Birth Defects and Developmental Disabilities in India : Prevalence, mortality and disability data[1]

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Ansari, H. (2021). Magnitude of Developmental Disabilities in India. *Birth Defects in India*, (pp169-194). Springer, Singapore.
Chutke, A. (2021). Magnitude and Characteristics of Children with Congenital Disabilities in India. In *Birth Defects in India* (pp. 195-207). Springer, Singapore.

Index

1.0 Summary

Birth defects (congenital anomalies) and developmental disabilities are major causes of childhood disability and chronic medical conditions. Multidisciplinary public health interventions are needed to address these disorders. Data on prevalence, mortality and disability provide an insight into the magnitude of the problem, and the resource requirements for a birth defects service. This report summarizes available data on these conditions in India. ***The purpose of this document is to draw attention to the immediate need to invest in data collection, as existing evidence points to a significant magnitude of these disorders in the country.***

Surveillance systems typically provide data on congenital anomalies and developmental disabilities. In lieu of birth defects surveillance, research studies, systematic review and meta-analysis, and modelled estimates are the main sources of data in India.

From available studies, the congenital anomaly birth prevalence in India ranged between 184.48 per 10 000 births (95% CI 164.74-204.21) to 230.51 per 10,000 live births (95%CI 170.99-310.11). This translates into 472,177 to 530 208 affected pregnancies each year. Mortality data estimate between 82 000 to 99 000 deaths among children below five years of age. Between 1990 and 2017, congenital anomaly neonatal mortality has shown marginal decline. The proportion of congenital anomaly mortality had increased from 4.0% in 1990 to 7.9% in 2017.

A study on developmental disabilities in India identified that the prevalence of autism and attention deficit hyperactivity disorders were similar to that of the US. Learning disabilities were lower in prevalence, but intellectual disabilities, epilepsy, and hearing and vision impairment were markedly higher in India. Using data from the Global Burden of Disease 2016 study, developmental disabilities were estimated to affect 11 560 118 (10 518 238 to 12 554 824) children under the age of five years in India.

Congenital disability data are limited. A national, respondent-reported disability survey identified that 30% of disability in India is present since birth. Modelled data estimates that at age five years, selected congenital anomalies contribute to 150 000 disability survivors per birth cohort in India. A small cohort study identified that 70% of congenital anomalies were non-fatal and children survived with disabilities and/or medical complications.

The report identifies a scarcity of well designed, good quality studies. However, the implications of the available data are significant. They suggest that birth defects and developmental disabilities affect sizeable numbers of pregnancies, cause neonatal deaths, and are responsible for considerable numbers of children with congenital disabilities in India. The data points to urgently invest in data collection to understand the true magnitude of these conditions, in order to address unmet service needs.

2.0 India

India is the seventh largest nation in the world, covering 32,87,263 sq. km. The estimated population in 2019 was 1.3 billion, which is nearly one-fifth of the global population. There are 28 states and 8 Union Territories [1], further subdivided into 718 districts, 5564 sub-districts, 7935 towns/municipalities, and 640 867 villages[2]. The population density is 464 persons per square kilometre. The enormity of public health responsibility is reflected in the magnitude of the population to be served[2].

https://www.mapsofindia.com/maps/india/india-political-map.htm

2.1 Health system characteristics

Data collection on disease and health events is complicated by the health system structure in India.

- The government health system stretches across the country and is primarily a rural service. It caters to 30% of the population from the lower socio-economic strata. However, usage of certain services is higher (for example, 52% of births occur at government facilities)[3].
- There are 25 650 Primary Health Centres (PHC) that supervise 156 231 community- based Sub-Centres that provide primary health care services. Community level data are routinely collected and reported by these units to the district health organization, from where they are collated at state level and forwarded for compilation into national statistics[2].
- Private sector large and small hospitals and private medical practitioners provide health care to 70% of the population. There is no compulsory reporting of disease data from these health care providers and facilities. There is no mechanism at present for reporting a malformed birth, or a child with a birth defect or developmental disability to any reporting system.
- This ‘mixed’ health system structure is further complicated by multiple systems of medicine. There are large numbers of practitioners from traditional and complementary systems of medicine (AYUSH, Ayurveda, yoga and naturopathy, unani, siddha and homeopathy). These systems of medicine have their own methods of disease diagnosis, categorization and treatment. There is no compulsory reporting of data from these practitioners.

3.0 Congenital anomalies (Birth defects) : Sources of data [4}

Prevalence data : Birth prevalence[2] data are available from different hospital-based cross-sectional studies, and a single cohort study. Population prevalence[3] data are available from limited community-based cross-sectional studies, and infrequently from the RBSK (Rashtriya Bal Swasthya Karyakram) child screening service. Estimated data on the magnitude of congenital anomalies are available from the Modell Global Database of Congenital Disorders (MGDb).

Mortality data : are available from several cause specific child mortality estimates.

Disability data : Estimated data on congenital disability caused by selected birth defects is available from the MGDb, a cohort study and a national disability survey.

3.1 Birth Prevalence of Congenital Anomalies

Different sources of data report birth prevalence of congenital anomalies between 184.48 to 230.51 per 10 000 births implying that there may be 472,177 to 530 208 affected births in the country each year (Table 1). Due to a paucity of data, it is difficult to decipher the prevalence by type of malformation.

Table 1 Prevalence of congenital anomalies

	Method	Measure	Rate	Absolute number
Birth prevalence	Systematic review and meta-analysis [5]	Total births, pooled prevalence	184.48 per 10 000 births (95% CI 164.74-204.21)	472,177
	Systematic review and meta-analysis[5]	Live births, hospital-based, pooled prevalence	203.33 per 10,000 live births (95% CI 171.32–235.34)	
Birth prevalence	Modell Global Database of Congenital Disorders[6]	total affected stillbirths and live births	20.83 per 1000	540 421
Birth prevalence	Cohort study[7]	Total births (live births, stillbirths, elective termination of pregnancy for foetal malformation)	230.51 per 10,000 births (95%CI 170.99-310.11)	530 208

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[2] Birth prevalence of congenital anomalies are the number of congenital anomaly affected newborns per 1000 population.

[3] Population prevalence reports the number of individuals with congenital anomalies resident in a population. Birth prevalence may be higher than population prevalence among younger children due to the high mortality associated with severe birth defects. On the other hand, if prevalence is measured at later ages (for example among children at 15 years of age), the population prevalence may be higher than the birth prevalence due to cumulative cohorts of surviving children.

Population prevalence	Systematic review and meta-analysis[5]	Live births, pooled prevalence	261.05 per 10 000 live births (95% CI 199.13–322.96)	

3.2 Population prevalence

RBSK data

Data on birth defects and developmental delays and disabilities are infrequently reported by the Rashtriya Bal Swasthya Karyakram, a child screening and early intervention programme. The service screens children between the ages of 2 to 18 years, attending government schools and playgroups (anganwadis) for selected birth defects and developmental disabilities (Table 2).

Screening data indicate that over 1% prevalence of birth defects among beneficiaries of the screening programme[8]. Data from the period 2015-16 indicate that among 187 million children screened, 300 000 were detected with birth defects, and 19 00 000 with developmental delays and disabilities[3].

Table 2 RBSK : Birth defects, and developmental disabilities included under the screening and intervention services

Birth defects	Developmental delays and disabilities
Congenital heart defects	Vision impairment
Down syndrome	Hearing impairment
Cleft lip and palate	Neuro-motor impairment
Talipes	Motor delay
Neural tube defects	Cognitive delay
Developmental dysplasia of hip	Language delay
Congenital cataract	Behavior disorder
Congenital deafness	Attention deficit hyperactivity disorder
Retinopathy of prematurity	
Where prevalent	
Congenital hypothyroidism, sickle cell anemia, thalassemia	

3.3 Mortality

Congenital anomaly mortality data are available from various studies[3].

- The Million Death Study reported a congenital anomaly neonatal mortality rate of 1.1 per 1000 livebirths. The study used verbal autopsy to elicit mortality data among 1.3 million randomly selected households[9].
- Another study estimated 71 802 (Uncertainty Interval (UI) 56 681-92 640) congenital anomaly neonatal deaths, and 28 035 (UI 21 820-33 777) deaths in the age group of 1 – 59 months[10].
- According to these estimates, in 2015, congenital anomalies were the fourth major cause of death, accounting for 10% of mortality, after prematurity (44%), intra-partum complications (19%), sepsis/meningitis (14%). Congenital anomalies were the fourth largest cause of child deaths in the 1-59 month age group (31% mortality due to pneumonia, 21% due to diarrhoea, 7% due to injuries, and 6% due to congenital anomalies).
- In regions of the country that had achieved the rate of <25 deaths per 1000 live births in children below five years of age, the leading causes were preterm birth complications (26.4%), followed by congenital anomalies (17.1%).
- The India State Level Disease Burden Initiative study on child mortality reported that the percentage of neonatal deaths due to congenital anomalies in the early and late neonatal periods were 8.2 (UI 7.1-9.4) and 10.1 (UI 8.8-11.2) respectively [11].
- This study also reported congenital anomalies as the fourth leading cause of neonatal deaths.

- Another study reported that 16% (82,436 out of 501,764) of global birth defect deaths among children younger than 5 years of age and 21% (37,104 out of 174,420) of global birth defect deaths in the early neonatal period occurred in India [12].
- Congenital anomaly deaths in the early neonatal period were nearly seven times that of high SDI countries, and double that of high-middle SDI countries (82,436 versus 42,205).
- The proportion of congenital anomaly mortality among all causes of mortality had increased from 4.0% in 1990 to 7.9% in 2017. This increasing *proportion* of deaths from birth defects could be explained by reduction in mortality from other major causes of mortality.

4.0 Developmental disabilities

4.1 Sources of data

Several screening and diagnostic tools for developmental disabilities have been developed and validated in India. However, understanding of the data is challenged by lack of stringency in study methodologies[13].

4.2 Prevalence

A recent multicentre study that used validated screening and diagnostic tools reported that the prevalence of neurodevelopmental disorders (visual impairment, epilepsy, cerebral palsy, hearing impairment, speech language impairment, autism spectrum disorders, intellectual disability, Attention Deficit Hyperactivity disorder and learning disabilities) was 12% (95% CI 11.0-13.0%) [14] .

Modelled estimates from the Global Burden of Disease 2016 data indicated that there were 11.5 million (11 560 118 (10 518 238 -12 554 824) cases of developmental disabilities in India in 2016 (10 308·6 (9379·5 to 11 195·6) cases per 100 000 population). There were 800 000 cases of epilepsy (42% of the global burden) and ASD (36% of global cases), and 3 million cases of intellectual disability (47% of global cases estimated worldwide). For all disabilities, India had the highest number of affected children, except for ADHD, The highest YLDs for all disabilities except ADHD were found in India (739·0 (555·3 to 957·5) YLDs per 100 000 population) [15].

5.0 Congenital disability

Data on congenital disability are limited[16]. One study identified that 70% of congenital anomaly affected neonates were live born (congenital anomaly live born rate 168.44 per 10 000 births) [7]. The MGDb is the only source that estimates survivors with disability. The data predicts over 150 000 survivors with congenital disability at five years of age per birth cohort in India.The data however estimates disability caused by selected congenital anomalies only.

The National Sample Survey, a nationwide disability survey covering 1172.86 million individuals across the country reported 2.2% prevalence of persons with disability (25.802 million). The proportion of individuals with disability since birth was 30% (approximately 7.74 million). Among the different types of disabilities, 88% of speech, 85% of multiple disability, 78% of cognitive and 63% of visual impairments was of congenital origin[17].

6.0 Concluding statement

There is a scarcity of well-designed studies on congenital anomalies and developmental disabilities in India. While there is data on congenital anomaly mortality, systematically conducted birth and population prevalence data are limited. Limited number of studies on prevalence of developmental disabilities are available. Data on congenital disability, or disability survivors among birth cohorts are scarce. The data reiterates the need to invest in data collection on congenital anomalies and developmental disabilities, and on the magnitude of childhood disability, in order to design a planned birth defects service with components of prevention, surveillance, medical care and rehabilitation and parent counseling and support.

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