

Tribal Odisha Eye Disease Study (TOES). Report # 10. Disability inclusive eye health survey in a tribal district (Rayagada) in Odisha, India

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Purpose: To estimate seeing and other disabilities in a population cohort in a tribal district, Rayagada, in the Indian state of Orissa. **Methods:** A door-to-door survey was conducted to identify the disabilities. The vision was measured at the residence of the subject, and other disabilities were documented from the history obtained from the subject/household/neighbor. All people with seeing disabilities were reexamined in the community eye center (primary or secondary), and required treatment was given at no cost to the patients. People with other disabilities were transported to the public health facility for appropriate care and disability certification. The results were compared with the 2011 national census data. **Results:** A total of 147,699 people were enumerated, and 106,339 (72%) were examined over one year period, 2016–17. In this cohort, 47.3% (n = 50,320) were male and 27.5% (n = 29,215) were 40 years or older. We recorded systemic disease in 0.6% (n = 689) people; hypertension was two times higher than diabetes mellitus. Disability was identified in 2.8% (n = 3022). Common disabilities were seeing (46.7%; n = 1411), hearing (36.8%; n = 1112), mobility (10.4%; n = 315), and mental retardation (3.2%; n = 98). Dual sensory disability (seeing and hearing) was seen in 6.4% (n = 251), and it was higher in the older age group. Seeing and hearing disabilities were higher than the 2011 state ($P < 0.001$) and national ($P < 0.001$) disability census. **Conclusion:** The first population-based survey in Rayagada, Odisha (India) in 2017 showed a higher proportion of people with seeing and hearing disabilities. It calls for an appropriate service strategy.

Key words: Disability, India, Odisha, Rayagada, tribal

Disability is any impairment that causes restriction or lack of ability to perform an activity considered normal for human beings. It is an umbrella term for impairments, activity limitations, and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and an individual's contextual factors (environmental and personal).^[1] The preamble to the United Nations Convention on the Rights of Persons with Disability (UNCRPD) acknowledges that disability results from the interaction between persons with impairment and the attitudinal and environmental barriers that hinder full and effective participation in the society on an equal basis with others.^[2] The International Classification of Functional Disability (ICF) has classified disability into six broad functional domains: Seeing, Hearing, Walking, Cognition, Mobility, Self-care, and Communication.^[3] The World Health Organization (WHO) estimates that over one billion people live with some form of disability globally. This is about 15% of the world's population. Moreover, up to 3.8% (190 million) of people aged 15 years and older have significant difficulties in functioning, often requiring

healthcare services.^[4] Most people with disabilities also live in poverty.^[5] The WHO *Global Disability Action plan 2014–2021* calls the Member States to remove the barriers and improve access to health services and programs, strengthen and extend rehabilitation, provide assistive devices and support services, design community-based rehabilitation, enhance the collection of relevant and internationally comparable data on disability, and allocate required resources for research on disability and related services.^[6] Inclusion of disability is considered a priority within the 2030 Sustainable Development Goals (SDGs).^[7]

In 2011, 26.8 million people in India (2.2% of India's population) had some form of disability (2011 national census).^[8] The common disabilities were movement (20%), seeing (19%), and hearing (19%). In the Indian state of Odisha (eastern India), an estimated 1.24 million people had a disability in the 2011 census; this was 2.86% of Odisha's population (Odisha's population was 41.97 million in 2011), and 4.64% of all disabled people in India. People with disabilities suffer from social and cultural exclusion and stigmas that result in denial of economic, social, and human development. These

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lead to deficits, reduced participation in decision-making and denial of civil and political rights.

With this background, we conducted a disability-inclusive eye care survey at Rayagada, a predominantly tribal district of Odisha state. The project aimed at covering 100,000 population in the catchment area of the community (secondary) eye care center of the host organization. The objective of the project was to identify people with disabilities, provide direct care to the people with seeing disabilities, and facilitate care for other disabilities through the public health system.

Methods

The study analyzed the information collected in 2016–17 from a door-to-door survey and people examined in the fixed primary and secondary eye care facilities. All eye examinations were performed after informed written consent. The study was approved by the institute’s review board (LEC BHR-R-05-21-658). The study adhered to the tenets of the Declaration of Helsinki. The study location was confined to the block of Rayagada (administrative unit in Indian districts that consists of several village councils [Panchayats]). Community health workers (CHWs) were recruited from the local community. The Comprehensive Community Eye Care and Community Based Rehabilitation Program methodologies were adopted^[9] [Fig. 1]. Briefly, it was door-to-door survey of the identified area to measure vision, record other self-reported disabilities at home, and transport the people identified with a disability to the eye (people with seeing disability) and other health facilities (people with other disabilities) for further examination and care.

Training. The training of the CHWs was held in the host’s secondary eye care facility (Community Eye Hospital) at Rayagada by experts with experience in training personnel in the community survey. In the 2-day session, the 15 CHWs

were trained for basic communication skills, elements of the household survey, documentation of persons with disabilities of any kind, (including seeing disabilities), and finally, facilitate transportation of people with disabilities to the nearest health care facilities as and when required.

Planning of survey. Before initiating the door-to-door survey, the survey coordinator and CHW met the president and other key opinion leaders in the village council (Panchayat). They explained the purpose of the project and its medical/social benefits. It was agreed to obtain verbal consent for screening at the house level and signed consent when the people with disabilities are examined in the hospitals.

Door-to-door survey. Survey of households in a predetermined village/area would start from a fixed point of the village, the first house of the left lane; the right lane houses were approached only when the left lane was covered. When the houses were not organized in the streets, it was agreed to start the survey from the left side. A family was considered as one when they cooked meals in one kitchen.

A survey format was used to collect the demographic information, household information, socioeconomic status of the entire household, and overall health status of every member of the house. The survey collected known disabilities (seeing and others). The CHWs interviewed the senior adults available at home. The survey included the screening of both eyes of all individuals; record of self-reported systemic conditions such as hypertension, diabetes, asthma, and others (cardiac, renal, arthritis); use of medications for controlling these conditions; and inquiry of any recent health check-up. The information on different disabilities was collected from the household member and neighbors when someone was less willing to share.

Visual acuity test procedure for screening. Presenting visual acuity (PVA) was tested for each individual separately. It was done outside the house in adequate daylight. Distance visual

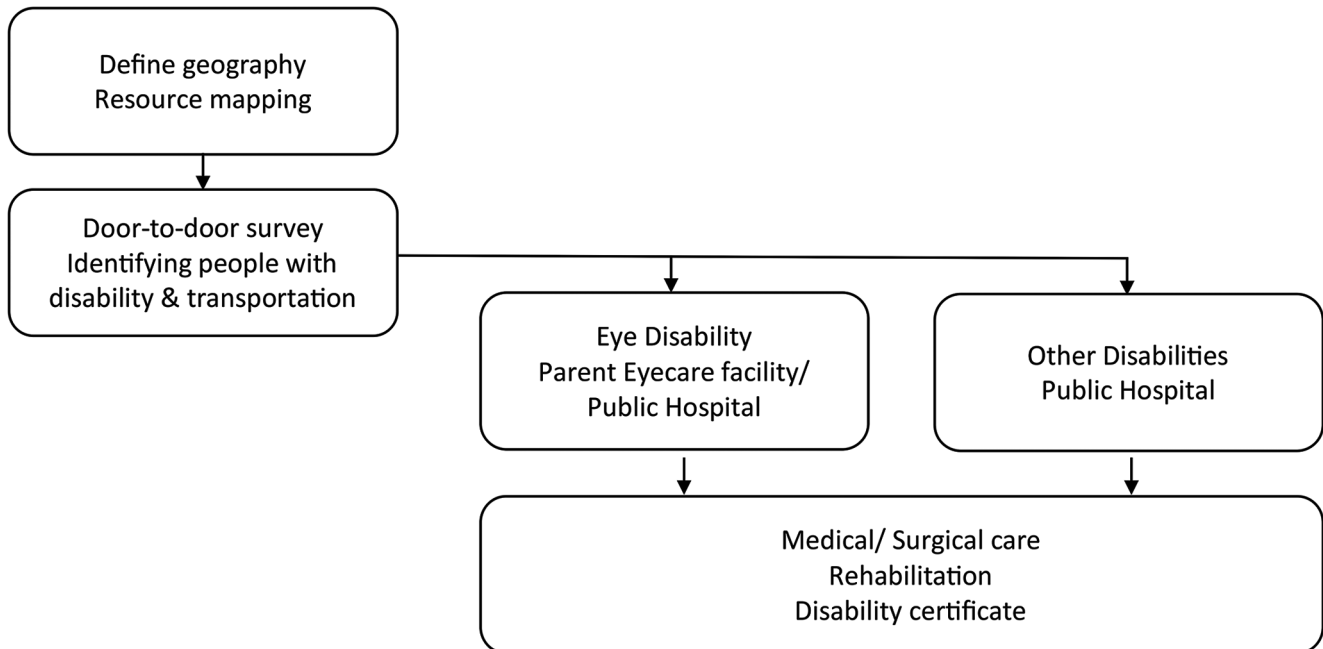


Figure 1: Disability Inclusive Eye Care Survey methodology flow chart Components of the project

acuity was measured at 6 m with spectacles, if any, for 5 years and above. A 6-m-long rope or a measuring tape was used to measure the distance. Snellen tumbling "E" chart was used for optotype sizes 6/12, 6/18, and 6/60.^[10] One eye (right eye first) was tested at a time, the other eye being occluded. If the person failed to identify the direction of the "E" in either eye, they were referred for a further eye check-up at the primary eye care center. Concordance was done for measuring visual acuity between the trainer and the CHW before the survey was conducted. The CHW also made a gross examination of the eye using a flashlight after recording the vision.

We categorized people with seeing disability when vision was less than 6/60; all deaf or partially deaf people were categorized under hearing disability. All people with lower-limb abnormality/deformity that affected their walking were categorized under mobility disability, and all people with recognizable disorientation were categorized under mental disability. Visual impairment was classified as per the definition of the National Program for Blindness and Visual Impairment (NPCBVI) India.^[11] Briefly, it was categorized as early, moderate, and severe visual impairment with available optical correction in the better eye as follows: early visual impairment (EVI)- PVA < 6/12–6/18; moderate visual impairment (MVI)- PVA < 6/18–6/60; and severe visual impairment (SVI)- PVA = 6/60–3/60. In this study, all people with severe visual impairment (PVA ≤ 6/60) were only counted to having a seeing disability.

Post-screening care. All those identified with eye ailments and the risk groups were referred to the nearest primary eye care center for further examination and secondary eye care center for appropriate management [Fig. 1]. The CHWs verified the government-issued disability certificates for persons with disabilities in the family and enrolled those who did not have such a certificate. Mothers were requested to bring their children below 5 for a complete eye check-up by the allied ophthalmic personnel (AOP) in the same village's Anganwadi Center ("Courtyard shelter" - a rural child care center in India) on a predetermined day. All those children identified with eye ailments were further referred for detailed examination and treatment needed to the secondary/tertiary eye care facility of the host institute. All patients with seeing disability received a comprehensive eye examination and needed care was given free of cost at the primary/secondary eye care facility. The CHWs transported all people with other disabilities to the public health facility. The survey coordinator facilitated appropriate care for obtaining the Health Authority disability certificate to avail certain government-approved concessions.

Results

We mapped 29 clusters (28 village councils and slums of Rayagada town in the Rayagada District, Odisha) [Fig. 2]. It was conducted over a year, 2016–2017. In this survey area, 147,695 people were enumerated, and 106,339 (72%) were available for survey. It consisted of 68% (n = 72,311) adults, and 47.3% (n = 50,320) males [Table 1].

Occupation: In this cohort, 43% (skilled and unskilled laborers) were dependent on daily wagers and were poor; 9% of the population was unemployed/retired/housewife and dependent. One-third of the population (34%) belonged to the school-going age group.

Systemic disease. Self-reported systemic disease was recorded in 0.6% (n = 689) people [Table 1]. Hypertension was most common and was the highest in the 40 + age group. Self-reported diabetes was higher in the 40–59 years age group.

Persons with Disability. In this cohort, 2.8% (n = 3,022) people had a disability; seeing (1.3%; n = 1,411) and hearing (1%; n = 1,112) were common, and these were higher in the elderly (60 + age group). Mobility disability was equally distributed between adults and elderly, and mental retardation was similarly distributed in young and elderly [Table 2].

Other disabilities associated with seeing disability were identified in 9.2% (n = 277) people, including 11 with more than one disability. The hearing was the most common association (20.6%; often termed as "dual sensory impairment"), and others included mobility disability (9.8%), mental retardation (6.1%), and multiple disabilities (12.8%) [Table 3]. These associations were higher in people 60 years and older- 89.9% (n = 249) people.

Visual impairment was recorded in 9.4% (n = 9,956) people. Nearly half of them (n = 4,789; 48.1% of people with any disability and 4.5% of the cohort) had moderate visual impairment [Table 4]. Of the referred patients, 3,400 people were examined, and 936 people were prescribed spectacles at the vision centers. At the community (secondary) center, 4,773 people were examined; 1,382 people had refractive errors, and 1,738 people were detected to have cataract (1,296 consented to surgery). The people referred to the secondary center outnumbered the people referred to the primary center as these people needed a dilated eye examination in the opinion of the vision technician (the current regulation does not allow eye dilation by a vision technician without the supervision of an ophthalmologist).

We compared the current data with the one generated in the 2011 national census in India and Odisha state [Table 5]. It showed that both seeing and hearing disabilities were higher in the current cohort ($P < 0.0001$); mobility and multiple including other disabilities were less ($P < 0.0001$) than the state and national average.

Discussion

Odisha is one of the eastern states in India [Fig. 2]. It is a relatively poor state, ranked 16th (of 33 Indian states and Union territories) in India,^[12] and the human development index (HDI) is 0.606.^[13] Rayagada is a relatively more impoverished district in Odisha and India. In 2018, it ranked 465 in 718 districts in India; the HDI of Rayagada was 0.18, and literacy was 49.76%^[14] against India's HDI of 0.645^[15] and literacy of 74%.^[16] Over 50% of people in this district belong to a tribal community as classified by the Government of India.^[17] We chose Rayagada district for three reasons: (1) we have one secondary (community) and five vision (primary) fixed eye care facilities; (2) the largest public health facility of the district is located at Rayagada town; (3) easy care provision logistics in this hilly and challenging terrain for people with disability for further care either by us (seeing disability) or by the public health system (other disabilities).

The current study was a population-based study of disability, including the seeing disability of people living in the semi-urban and slums in the Rayagada block of the district. It showed that both seeing and hearing are the major disabilities. Both of them were higher than the state ($P < 0.0001$) and national ($P < 0.0001$)

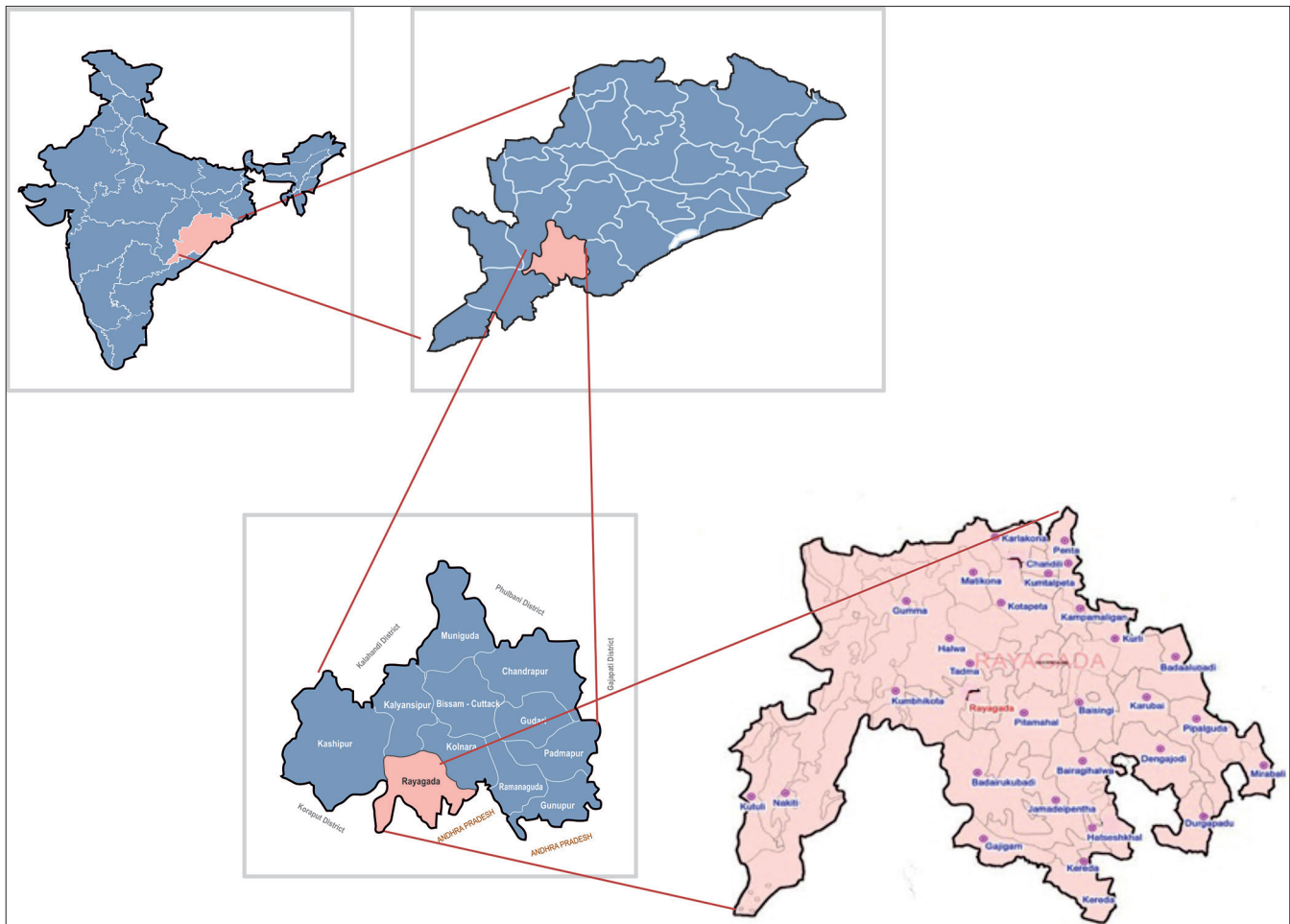


Figure 2: Study site. Rayagada block (lower right) area in Rayagada district (lower left) in the Odisha state (upper right) and India (upper left)

Table 1: Demography and systemic diseases

Age groups in years	Total (% of total)	Gender		Systemic disease				
		Male (%)	Female (%)	Total (% of Total)	HTN (% syst dis)	DM (% syst dis)	Asthma (% syst dis)	Others (% syst dis)
0-5	8048 (7.6%)	3915 (48.6%)	4133 (51%)	5 (0.7%)	2 (40.0%)	0 (0.0%)	0 (0.0%)	3 (60.0%)
6-16	23940 (22.5%)	12056 (50.4%)	11884 (50%)	8 (1.2%)	1 (12.5%)	0 (0.0%)	1 (12.5%)	6 (75.0%)
17-39	45136 (42.4%)	21319 (47.2%)	23817 (53%)	94 (13.6%)	34 (36.2%)	12 (12.8%)	21 (22.3%)	27 (28.7%)
40 and 59	21138 (19.9%)	10081 (47.7%)	11057 (52%)	304 (44.1%)	129 (42.4%)	76 (25.0%)	32 (10.5%)	67 (22.0%)
60 and above	8077 (7.6%)	2949 (36.5%)	5128 (63%)	278 (40.3%)	149 (53.6%)	39 (14.0%)	26 (9.4%)	64 (23.0%)
Total	106,339	50320 (47.3%)	56019 (53%)	689 (0.6%)	315 (45.7%)	127 (18.4%)	80 (11.6%)	167 (24.2%)
Percentage of total					0.29%	0.12%	0.07%	0.15%

DM - diabetes mellitus; HTN - hypertension; Other systemic diseases included cardiac, renal, and arthritis

average, and there was a higher number of people with seeing disability between the two. Moreover, the number of people with known hypertension was nearly two times higher than the number of people with known diabetes. These systemic conditions were lower than our earlier report of a hospital-based study in the same district: diabetes (5% hospital; 0.12% current study) and hypertension (6.6% hospital; 0.29% current study).^[18]

The WHO defines disability in three dimensions: impairment, activity limitation, and participation restriction.^[19] Impairment

is an absence of or significant difference in a person’s body structure or function (such as loss of seeing or hearing). Structural impairment is a significant problem with an internal or external component of the body (such as limb amputation, nerve damage causing multiple sclerosis). Functional impairment includes complete or partial loss of function of a body part (such as too stiff joints). Impairment results in reduced activity and poor participation. The ICF defines *activity* as the “execution of a task or action by an individual”; *participation* is the “person’s involvement in a life situation.”^[19] Similarly, *disability* documents the physical

Table 2: Age-specific distribution of disabilities

Age groups in years	Seeing	Hearing	Mobility	Mental Retardation	Multiple	Total
0-5	0	4	3	3	5	15
6-16	11	40	36	23	24	134
17-39	22	173	95	33	28	351
40-59	178	251	83	28	14	554
60 and above	1200	644	98	11	15	1968
Total	1411	1112	315	98	86	3022
% of disability	46.7	36.8	10.4	3.2	2.8	-
% of cohort	1.3	1.0	0.3	0.1	0.1	2.8

Table 3: Seeing disability with other disabilities

Disability	Hearing		Mobility		Mental		Multiple	
	Total <i>n</i>	With vision loss	Total <i>n</i>	With vision loss	Total <i>n</i>	With vision loss	Total <i>n</i>	With vision loss
Age groups (years)	1112	229 (20.6%)	315	31 (9.8%)	98	6 (6.1%)	86	11 (12.8%)
0-5	4	-	3	-	3	-	5	-
6-16	40	1 (2.5%)	36	-	23	1 (4.3%)	24	-
17-39	173	3 (1.7%)	95	-	33	1 (3.0%)	28	-
40-59	251	16 (6.4%)	83	2 (2.4%)	28	2 (7.1%)	14	2 (14.3%)
60+	644	209 (32.5%)	98	29 (29.6%)	11	2 (18.2%)	15	9 (60.0%)

Table 4: Better eye vision

Age group (years)	No VI	Visual Impairment			Total VI	Total cohort
	Can read $\geq 6/12$	Can read $\leq 6/18$ (MVI)	Can read $\leq 6/60$ (SVI)	$< 3/60$ (Blind)		
0-5	8038	3	7	0	10	8048
6-16	23910	12	7	11	30	23940
17-39	44779	286	49	22	357	45136
40-59	17323	2554	1083	178	3815	21138
60 and above	2333	1934	2610	1200	5744	8077
Total	96383	4789	3756	1411	9956	106339
% of VI	-	48.1	37.7	14.2	-	-
% of Cohort	90.6	4.5	3.5	1.3	9.4	-

MVI - moderate visual impairment; SVI - severe visual impairment; VI - visual impairment

Table 5: Comparison of proportion of disability in current Rayagada cohort with published national and state level disability

Cohort	Proportion of disability (percentage)				
	Seeing	Hearing	Mobility	Mental retardation	Multiple disabilities and others
Rayagada (2017)	46.7	36.8	10.4	3.2	2.8
Odisha (2011) ^[8]	21.2	19.1	20.9	5.8	33.0
India (2011) ^[8]	18.8	18.9	20.3	5.6	36.4

Seeing and hearing disabilities were significantly higher than the state ($P < 0.0001$) and national ($P < 0.0001$) average; mental, and multiple disabilities including others were significantly lower than the state ($P < 0.0001$) and national ($P < 0.0001$) average

limitation and loss of activity, but a *person with a disability* is also a function of features of the environment in which one lives.^[20]

The social, cultural, and economic implications of disability are high. In this study cohort, 34.8% ($n = 1054$) of less-abled people were under 60 years (half of them under 40 years), 9% ($n = 259$) adults were unemployed, and 43% ($n = 1235$) of adults with disabilities were daily wagers. There cannot be

adequate economic growth unless this large population segment is given equal education, health, and employment opportunities.

In 2006, the United Nations adopted the *Convention on the Rights of Persons with Disabilities* (UNCRPD); it came into force in May 2008, and 182 ratifying Member States pledged to promote the full inclusion of people with disabilities in all areas of the society.^[21] However, it is not

uniformly implemented. The national census in India has documented that the number and proportion of people with disabilities have increased between 2001 and 2011. It was disproportionately high in eight Indian states and higher in an economically disadvantaged community.^[22] The people living in a predominantly tribal district (such as Rayagada, Odisha) are economically weaker and less advantaged. While we do not have the data of people with disabilities in other blocks of the Rayagada district, we would like to presume that it could be worse because of the hilly terrain and tribal community.

Limitations and strengths

Limitations. There were three limitations. First, the current study was confined to only one of the eleven blocks of the district; other blocks not studied are, in fact, less developed. Second, our involvement in the care of people with a disability other than seeing disability was confined only to qualifying them and transporting them to the public health facility. Third, the estimation of disabilities other than seeing disability was self-reported, not based on an objective examination of people.

Strengths. There were three strengths. First, over 70% of enumerated people were examined. Second, it was the door-to-door survey, involved good documentation, and provided complete care for all eye ailments at no cost to the patient and family. Third, the people in the urban slums were included; this population is often neglected in population surveys.

Disability is a public health issue. People with disabilities encounter a range of barriers when attempting to access healthcare; these are related to prohibitive costs, limited availability of services, physical barriers, and limited knowledge of caregivers. In general, it needs appropriate policy and legislation, adequate finance, and well-trained, skilled professionals. In June 2019, the United Nations launched the *UN Disability Inclusion Strategy* (UNDIS), which calls to promote “sustainable and transformative progress on disability inclusion through all pillars of the work.”^[23]

Conclusion

It was the first population-based survey in Rayagada, Odisha (India) measuring the major disabilities. It showed a higher proportion of people with seeing and hearing disabilities. It calls for an appropriate service strategy. We hope the Odisha Government and other organizations working in the disability sector in the state will utilize these data for necessary program planning and policy changes.

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Conflicts of interest

There are no conflicts of interest.

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