## **Research Article**



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# Prevalence of Disability in Children and Adolescents in India, 2011

## Abstract

*Background:* Child disability is an emerging global health priority. There is lack of statebased analysis of all types of disabilities in children and adolescents in India.

*Objective:* To measure the prevalence of disability and describe the types of disability by gender, advancing age, states and geographical regions in Indian population aged 19 years and below.

*Methods:* Disability data restricted to age 19 years and below of the 2011 Census of India was analyzed. Disability rates per 100,000 children and adolescent population and age-adjusted disability rates were calculated.

*Results:* Disability rate of 1640 per 100,000 was observed in those aged 19 years and below in India in 2011. Nine Indian states and Union Territories had disability rates above the national average. Of the total disability, hearing, seeing and movement related disabilities were 20, 18 and 13% respectively. Disability rates increased with the advancement of age; highest disability rate of 1926 per 100,000 in those aged 10 to 19 years. Males had higher disability rates compared to females (1754 vs. 1516 per 100,000). The disability rates were higher in urban than in rural areas (1805 vs. 1582 per 100,000).

*Conclusion:* There was 1.6% of those aged 19 years and below in India with either physical or mental disability. Further studies on the underlying causes and prevention strategies are essential to reduce the burden of disability in the population aged 19 years and below.

### Introduction

Disability is an umbrella term for impairments, activity limitations, and participation restrictions according to the International Classification of Functioning, Disability and Health (ICF).<sup>1</sup> Childhood (0-14 years) disability in 2004 was estimated to be 95 million (5.1%) children, of whom 0.7% had severe disability.<sup>2</sup> However, this global estimate is essentially speculative being derived from data of quality, which too varied due to lack of consistency in definitions of disability used across studies.<sup>3</sup> Measuring child disability is challenging since children develop and learn to perform basic tasks at different speeds, it can be difficult to assess function and distinguish significant limitations from variations in normal development.<sup>4</sup> International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) includes body structures, body functions, limitations on activity and restrictions on participation.<sup>5</sup> Disability is an important source of vulnerability among children, mainly in developing countries due to shortage in health services, insufficient training of health services providers, lack of community education programs and limited rehabilitation services.<sup>6</sup> There is a need to quantify the burden of disability since this information is essential for the government to allocate adequate resources, plan policies and implement appropriate programs for persons with disability. Community-based cross-sectional studies on prevalence of disability among children in India are limited.<sup>6-8</sup>

Information on physical and mental disability in India, is documented during the census survey once in every 10 years and during periodic surveys by National Sample Survey Organization (NSSO). There is lack of publication on disability among children and adolescents in India which focuses on state-based analysis of all types of disabilities.

The objective of this analysis was to measure the prevalence of disability and describe the types of disability in children and adolescent (aged  $\leq$ 19 years) Indian population, based on the data on disabilities available in the public domain under the Census 2011 database. We also estimated the distribution of disabilities by gender, age, states and geographical regions.

### Methodology

This article is based on analysis of the 2011 census data of India. The census questionnaire had three questions with reference to disability. They captured information on (1) presence of mental or physical disability (Yes-1; No-2); (2) the disability type seeing-1, hearing-2, speech-3, movement-4, mental retardation-5, mental illness-6, any other-7, multiple disability-8; and (3) multiple disability (maximum of 3 disabilities). <sup>9</sup> The definitions used for various types of disabilities and the procedures to collect the information are outlined in the manual of disability statistics.<sup>9</sup>

### **Data Analysis**

Disability rates per 100,000 population were calculated. The numerators were number of disabled persons by type of disability and age, gender, type of residence (rural/urban)-C20 table (India and States/UTs District level).<sup>10</sup> The denominators were extracted from C14 Table of Census 2011. This table provides information on the number of people in the Indian population in various age groups with a 5-yearly interval starting from 0-4 years, up to 75-79 years and 85+ years.<sup>11</sup> In addition, information on residence (rural/ urban) and gender was used. Data were obtained for age groups 19 years and below for the analysis above mentioned C20 and C14 tables.

Age-adjusted disability rates by direct standardization method using 2011 population of India aged 19 years and below as the standard population were used for comparison of the Indian states and Union Territories with respect to each type of disability. The data was analyzed using Microsoft Excel Windows 2007. ArcGIS Desktop: Release 10. Redlands, CA: ESRI, Inc. 2011 was used to represent geographical distribution of disability rates in different states of India.

### Results

A total of 78,62,921 of population aged 19 years and below were disabled in India in 2011 accounting for a disability rate of 1640 per 100,000 children and adolescent population (1.6%) (2011 Indian  $\leq$ 19 years population-479356778].

The disability rates in hearing (323 per 100,000), seeing (286 per 100,000 each), movement (212 per 100,000) and due to other causes (349 per 100,000) were high. Disability rates associated with speech, multiple disability, mental retardation and mental illness were 139, 138, 121 and 28 per 100,000 respectively.

Hearing accounted for nearly 20%, seeing 18% and movement 13% of the total disability burden. In addition, multiple disability and disability in speech constituted 9% each, mental retardation 8% and mental illness 2% of the total disability respectively. The remaining 22% of the disability was due to other causes.

# Disability Rates in Indian States and Union Territories

The disability rates in the Indian states and union territories are shown in Figure 1 and Table 1. Of the total of 35 states and Union territories, the disability rates in 9 states and union territories were above the national average of 1640 per 100,000 population and ranged from 1728 to 2036 per 100,000 population. Maharashtra, Odisha and Jammu and Kashmir states reported the highest disability rates of 2036, 2007 and 1879 per 100,000 population respectively. Mizoram and the union territory of Daman and Diu had the lowest disability rates of 820 and 614 per 100,000 population respectively.

Disability in seeing, hearing, speech and movement was highest in Manipur (615 per 100,000), Bihar (473 per 100,000), Maharashtra (290 per 100,000) and Chattisgarh (308 per 100,000) respectively. Mental retardation, mental illness and multiple disability was highest in Puducherry (238 per 100,000), Jammu and Kashmir (67 per 100,000) and Lakshwadeep (345 per 100,000) respectively (Table 1).



Figure 1.Age Standardized Disability Rates per 100000 in the Age Group <19 Years in the Indian States and Union territories, India 2011

# Disability Rates by Age, Gender and Type of Residence

The disability rates in the age group 19 years and below were higher in males compared to females (1754 vs. 1516 per 100,000) and higher in urban areas compared to rural areas (1805 vs. 1582 per 100,000). The disability rates in males and females in rural areas were 1702 vs. 1452 per 100,000 respectively compared to 1902 vs. 1698 per 100,000 in urban areas.

Analysis of disabilities by age (categorized as 0 to 4 years, 5 to 9 years and 10 to 19 years), gender and type of residence (urban/rural) has been presented in Table 2. Disability rates increased as age advanced with the highest disability rate of 1926 per 100,000 in the age group 10 to 19 years. Disability rates were higher in males and there was an urban preponderance across different age groups.

S. No.	State/ Union	Seeing	Hearing	Speech	Movement	Mental Retardation	Mental Illness	Multiple Disability
1	Jammu and Kashmir	333	393	143	224	107	67	222
2	Himachal Pradesh	181	191	107	144	125	32	178
3	Punjab	204	442	86	195	153	37	132
4	Chandigarh	135	174	86	175	127	51	135
5	Uttarakhand	151	250	102	175	100	31	143
6	Haryana	167	353	85	181	114	38	137
7	Delhi	110	142	89	159	105	40	131
8	Rajasthan	216	176	93	193	108	28	138
9	Uttar Pradesh	283	439	114	201	80	25	84
10	Bihar	442	473	144	242	75	23	92
11	Sikkim	181	354	132	143	58	35	160
12	Arunachal Pradesh	269	402	84	121	80	22	91
13	Nagaland	109	238	79	93	36	19	80
14	Manipur	615	299	83	87	127	20	89
15	Mizoram	123	133	76	90	94	40	121
16	Tripura	152	190	121	169	84	32	148

# Table 1.Age-Standardized Disability Rates per 100000 in the Indian States and Union Territories According to Type of Disability in the Age Group <19 Years, 2011

17	Meghalaya	163	327	86	133	62	50	104
18	Assam	151	217	114	126	59	22	98
19	West Bengal	295	245	155	188	126	41	184
20	Jharkhand	427	383	137	228	104	33	138
21	Odisha	402	392	156	265	178	37	221
22	Chattisgarh	236	177	109	308	126	38	192
23	Madhya	243	267	91	262	95	31	134
	Pradesh							
24	Gujarat	258	218	99	185	129	35	126
25	Daman and Diu	98	91	61	106	72	25	82
26	Dadra and	84	152	64	112	74	18	194
	Nagar Haveli							
27	Maharashtra	408	321	290	231	181	20	150
28	Andhra Pradesh	255	276	213	256	170	29	212
29	Karnataka	316	314	163	257	174	16	184
30	Goa	160	229	249	106	144	46	130
31	Lakshadweep	316	261	86	227	217	0	345
32	Kerala	129	178	103	139	190	16	201
33	Tamil Nadu	107	220	104	159	182	10	141
34	Puducherry	129	240	117	222	238	15	148
35	Andaman and	113	184	163	186	81	64	195
	Nicobar							
	India	286	323	139	212	121	28	138

Table 2.Age, Gender and Geographic Differences in Disability Rates in the Age Group <19 Years in India, 2011

		Age 0 to 4 Years		Age 5 t	o 9 Years	Age 10 to 19 Years		
		(Total = 1	12,782,125)	(Total = 12	26,896,264)	(Total = 239,678,389)		
Site	Gender	Total	Total Rate per		Rate per	Total	Rate per	
		disabled	100,000	disabled	100,000	disabled	100,000	
Rural	Male	485464	1128	785355	1609	1853297	2018	
	Female	422118	1057	633227	1408	1411006	1662	
	Total	907582	1094	1418582	1513	3264303	1847	
Urban	Male	204887	1314	296243	1695	756877	2289	
	Female	178863	1257	240714	1539	594870	1992	
	Total	383750	1287	536957	1621	1351747	2148	
Total	Male	690351	1178	1081598	1632	2610174	2090	
	Female	600981	1110	873941	1442	2005876	1748	
	Total	1291332	1145	1955539	1541	4616050	1926	

# Types of Disability by Basic Demographic Variables

Disability rates associated with different types of disabilities increased as age advanced (Table 3). Disability in hearing was the highest across different age groups-1 to 4 years (280 per 100,000), 5 to 9 years (320 per 100,000) and 10 to 19 years (364 per 100,000). Seeing related disability was 246, 283 and 323 per 100,000 in the age group 0 to 4 years, 5 to 9 years and 10 to 19 years respectively.

Disability rates by age, gender and type of residence according to the type of disability are summarized in Table 4. Disability associated with hearing had an urban preponderance across all age categories and was higher in females in the (261 vs. 259 per 100,000) and urban (339 vs. 330 per 100,000) areas respectively in age group 0 to 4 years. The disability related to movement and multiple disabilities showed a male and rural preponderance in all age categories. Disability associated with seeing, speech, mental retardation and mental illness was higher in males with urban preponderance across all age categories.

### Table 3.Age Differences in Disability Rates According to the Type of Disability in the Age Group <19 Years in India, 2011

Types of Disability	Age 0 to 4 Years		Age 5 to (Total = 12	9 Years	Age 10 to 19 Years (Total = 239 678 389)		
	Total Per 100000		Total	Per 100000	Total	Per 100000	
	Disabled		disabled		disabled		
Movement	117326	104	210662	166	717668	299	
Seeing	277006	246	359118	283	774034	323	
Hearing	315485	280	406281	320	872483	364	
Speech	32461	29	212818	168	438423	183	
Mental Retardation	49361	44	135709	107	410019	171	
Mental Illness	8352	7	26240	21	101189	42	
Multiple Disability	78651	70	187477	148	412313	172	
Any Other	412690	366	417234	329	889921	371	

# Table 4.Disability Rates by Age, Gender and Type of Residence (Urban/Rural) According to the Type of Disability in the Age Group <19 Years in India, 2011

Type of Disability	Site	Gender	Age 0 to 4 years		Age 5 to	9 Years	Age 10 to 19 Years	
			(Total = 112,782,125)		(Total = 126	,896,264)	(Total = 239	,678,389)
			Total	Rate	Total	Rate	Total	Rate
			Disabled	per	Disabled	per	Disabled	per
				100000		100000		100000
Movement	Rural	Total	92288	111	165889	177	559775	317
		Male	53864	125	100358	206	345813	377
		Female	38424	96	65531	146	213962	252
	Urban	Total	25038	84	44773	135	157893	251
		Male	14646	94	26860	154	96898	293
		Female	10392	73	17913	114	60995	204
Seeing	Rural	Total	191232	231	255232	272	528037	299
		Male	99344	231	135614	278	287549	313
		Female	91888	230	119918	266	240488	283
	Urban	Total	85774	288	103886	314	245997	391
		Male	45153	290	55790	319	133898	405
		Female	40621	286	48096	307	112099	375
Hearing	Rural	Total	215744	260	286320	305	590580	334
		Male	111458	259	149788	307	941	345
		Female	104286	261	136582	304	273639	322
	Urban	Total	99741	334	119961	362	281903	448
		Male	51531	330	63241	362	149868	453
		Female	48210	339	56720	363	132035	442
Speech	Rural	Total	22964	28	154916	165	307981	174
		Male	12788	30	88496	181	176006	192
		Female	10176	25	66420	148	131975	155
	Urban	Total	9497	32	57902	175	130442	207
		Male	5270	34	32330	185	72509	219
		Female	4227	30	25572	163	57933	194
Mental retardation	Rural	Total	33558	40	98882	105	289205	164
		Male	18347	43	57363	118	168256	183
		Female	15211	38	41519	92	120949	142
	Urban	Total	15803	53	36827	111	120814	192
		Male	8796	56	21648	124	71191	215
		Female	7007	49	15179	97	49623	166
Mental illness	Rural	Total	5689	7	19164	20	72218	41

		Male	3315	8	11437	23	41947	46
		Female	2374	6	7727	17	30271	36
	Urban	Total	2663	9	7076	21	28971	46
		Male	1545	10	4242	24	17228	52
		Female	1118	8	2834	18	11743	39
Multiple Disability	Rural	Total	59141	71	140526	150	301372	171
		Male	34187	79	83754	172	179179	195
		Female	24954	62	56772	126	122200	144
	Urban	Total	19510	65	46951	142	110941	176
		Male	11163	72	27756	159	65714	199
		Female	8347	59	19195	123	45227	151

#### Discussion

Our analysis showed that nearly one in every sixty children aged 19 years and less (1640 per 100,000 children) is either physically or mentally disabled based on the data of census survey of 2011. The disability rate for the age group 0-4 years, 5-9 years, 10-19 years observed in our analysis is higher compared to the 2002 NSSO survey with 1145 vs. 523, 1541 vs.1167 and 1926 vs. 1549 (10-14 years), 1748 (15-19 years) per 100,000 respectively.<sup>12</sup> In a multi-centric study in India, the prevalence of disability among children below 6 years of age was found to be 8.8, 6.5 and 12.5 per 1000 in Delhi, Jaipur and Lucknow respectively.<sup>6</sup>

The National Health Interview Survey (NHIS) data of United States showed that the overall rate of disability for non-institutionalized children <18 years old had increased 15.6% between 2001 and 2002 and 2010 and 2011.<sup>13</sup> A cross-sectional survey including 907,734 children aged 0-17 across 30 countries in 2012 reported prevalence of disability ranging from 0.4%-3.0%.<sup>14</sup> A median 23% (range 3-48) of children screening positive for disability among 191,199 children aged 2-9 years in 18 countries.<sup>15</sup> The variations in the prevalence of disability across studies could be attributed to the case definitions used and the survey methodologies.

Disability among children aged 19 years and less was more common in the urban compared to rural areas in our analysis. The reasons for geographical variations in the distribution of disability which is observed in our analysis need to be explored further to generate evidence for designing locally relevant interventions. The disability rates were higher in male children and adolescents compared to females in our analysis. Prevalence of disability was reported to be 1.3-1.4 fold higher in boys than girls among children aged 0-17 years in 22 of the 30 countries assessed.<sup>14</sup> Further research is warranted for gender differences in disability in children and adolescents. The main type of disability in children aged 19 years and less was associated with hearing, seeing and movement in our analysis. An earlier study in India documented locomotor-, hearing- and speech-related disability to be higher among children below 6 years of age.<sup>6</sup> Hearing impairment in children had global prevalence; estimates ranged from 0.4 to 19.7% and visual impairment between 0.1 and 12.5%.<sup>16</sup> Common etiologies for hearing impairment reported in a review from Sub-Saharan African countries in children were meningitis, measles, maternal rubella, febrile illnesses, and genetic causes; there was a large proportion of unknown etiology.<sup>17</sup> The 2002 NSSO survey identified ear discharge, injury other than burns, noise-induced, German measles as reasons for hearing-related disability; sore eyes, cataract, glaucoma, corneal opacity, other eye diseases, injury other than burns for low vision and blindness; polio, injury other than burns, stroke, cerebral palsy, leprosy cured for locomotor disability. However these reasons were general and not specific to children.<sup>18</sup> Maternal malnutrition can affect the development of the fetus, cause intra-uterine growth delay and increase the risk of the infant developing impairments.<sup>19</sup> Infants and young children who are underweight and stunted are more likely to screen positive for disability.<sup>15</sup> Understanding the causes of disability in children is important to plan appropriate preventive strategies and research is essential in this arena.

Mental retardation since birth was reported to be higher in rural than in urban. This is a matter of concern and warrants further research for reasons pertaining to disability in the intra-uterine period. Major reasons for mental retardation or mental illness identified in the 2002 NSSO survey included serious illness or head injury during childhood, pregnancy and birth related effects and hereditary disorders.<sup>18</sup> A multi-country crosssectional survey in children aged 3-9 years reported high severe mental retardation in India (40.3 in 1000) with mild mental retardation being 18 in 1000. Further, the study documented causes of mental retardation as genetic and prenatal.<sup>20</sup>

Survey in selected countries showed that children from poorer households and those in ethnic minority groups are at significantly higher risk of disability than other children.<sup>4</sup> Economically disadvantaged children with highest rates of disability and economically advantaged children with greater increases in disability have been documented in a study from the United States.<sup>13</sup> A study in India documented prevalence of serious disability in children 2-9 years to be more common among children of the lowest-class families (17.2% vs. 8.4%).<sup>8</sup> We could not document disability according to socio-economic status in our analysis due to non-availability of data in the public domain.

The greatest strengths of the census survey include its implementation through universal reach and use of standardized protocols in data collection. However, there are certain limitations due to non-response. In addition, the possibility of under-reporting might result due to inability to capture the complex and sensitive information related to disability in limited number of questions of the census questionnaire. Current burden of disability could be estimated by applying appropriate statistical modeling to the census data of 2011.

In India, the national programs on mental health, prevention and control of deafness and blindness control have to play a major role in providing preventive, curative and rehabilitative services to reduce the burden of disability in their areas of operation. The launching of Rashtriya Bal Swasthya Karyakram (RBSK) is a national program for screening, diagnosis and treatment of neuro-developmental disorders (NDD)s is an initiative to address diseases and deficiencies in addition to defects and disability.<sup>21</sup> The program managers have to address the barriers to healthcare, rehabilitation, education, support and assistance services and create enabling environments.<sup>2</sup>

Child disability is an emerging global health priority.<sup>15</sup> Our analysis has shown that the prevalence of disability rates in adults and adolescents in one-third of the Indian states varies between 2036 and 1748 per 100,000. Disability in children entails a range of immediate and long-term economic costs that have important implications for the well-being of the child, the family, and society.<sup>22</sup> Better understanding of underlying causes and implementing preventive strategies will help reduce the burden of disability in adults and adolescents.

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