD ranged between 5.9 and 7.1% [68]. Another systematic review conducted in 2015 examined the pooled prevalence by DSM criteria, and by other factors such as informants, sampling frames, measurements, full versus part DSM criteria and regions on the prevalence of ADHD. There were 175 eligible studies which yielded a pooled estimate of 7.2% (95% CI 6.7–7.8). The study did not find any difference in prevalence between DSM editions used in data collection. The analysis also identified a 2% higher prevalence in the US as compared to studies done in Europe [65].

In India, a tool that can be used at the community level by clinicians has been developed and used to report data on ADHD from a systematically drawn sample. The prevalence of ADHD was 1% [2, 47].

Data from Global Burden of Disease Study

The Global Burden of Disease 2016, presented modeled estimates of the magnitude of epilepsy, intellectual disability, hearing loss, vision loss, ASD, and ADHD in children less than 5 years from 195 countries. The GBD estimated 53 million children with any of the six developmental disabilities, as compared to 52.9 million in 1990. Nearly, 94% (around 50 million) children lived in LMICs, while just 5% (2.7 million) were resident in high-income countries. The male-to-female proportions depended on the type of developmental disability, but was slightly higher (54%) among males. The most prevalent developmental disability was vision loss (26.4 million), followed by hearing loss which affected nearly 15 million children. Although the absolute numbers of children with hearing loss increased, the prevalence decreased between 1990 and 2016. ADHD was the least prevalent of all disabilities (890,229 cases). The years lived with disability (YLD) was the highest for intellectual disability, followed by epilepsy, hearing loss, vision loss, ASD, and ADHD. The GBD 2016 data estimated that the prevalence of developmental disabilities had increased in sub-Saharan Africa, North Africa, and Middle East. The highest prevalence of developmental disabilities was in South Asia, whereas the lowest prevalence was in North America [24].

India

The modeled estimates indicated that there were 11.5 million (11,560,118 (10,518,238–12,554,824)) cases of developmental disabilities in India in 2016, which was a small reduction from 1990 (10,524–10,308 cases per 100,000 population). India had the highest number of cases globally. By type, there were 800,000 cases of epilepsy, which constituted 42% of the estimated 1,979,233 cases occurring globally, over 800,000 cases of ASD which constituted 36% of 2,366,873 cases worldwide. There were an estimated three million cases of intellectual disability, which was 47% of 6,830,618 cases estimated worldwide. There were three and a half million individuals with hearing loss, and five million with vision loss, constituting 40% of 8,872,948 and 37% of 13,427,729 global cases. The proportion of ADHD cases (16%) was relatively lower (67,000 out of 429,470 cases). In both numbers of cases and YLDs, India was ranked first for all these conditions, with the exception of ADHD where it was ranked second after China. However, in terms of rates per 100,000 population, India was not among the top ten ranked nations, with the exception of intellectual disability (8th rank) and hearing loss (10th rank), globally. The highest YLDs were found in India for all disabilities except ADHD (Table 7.6).

Table 7.6 Prevalence of developmental disabilities in India in 2016 (with 95% uncertainty interval)

	Prevalence		YLD	
	Number	Rate	Number	Rate
Epilepsy	823,482.41 (657,410.91–1,058,323.00)	734.33 (586.24–943.75)	306,008.29 (217,777.39–439,166.06)	272.88 (194.20–391.62)
Intellectual disability	3,190,464.53 (2,523,762.73–3,872,888.30)	2845.06 (2250.53–3453.60)	395,583.05 (286,635.52–544,194.07)	352.76 (255.60–485.28)
Hearing loss	3,533,324.00 (3,096,058.16–4,026,636.56)	3150.80 (2760.87–3590.70)	232,015.36 (159,169.76–325,299.93)	206.90 (141.94–290.08)
Vision loss	5,097,650.84 (4,575,076.44–5,690,437.75)	4545.77 (4079.77–5074.38)	233,730.90 (154,052.91–360,515.41)	208.43 (137.37–321.49)
Autism spectrum disorder	850,811.93 (696,988.94–1,037,775.28)	758.70 (621.53–925.42)	114,372.85 (73,029.39–165,266.55)	101.99 (65.12–147.37)
Attention deficit hyperactivity disorder	66,937.19 (60,271.03–75,229.70)	59.69 (53.75–67.09)	802.50 (463.09–1273.98)	0.72 (0.41–1.14)

Conclusion

In conclusion, this review identifies a substantial number of children with developmental disabilities in the country. Table 7.7 compares the findings from the multicentric Indian study [2] with the period prevalence estimates reported from the USA [71]. The comparison shows that the prevalence of AHD and ASD were more or less similar, the prevalence of learning disability was markedly lower, but for all other developmental disabilities (vision impairment, cerebral palsy, hearing impairment and intellectual disability), the prevalence was notably higher in India. The GBD estimates that India is likely to harbor the highest number of children with developmental disabilities, and any specific type of developmental disability. The healthcare implications can be understood, as the GBD estimates over 3 million children with intellectual disability, 3.5 million, and 5 million children with hearing and vision loss in the country. The magnitude of developmental disabilities may contribute to the magnitude of childhood disabilities, captured in the Census 2011 data [54].

The high prevalence of developmental disabilities may be influenced by the higher prevalence of several well-documented maternal, environmental and healthcare system-related risk factors, identifying the need for a specific package of maternal health and health service-related interventions for these conditions. Developmental disabilities trends show negligible reduction over time [24] while at the same time, other common causes of neonatal and child mortality have reduced. Such trends imply that health services of LMICs including India are likely to be overwhelmed by the magnitude of these conditions. The functioning and quality of life of children with several types of developmental disabilities can be improved by early intervention (Chap. 13). At present, there is no developmental screening for children in India, although children discharged from neonatal intensive care unit

Table 7.7 Comparison of data on the prevalence of developmental disabilities

	India		The United States	GBD (India) (rate per 100,000)
	2-<6 (%)	6–9 (%)	<8 years (%)	<5
Attention-deficit/hyperactivity disorders		1	9	59.69
Autism spectrum disorders	1	1.6	1.74	758.7
Visual impairment	0.7		0.16	4545.7
Cerebral palsy	2.1	1.3	0.31	–
Hearing impairment	3.3	2.6	0.63	3150.8
Learning disorders	1.6		7.7	–
Intellectual disability	3.1	5.2	1.1	2845.0
Epilepsy	1.1	2.2	0.77	734.33

are supposed to be followed up by community health workers for a period of one year under the RBSK programme. Increasing parental awareness about developmental milestones, and appropriate child development and nurturing may increase the detection of developmental disabilities. Translation of knowledge into action has already been demonstrated through the extensive community based work done by the Child Development Centre, Kerala [52].

Estimation of prevalence of developmental disabilities brings to the fore the issue of screening tools. One of the major challenges of tools developed in industrialized countries is that they may not be culturally appropriate, and they may loose their psychometric properties after translation [2]. Another reality that is more pronounced in India is that there are 22 official, and a total of 121 languages in the country [54]. Several tools have been developed in India, but with the major focus on ensuring that they can be used by healthcare workers, many of them lack optimal psychometric properties. Developing context specific tools will help in early identification, referral and intervention which in turn will help to reduce the magnitude of developmental disabilities.

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