

Chapter 8

Magnitude and Characteristics of Children with Congenital Disabilities in India



Amruta Chutke

Abstract Non-fatal birth defects and developmental disorders cause congenital disabilities, that is disabilities that are present since birth. There is limited data on the number of survivors with congenital disabilities in India. This article describes the magnitude and characteristics of children with congenital disabilities in the country. It uses data from the National Sample Survey (NSS) 2002. The survey collected data on the time of onset of disability, which provided an opportunity to categorize disability as congenital, that is disability since birth, or acquired, that is disability that occurred later in life. The data indicated that 58% of disabilities among children below 18 years of age were of congenital origin. Among the different types of disabilities, 88% of speech, 85% of multiple, 78% of cognitive, and 63% of visual impairments were of congenital origin. Congenital disability prevalence was four-fold higher at birth as compared to acquired disability and achieved its highest prevalence in the age group of 15–19 years. The impact of congenital disability was considerable, as the person-years lived with disability since birth was nearly double than that due to acquired causes. Severity of disability was more among children born with disabilities. These data suggest the need for further research, and the need to link disability services to maternal and child health services in order to address the needs of children born with disabilities.

Keywords Children with disability · Congenital · Acquired · Birth defects · Vision disorders · Hearing disorders · Speech disorders

This article describes the magnitude and the socio-demographic profile of children with congenital disabilities in India. Childhood disability may be acquired, caused by injuries, chronic conditions like cancer, infections such as poliomyelitis and leprosy [1], vitamin deficiencies causing rickets or blindness, poor nutrition, poverty, and lack of access to needed medical care and rehabilitation [2, 3]. Congenital disability, that is disability since birth, results from a diverse group of congenital disorders, collectively termed birth defects and developmental disabilities. Examples include common

A. Chutke (✉)

Department of Community Medicine, Bharati Vidyapeeth DTU Medical College, Pune, India

childhood conditions like cerebral palsy, cleft palate, congenital deafness, congenital cataract, intellectual disabilities, spina bifida, and congenital talipes equinovarus.

Congenital disabilities are highly incapacitating conditions, causing cognitive, speech, hearing, vision, and locomotor impairments [4]. They have serious public health implications as children have special medical and rehabilitation needs, majority of which are lifelong in nature [5]. Children require special education and skills to ensure participation in society [6]. Congenital disorders contribute to considerable number of Years Lived with Disability (YLD) [7–10]. Families confront substantial economic burden [11]. Thus, living with disabilities since birth has several health, social and economic consequences for individuals and families, especially in resource-constrained settings where organized disability services are not in place.

Disability data are primarily available from high-income countries [12–15]. The overall magnitude of children with disabilities (CWD) is not well characterized in low and middle-income countries (LMICs). Available data suggest that disability disproportionately affects children in these countries. The World Health Organization enumerated that nearly 80% of the 100–200 million children living with disability worldwide were from LMICs [16]. The report estimated 93 million (5.1%) children below 14 years of age with moderate disability and 13 million (0.7%) children with severe disability in 2004. These estimates indicated that there may be 1.86 billion disabled children below 15 years of age in 2010. The World Bank review of 13 LMICs identified a wide range of disability prevalence, ranging from 0.49 to 3.2% among school-going children [17]. A cross-sectional survey of 900,000 children aged 0–17 years from 30 countries participating in the Plan International Sponsorship Programme in 2012 estimated the prevalence of disability in the range of 0.4–3% [18].

There is even less data on children born with congenital disabilities (CWCD). Among available studies, a study from rural Pakistan reported disability prevalence in children less than two years of age was 5.5 out of 1000, while the prevalence was 5.4 out of 1000 for children between two to five years of age. Almost 56% of disability was present since birth and cerebral palsy was the most common disability among children under five years of age [19]. Another study conducted in rural Cambodia reported 40% of caregivers recalled that disability was present since birth [20]. A study done in Rwanda identified that more than one-third of musculoskeletal impairments were due to congenital deformity and neurological causes [21]. A study in Ethiopia identified a smaller proportion (15%) of individuals reporting disability during infancy, with 5.7% describing the cause of disability to be congenital [22]. An Indian study from the state of Gujarat showed that 60% of individuals had disability during infancy [23]. A 30-country study reported that about 80–90% of speech, multiple and cognitive disabilities was present since birth [18]. Another study from Uttar Pradesh, India reported that speech disability was primarily of congenital origin [24].

Data on birth defects and developmental disability survivors is an extremely important child health indicator, as these children require appropriate services. Global data shows that epidemiological transition has resulted in a shift in the major causes

of childhood morbidity and mortality and emergence of chronic and disabling conditions of childhood [25–28]. As health service activities improve survival of premature and low birth weight infants, the likelihood of survival with developmental disabilities increase. With decrease in other causes of neonatal mortality (such as prematurity, intrapartum complications, and neonatal sepsis), the visibility of birth defects as contributors to child mortality will increase. Modell and colleagues offer an indicator, the ratio of increase in disability to proportion of congenital disorder deaths [29]. This is an important indicator for service planning, as disability survivors have to be provided appropriate services. It is also an indicator that identifies the need for interventions to prevent these conditions.

In India, disability statistics are available from the decadal Census [30] and from the National Sample Surveys (NSS) [31, 32]. The decadal Census enumerates the total Indian population and collects disability data through a single question to measure the magnitude of disability in the country. Disability is categorized as impairment in vision, hearing, speech, and movement, and mental retardation, mental illness, and multiple disabilities. Additionally, the National Sample Survey Office (NSSO) has conducted two disability surveys in the last two decades. The NSS 58th round (2002) [31] and the 76th round (2018) [32] measured household, socio-demographic, and disability characteristics from a nationally representative stratified sample of individuals across the country.

The NSS is the only source from which data on congenital disability may be obtained, as it includes a question on the time of onset of disability. The data is respondent reported, and not further validated with other records. The time of onset of disability provides the opportunity to categorize children into two groups, those born with disabilities (congenital disability) and those who acquired the disability later in life (acquired disability). The NSS collected data on the severity of disability, self-care, treatment received, and education, providing an insight into the lives of affected children. This article describes the epidemiology of children with disabilities (CWD) and children with congenital disabilities (CWCD) under 18 years of age in India.

A note of caution on the absolute numbers in this article is warranted. The data are from the period 2002 as disaggregated data from the 2018 survey was not available at the time of writing. Furthermore, despite the similarity in categorization of disability types between the Census and the NSS data sets, there are substantial differences in prevalence estimates, mainly due to differences in the definitions used in these two surveys [33]. Nevertheless, the NSS data provide an insight into the characteristics of CWCD in India.

Magnitude of CWD

The magnitude of disability across all age groups in India is reflected in the sheer number of disabled persons in the country. The NSS in 2002 estimated 18.49 million (1.80%) disabled individuals. Disabled children made up 1.14% that is 5.27 million

Table 8.1 Disability prevalence by residence and gender

Residence	Numbers in 00,000 (%)		
	Male	Female	Total
Rural	25.36	16.15	41.51 (79%)
Urban	6.56	4.66	11.22 (21%)
Total	31.92 (61%)	20.81 (39%)	52.73

children with disability under 18 years of age in the country. Nearly 0.5% (that is 0.54 million) children under five years of age were estimated to be disabled. Disability was a larger problem in rural areas, with 75% children with disabilities (over 4 million) being resident in rural areas (Table 8.1). Disability was higher in boys (about 3.2 million, 61%) than girls (2 million, 39%) (Table 8.1).

Prevalence of Childhood Disability by Type of Disability

The disability rate for children below 18 years of age was 114 per 10,000 children. The rates were highest for locomotor disability (66 per 10,000), followed by multiple disability (16 per 10,000), cognitive disability (12 per 10,000), speech (10 per 10,000), and hearing and visual impairments (5 each per 10,000) (Table 8.2).

Table 8.2 Age-specific prevalence of childhood disabled by type of disability

Type of disability	Childhood disability prevalence (per 10,000) and absolute numbers (in 0000)	Childhood congenital disability prevalence (per 10,000) and absolute numbers (in 0000)	Childhood acquired disability prevalence (per 10,000) and absolute numbers (in 0000)	Rate ratio (95% CI) (congenital/acquired disability rate)
Cognitive	11 (45.89)	8 (35.88)	2 (10.01)	3.58 (3.56–3.61)*
Visual	5 (2.18)	3 (1.37)	2 (0.81)	1.7 (1.68–1.71)*
Hearing	5 (2.09)	2 (0.94)	3 (1.15)	0.82 (0.81–0.82)*
Speech	10 (4.32)	9 (3.79)	1 (0.52)	7.26 (7.20–7.33)*
Locomotor	63 (26.52)	28 (11.71)	35 (14.81)	0.79 (0.79–0.79)*
Multiple	16 (6.64)	13 (5.61)	2 (1.03)	5.47 (5.43–5.50)*
Total	110 (46.33)	64 (27.01)	46 (19.32)	1.4 (1.40–1.40)*

**p* value <0.05

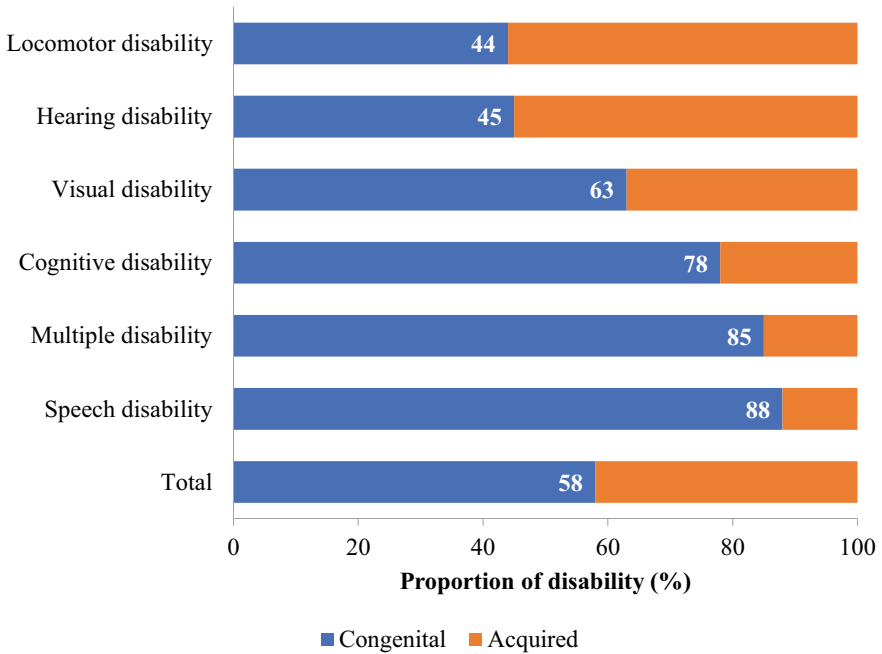


Fig. 8.1 Proportion of disability since birth

Magnitude of CWCD

The data indicated that 58% of children were 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 (Table 8.2). The data indicated that 88% of speech disability, 85% of multiple disability, 78% of cognitive disability, 63% of visual disability, 45% of hearing, and 44% of locomotor disability were reported to have been present since birth (Fig. 8.1).

The rate ratio of congenital to acquired disability was significantly higher for speech, multiple, cognitive, and visual disability ($RR > 1, p < 0.05$) indicating these conditions to be more likely among children due to congenital disorders. Hearing and locomotor disability were more likely to be acquired ($RR < 1, p < 0.05$) (Table 8.2).

Age-Specific Prevalence Per 10,000

Figure 8.2 shows the age-specific prevalence of childhood congenital and acquired disability. As compared to acquired disability, congenital disability was four-fold higher (39 vs. 9 per 10,000) among children under five years of age, and achieved highest prevalence in the age group of 15–19 years (77 vs. 66 per 10,000). After the

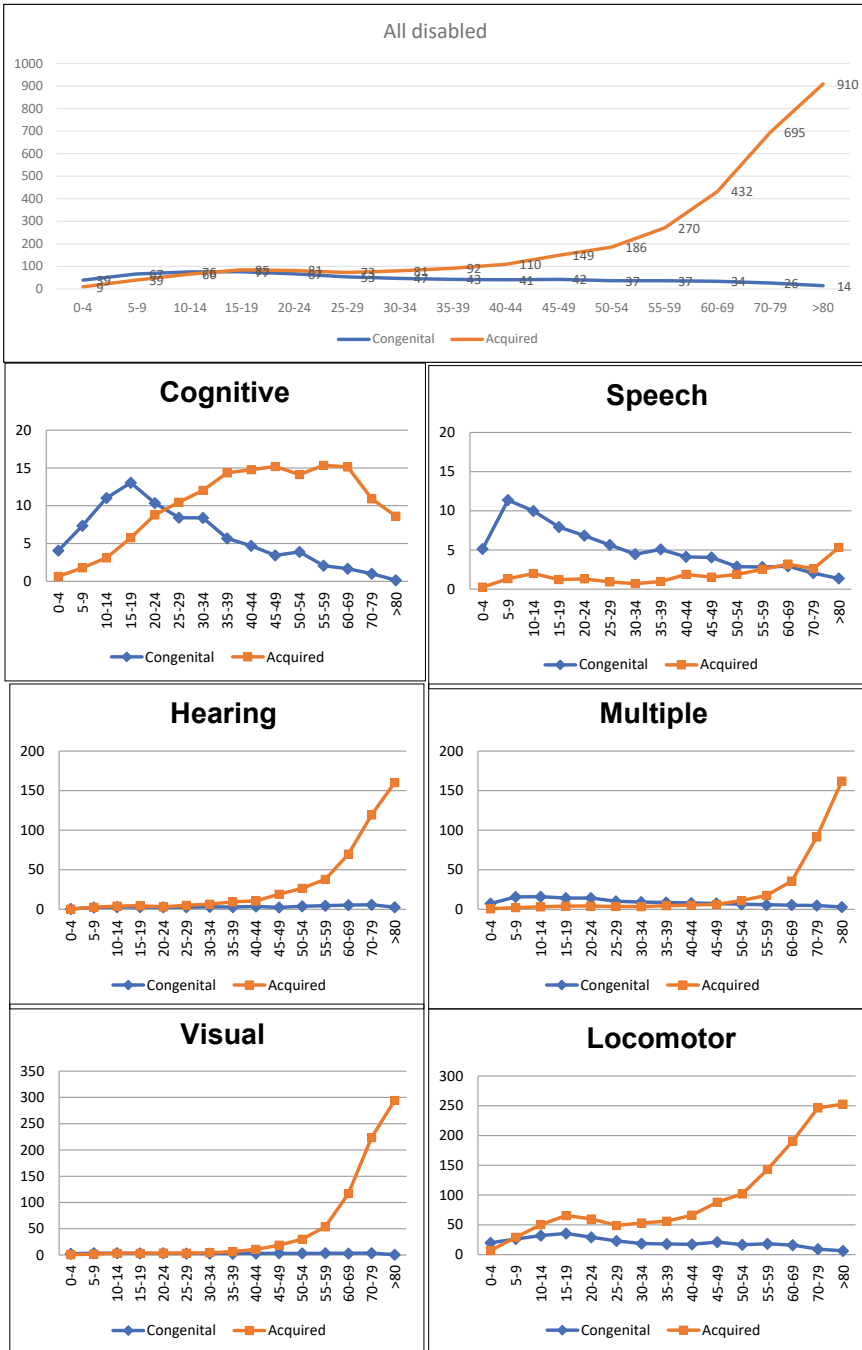


Fig. 8.2 Age-specific prevalence by disability type. X-axis indicates age groups and Y-axis indicates rate per 10,000 population.

age of 19 years, congenital disability rates declined (67 vs. 81 per 10,000), reflecting reduced survival of CWCD.

Congenital locomotor disability prevalence was highest in the age group of 15–19 years (35 per 10,000), and remained as high as 16 per 10,000 till the age group of 60–69 years (Fig. 8.2). The next highest prevalence was for multiple disability, which had the highest prevalence in the age group of 5–9 years (16 per 10,000). The prevalence of congenital speech disability and cognitive impairment were similar. Congenital speech impairment was highest in the age group of 5–9 years (11 per 10,000), while cognitive impairment was the highest in the age group of 15–19 years (13 per 10,000). Congenital visual impairment rate was highest in the age group of 5–9 years (4 per 10,000) but the age-specific hearing impairment prevalence remained more or less constant (around 3 per 10,000) over age groups (Fig. 8.2).

Duration of Disability

The mean age years lived with congenital disability was significantly higher (10.05 years, 95% CI 10.04–10.06) than that of children with acquired disability (7.66 years, 95% CI 7.66–7.67) ($p < 0.001$) (Table 8.3). The person-years lived with congenital disability was 27.15 million which was nearly double than that of childhood disability due to acquired causes (14.80 million). The person-years lived with congenital disability was highest for locomotor disability (11.62 million), followed by multiple disability (5.52 million), cognitive impairment (3.90 million), speech disability (3.74 million), visual impairment (1.33 million), and hearing impairment

Table 8.3 Years lived with disability

Type of disability	Acquired disability		Congenital disability		P value
	Mean number of years lived with disability (95% CI)	Person-years lived	Mean number of years lived with disability (95% CI)	Person-years lived	
Cognitive	7.14 (7.10–7.17)	0.71	10.87 (10.85–10.89)	3.90	*0.0001
Visual	6.02 (6.00–6.05)	0.49	9.69 (9.66–9.73)	1.33	*0.0001
Hearing	6.11 (6.08–6.14)	0.70	11.08 (11.03–11.12)	1.04	*0.0001
Speech	6.87 (6.83–6.92)	3.74	9.87 (9.85–9.89)	3.74	*0.0001
Locomotor	7.96 (7.96–7.97)	11.79	9.92 (9.91–9.93)	11.62	*0.0001
Multiple	7.25 (7.22–7.27)	0.74	9.84 (9.83–9.86)	5.52	*0.0001
Total	7.66 (7.66–7.67)	14.80	10.05 (10.04–10.06)	27.15	*0.0001

* $p < 0.001$

(1.04 million). The person-years lived with speech and locomotor disability due to congenital or acquired cause was almost similar (Table 8.3).

Characteristics of CWCD

Table 8.4 shows that CWCD were more likely to report higher proportion of parental consanguinity (17% and 12% among CWCD and acquired disability respectively), belong to families with smaller household size, and appear to have more than one child with a congenital disability. CWCD were more likely to be male, uneducated, belong to socially deprived groups (scheduled castes, other backward castes), and among families with lower average monthly expenditure.

Severity of Disability

Disability appeared more severe in CWCD. Table 8.5 shows that the risk of no perception to light was nearly double in CWCD as compared to those with acquired disability (61% congenital to 48% acquired). Children who were unable to speak were fifteen times more likely to have been born with this impairment (31% vs. 14%). The risk of being able to communicate in single words was nine times higher among children with congenital disabilities. Children born with communication impairments had a seven times higher risk of speaking unintelligibly, four times higher risk of stammering, had nearly six times increased risk of speaking with abnormal voice as compared to children reporting acquiring this disability. The risk of profound hearing impairment was two and a half times elevated for congenital disability (30% vs. 10%). Locomotor disability due to acquired causes was higher, but the proportion of limb deformity was higher among CWCD (64% vs. 58%).

Self-care and Utilization of Services

Another reflection of the severity of congenital disability was the dependence on others for self-care. The proportion was significantly higher (17.5%) among CWCD as compared to children with acquired disability (9.37%) (Table 8.6). A higher proportion of CWCD (25.8%) was without treatment as compared to children with acquired disabilities (9.76%). In the sample, 11.78% CWCD had not tried an aid/appliance or the aid/appliance was not available as compared to 8.9% of children with acquired disabilities. However, less than 1% of CWCD and even lower proportions of children with acquired disabilities were enrolled in special schools.

Table 8.4 Characteristics of CWCD

	Characteristics	Congenital <i>n</i> in 00,000 (%)	Acquired <i>n</i> in 00,000 (%)	OR (95% CI)
i	<i>Sex</i>			
	Male	15.83 (58.61)	11.82 (61.22)	*1.12 (1.11–1.12)
	Female	11.18 (41.39)	7.49 (38.78)	Ref
ii	<i>Place of residence</i>			
	Rural	21.28 (78.78)	15.33 (79.36)	*1.04 (1.03–1.04)
	Urban	5.73 (21.22)	3.99 (20.64)	Ref
iii	<i>Social group</i>			
	Schedule tribe	2.34 (8.67)	1.38 (7.17)	*0.95 (0.94–0.95)
	Schedule caste	6.09 (22.55)	4.71 (24.37)	*1.24 (1.23–1.24)
	Other backward castes	11.08 (41.01)	8.53 (44.18)	*1.23 (1.23–1.24)
	Others	7.50 (27.77)	4.69 (24.28)	Ref
iv	<i>Consanguinity</i>			
	Yes	4.38 (17.01)	2.32 (12.43)	*0.69 (0.69–0.70)
	No	21.34 (82.99)	16.38 (87.57)	Ref
v	<i>Household size</i>			
	1–4 members	6.93 (25.65)	3.51 (18.16)	Ref
	5–9 members	17.35 (64.21)	13.49 (69.83)	*1.54 (1.53–1.54)
	Members 10+	2.74 (10.13)	2.32 (12.01)	*1.67 (1.66–1.69)
vi	<i>Education of the individual (6–17 years)</i>			
	No education	34.14 (61.14)	63.61 (53.79)	*0.60 (0.59–0.60)
	Primary	17.94 (32.12)	42.88 (36.26)	*0.77 (0.76–0.77)
	Secondary and higher	3.76 (6.74)	11.76 (9.95)	Ref
vii	<i>Average monthly expenditure</i>			
	Low (<4000)	23.38 (86.54)	16.68 (86.38)	*1.43 (1.40–1.45)
	Middle (4000–8000)	3.22 (11.92)	2.42 (12.54)	*1.50 (1.48–1.53)
	High (>8000)	0.41 (1.54)	0.21 (1.08)	Ref
viii	<i>No. of disabled children in the household</i>			
	1	23.04 (85.27)	17.10 (88.53)	Ref
	2	3.30 (12.22)	2.02 (10.45)	*2.54 (2.50–2.58)
	≥3	0.68 (2.51)	0.20 (1.03)	*2.09 (2.06–2.13)

**p* < 0.001

Table 8.5 Severity of disability

Severity of physical disability (<i>n</i> in 0000)	Disabled children		
	Prevalence for congenital disability per 100,000 (<i>n</i> in 0000)	Prevalence for acquired disability per 100,000 (<i>n</i> in 0000)	Rate ratio (congenital to acquired)
<i>Visual disability n = 21.66</i>			
No light perception	1.96 (8.29)	0.90 (3.80)	*2.18 (2.15–2.21)
Light perception, cannot count fingers upto 1 m, normally uses spectacles	0.17 (0.71)	0.17 (0.70)	1.01 (0.98–1.05)
Cannot count fingers upto 1 m, normally does not use spectacles	0.53 (2.26)	0.34 (1.42)	*1.59 (1.56–1.62)
Cannot count 1–3 m, use spectacles	0.16 (0.67)	0.17 (0.73)	*0.92 (0.89–0.95)
Cannot count 1–3 m, do not use spectacles	0.42 (1.77)	0.31 (1.30)	*1.36 (1.33–1.39)
<i>Speech disability n = 43.08</i>			
Cannot speak	2.79 (11.79)	0.17 (0.74)	*15.98 (15.61–16.37)
Speak single words	1.81 (7.63)	0.20 (0.84)	*9.12 (8.92–9.33)
Speak unintelligibly	1.61 (6.81)	0.23 (0.95)	*7.14 (6.99–7.30)
Stammers	1.77 (7.49)	0.44 (1.85)	*4.04 (3.97–4.10)
Speaks with abnormal voice	0.62 (2.61)	0.11 (0.45)	*5.77 (5.59–5.95)
Others	0.36 (1.54)	0.09 (0.37)	*4.13 (3.99–4.29)

(continued)

Conclusions

In conclusion, the NSS survey provides an opportunity to understand the magnitude and quality of survival of children born with disabilities in India. The data suggests that 58% of disability among children below the age of 18 years was caused by congenital causes. The numbers of CWCD increased due to accrual of birth cohorts till the end of the first decade of life, or during the first half of the second decade of life. Subsequently, the prevalence declined, implying higher mortality at these ages. As reported in other studies, CWCD were likely not to have received treatment, nor were children enrolled in schools [34, 35]. One of the major impacts of disability was that the person-years lived with disabilities were nearly two-fold higher in children with congenital disabilities, not necessarily because the children lived longer, but because the onset of disability was since birth.

Table 8.5 (continued)

Severity of physical disability (<i>n</i> in 0000)	Disabled children		
	Prevalence for congenital disability per 100,000 (<i>n</i> in 0000)	Prevalence for acquired disability per 100,000 (<i>n</i> in 0000)	Rate ratio (congenital to acquired)
<i>Hearing disability n = 20.89</i>			
Profound	0.66 (2.78)	0.27 (1.12)	*2.48 (2.42–2.53)
Severe	0.89 (3.76)	1.26 (5.33)	*0.71 (0.70–0.72)
Moderate	0.68 (2.87)	1.19 (5.03)	*0.57 (0.56–0.58)
<i>Locomotor disability n = 202.36</i>			
Paralysis	2.34 (9.91)	4.44 (18.75)	*0.53 (0.52–0.53)
Deformity of limb	17.76 (75.10)	20.16 (85.25)	*0.88 (0.88–0.88)
Loss of limb	1.00 (4.22)	1.84 (7.80)	*0.54 (0.53–0.55)
Dysfunction of limb joints	4.02 (17.02)	5.33 (22.55)	*0.75 (0.75–0.76)
Others	2.55 (10.78)	3.15 (13.31)	*0.81 (0.80–0.82)

n—number of disabled children

**p* value <0.05

Table 8.6 Self-care and service utilization

Characteristics <i>n</i> (in 00,000)	Congenital <i>n</i> (in 00,000) (%)	Acquired <i>n</i> (in 00,000) (%)	OR
<i>Extent of disability n = 42.30</i>			
Cannot take self-care even with aid/appliance	4.26 (17.5)	1.73 (9.37)	*0.46 (0.46–0.46)
Can take self-care with only aid/appliance	2.43 (10.17)	2.28 (12.37)	*1.06 (1.05–1.06)
Aid/appliance not tried/not available	2.81 (11.78)	1.64 (8.90)	*0.66 (0.65–0.66)
Can take self-care without aid/appliance	14.38 (60.20)	12.77 (69.36)	Ref
<i>Services for disabled children n = 46.33</i>			
Attending special school	0.15 (0.57)	0.02 (0.10)	*0.14 (0.13–0.14)
No treatment	6.97 (25.80)	1.89 (9.76)	*0.30 (0.30–0.30)
Yes: undergoing treatment: consulting doctor	1.85 (6.85)	0.11 (5.81)	*0.67 (0.66–0.67)
Yes: taken: otherwise	1.01 (3.73)	0.84 (4.33)	*0.91 (0.91–0.92)
Yes: taken: consulting doctor	17.03 (63.05)	15.45 (80.01)	Ref

**p* < 0.001

The data has some limitations, including definitions, categorization, and validation of respondent reported information. The survey data cannot be compared with the Census disability data. Issues related to stigma, lack of diagnosis, poor awareness, and perception of disability may contribute to non-reporting of disability and underestimation [33]. Despite these limitations, the data remains an invaluable source of information on the lives of children born with disabilities. The use of standard definitions, tools such as the UN Washington Group on Disability Statistics Short Set questions [34], which can yield globally comparable data would be effective in further enhancing the quality, applicability, and utility of the data.

References

1. Narang T, Kumar B (2019) Leprosy in children. *Indian J Paediatr Dermatol* 20(1):12–24
2. Groce NE, Kerac M, Farkas A, Schultink W, Bieler RB (2013) Inclusive nutrition for children and adults with disabilities. *Lancet Glob Health* 1(4):e180–e181
3. DeCesaro A, Hemmeter J (2009) Unmet health care needs and medical out-of-pocket expenses of SSI children. *J Vocat Rehabil* 30(3):177–199
4. Perrin EC, Cole CH, Frank DA, Glick SR, Guerina N, Petit K et al (2003) Criteria for determining disability in infants and children: failure to thrive. *Evid Rep Technol Assess (Summ)* 72:1
5. Boulet SL, Boyle CA, Schieve LA (2009) Health care use and health and functional impact of developmental disabilities among US children, 1997–2005. *Arch Pediatr Adolesc Med* 163(1):19–26
6. Imms C, Reilly S, Carlin J, Dodd K (2008) Diversity of participation in children with cerebral palsy. *Dev Med Child Neurol* 50(5):363–369
7. Vos T, Allen C, Arora M, Barber RM, Bhutta ZA, Brown A et al (2016) Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet* 388(10053):1545–1602
8. Higashi H, Barendregt JJ, Kassebaum NJ, Weiser TG, Bickler SW, Vos T (2015) The burden of selected congenital anomalies amenable to surgery in low and middle-income regions: cleft lip and palate, congenital heart anomalies and neural tube defects. *Arch Dis Child* 100(3):233–238
9. McKenna MT, Michaud CM, Murray CJ, Marks JS (2005) Assessing the burden of disease in the United States using disability-adjusted life years. *Am J Prev Med* 28(5):415–423
10. Groce NE (2018) Global disability: an emerging issue. *Lancet Glob Health* 6(7):e724–e725
11. Gupta VB (2007) Comparison of parenting stress in different developmental disabilities. *J Dev Phys Disabil* 19(4):417–425
12. McDermott V. Disability in the United Kingdom 2016 facts and figures. Papworth Trust. Available at <https://www.papworthtrust.org.uk/about-us/publications/papworth-trust-disability-facts-and-figures-2018.pdf>. Accessed 13 Aug 2020
13. Madden R, Collins P (2004) Children with disabilities in Australia. Australian Institute of Health and Welfare, Canberra. Available at <https://www.aihw.gov.au/getmedia/a792fd34-61db-4f62-91f8-9aa8e41f8207/cda.pdf.aspx?inline=true>. Accessed 13 Aug 2020
14. Blackburn CM, Spencer NJ, Read JM (2010) Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey. *BMC Pediatr* 10(1):21
15. Banks J, Maître B, McCoy S (2015) Insights into the lives of children with disabilities: findings from the 2006 National Disability Survey. Economic and Social Research Institute (ESRI). Available at <https://www.esri.ie/system/files?file=media/file-uploads/2015-08/BKMNEXT274.pdf>. Accessed 13 Aug 2020

16. World Health Organization (2011) World report on disability 2011. World Health Organization. Available at https://www.who.int/disabilities/world_report/2011/en/index.html. Accessed 25 Mar 2018
17. Filmer D (2008) Disability, poverty, and schooling in developing countries: results from 14 household surveys. *World Bank Econ Rev* 22(1):141–163
18. Kuper H, Monteath-van Dok A, Wing K, Danquah L, Evans J, Zuurmond M et al (2014) The impact of disability on the lives of children; cross-sectional data including 8,900 children with disabilities and 898,834 children without disabilities across 30 countries. *PLoS ONE* 9(9):e107300
19. Ibrahim SH, Bhutta ZA (2013) Prevalence of early childhood disability in a rural district of Sind, Pakistan. *Dev Med Child Neurol* 55(4):357–363
20. VanLeit B, Channa S, Rithy P (2007) Children with disabilities in rural Cambodia: an examination of functional status and implications for service delivery. *Asia Pac Disabil Rehabil J* 18(2):33–48
21. Rischewski D, Kuper H, Atijosan O, Simms V, Jofret-Bonet M, Foster A et al (2008) Poverty and musculoskeletal impairment in Rwanda. *Trans R Soc Trop Med Hyg* 102(6):608–617
22. Fitaw Y, Boersma JM (2006) Prevalence and impact of disability in north-western Ethiopia. *Disabil Rehabil* 28(15):949–953
23. Morris A, Sharma G, Sonpal D (2005) Working towards inclusion: experiences with disability and PRA. General section, 5. Available at <https://pubs.iied.org/pdfs/G02138.pdf>. Accessed 13 Aug 2020
24. Srivastava DK, Khan JA, Pandey S, Pillai DS, Bhavsar AB (2014) Awareness and utilization of rehabilitation services among physically disabled people of rural population of a district of Uttar Pradesh, India. *Int J Med Sci Public Health* 3:1157–1160
25. Liu L, Oza S, Hogan D, Perin J, Rudan I, Lawn JE et al (2015) Global, regional, and national causes of child mortality in 2000–13, with projections to inform post-2015 priorities: an updated systematic analysis. *Lancet* 385(9966):430–440
26. Were WM, Daelmans B, Bhutta Z, Duke T, Bahl R, Boschi-Pinto C et al (2015) Children’s health priorities and interventions. *BMJ* 351:h4300
27. Santosa A, Wall S, Fottrell E, Högberg U, Byass P (2014) The development and experience of epidemiological transition theory over four decades: a systematic review. *Glob Health Action* 7(1):23574
28. Perrin JM, Anderson LE, Van Cleave J (2014) The rise in chronic conditions among infants, children, and youth can be met with continued health system innovations. *Health Aff* 33(12):2099–2105
29. Modell B, Darlison MW, Malherbe H, Moorithie S, Blencowe H, Mahaini R et al (2018) Congenital disorders: epidemiological methods for answering calls for action. *J Community Genet* 9:335–340
30. Office of the Registrar General & Census Commissioner, India. Ministry of Home Affairs, Government of India. Census 2011. Available at <https://censusindia.gov.in>. Accessed 25 Mar 2018
31. National Sample Survey Organization, Ministry of Statistics and Programme Implementation, Government of India (2002) Disabled persons in India NSS 58th round (July–December 2002). Available at <https://mospi.nic.in/nssso>. Accessed 25 Mar 2018
32. Ministry of Statistics and Programme Implementation (2018) Persons with disabilities in India NSS 76th round, July to August 2018. Available at https://www.mospi.gov.in/sites/default/files/publication_reports/Report_583_Final_0.pdf. Accessed 26 May 2020
33. Mitra S, Sambamoorthi U (2006) Measurement of disability: disability estimates in India—what the census and NSS tell us. *Econ Polit Wkly* 41(38):23–29
34. Madans JH, Loeb ME, Altman BM (2011) Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. *BMC Public Health* 11(Suppl 4):S4
35. Human Resources and Skill Development, Canada (HRSDC) (2011) Disability in Canada: a 2006 profile. Available at https://www.hrsdc.gc.ca/eng/disability_issues/reports/disability_profile/2011/index.html. Accessed 15 May 2017