

Birth Defects and Childhood Disability Toolkit

Section 6 - Childhood disability



Birth Defects Research Foundation, Pune, India

A research NGO working for evidence based policies and advocating for the rights of children with disabilities caused by congenital, developmental and genetic disorders

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6.1 What is disability?

1. Many congenital disorders are responsible for childhood disability.

2. Disability is NOT a medical condition, that is clubfoot is not a disability

3. Disability is a complex, multidimensional, dynamic situation, caused by the interaction of the physical and social environment with the body function (impairment), that determines functioning, activity, and participation of an individual.

- **Impairment** : absence of or significant difference in body functions caused by structural (eg. missing limb), or functioning issues (eg. a child who is hard of hearing since birth)

- **Activity restriction** : inability to perform a piece of work or inability to execute an act (eg. parents thought that the child who cannot walk need not go to school, or

- **Participation** : difficulty to involve in daily activities within or outside the household

- **Impairment** : a child with missing lower limb

- **Activity restriction** : cannot move

- **Participation** : does not attend school

- **Impairment** : a child who is hard of hearing since birth.

- **Activity restriction** : cannot hear

- **Participation** : does not attend school

1. Counseling of caregivers, referral to social welfare services (registration under UDID for different benefits)
2. Access to assistive devices (wheelchair, hearing aids)
3. Community sensitization about inclusion of children with disabilities, rights under RPwD Act 2016
4. Increasing community awareness about accessibility, accessible spaces; awareness among school teachers, inclusive schools, teaching all children non-verbal communication (sign language)

• **Attends school, participates in community life**



6.2 Childhood Disability

1. Different methods and data collection tools make it difficult to reconcile data on numbers of children with disabilities
2. 1 in 10, that is 240 million children and young adolescents have some form of disability (UNICEF, 2021)
3. 291 million (under 20 years) (53 million children under 5 years of age) affected by epilepsy, intellectual disability, vision loss, or hearing loss autism and ADHD. (Olusanya et al.)
4. 95% children with disabilities are in LMICs
5. Disability primarily affects functioning in a single domain
6. Psychosocial domain most affected
7. Disability is more likely to be moderate than severe
8. Most prevalent among conditions studied were vision loss, hearing loss, intellectual disability, and autism spectrum disorders (Olusanya et al.)
9. Children with disabilities were more likely to be from poorer households, single parent household
10. In many studies, a clustering of adult and child disability was observed in households
11. Disability risk is ten times higher than child mortality in children below 5 years of age (Olusanya et al)

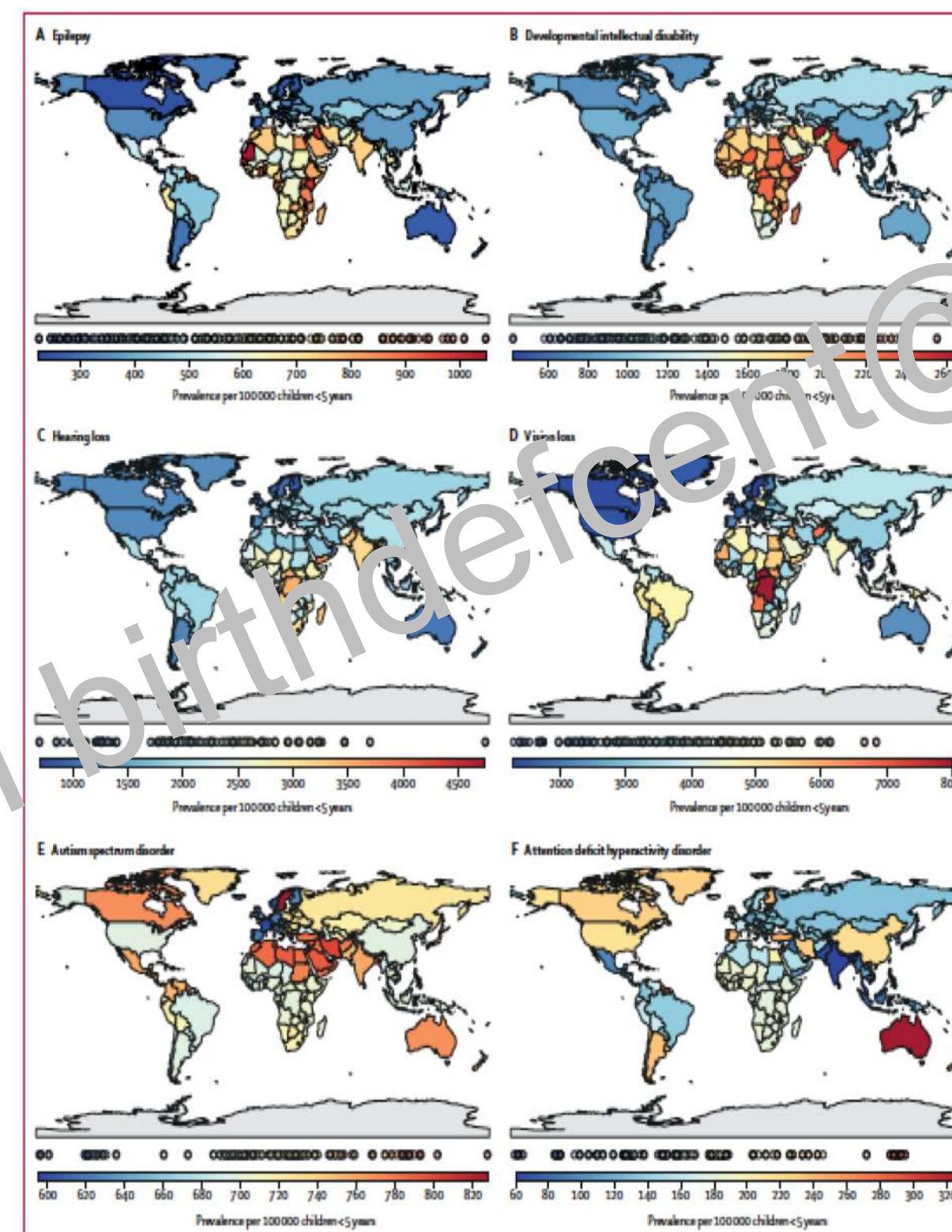


Figure 3. Global prevalence per 100 000 population of developmental disabilities among children younger than 5 years in 2016



Limited epidemiological data from LMICs on numbers, characteristics and circumstances of children with disabilities; need for primary research using standard tools

References

Global Research on Developmental Disabilities Collaborators. *Lancet Glob Health* 2018;6:e1100–21. 10.1016/S2214-109X(18)30309-7 ; Olusanya BO et al. *Pediatrics* 2020;146:e20192623. 10.1542/peds.2019-2623; United Nations Children's Fund (UNICEF). *Seen, counted, included: using data to shed light on the well-being of children with disabilities*. New York: UNICEF, 2021. <https://data.unicef.org/resources/children-with-disabilities-report-2021/>

6.3 RPwD Act 2016 and the CRPD

- The Rights of Persons with Disabilities Act, 2016 (RPWD) is a legislation that ensures that “all persons with disabilities can lead their lives with dignity, without discrimination and with equal opportunities”.
- The Act includes specific provisions to uphold such rights. It was enacted in India to give effect to the United Nations Convention on the Rights of Persons with Disabilities, to which India is a signatory.

United Nations Convention on the Rights of Persons with Disability (UNCRPD)

- An agreement to advocate and implement the human rights of persons with disabilities and act against discrimination.
- Adopted on 13 December, 2006

Purpose of the UNCRPD

- To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Promotes inclusion of disabled people into the society in lieu of creating special rules and institutions

Rights provided to Persons with Disabilities

- Engagement
- Awareness
- Access
- Right to life
- Equality before the Law
- Liberty and security
- Independent living
- Education
- Health
- Employment
- Adequate standard of living

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| 1. Physical disability
A. Locomotor disability
(a) "leprosy cured person"
(b) "cerebral palsy"
(c) "dwarfism"
(d) "muscular dystrophy"
(e) "acid attack victims"
B. Visual impairment—
C. Hearing impairment
D. Speech and language disability | 2. Intellectual disability
Disability caused due to
(a) "specific learning disabilities"
(b) "autism spectrum disorder"
(c) Mental behavior
3. Disability caused by
(a) chronic neurological conditions (multiple sclerosis, Parkinson's disease,
(b) Blood disorders (hemophilia, thalassemia, sickle cell anemia)
4. Multiple Disabilities
5. Any other category notified by Central Government |
|--|--|






Reference United Nations *United Nations Convention on the Rights of Persons with Disabilities*. 2006. Available at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> ; Math et al.(2019). The rights of persons with disability act, 2016: Challenges and opportunities. *Indian journal of psychiatry*, 61(Suppl 4), S809.

6.4 Welfare Services for Persons with Disability

- Persons with disabilities (PwD) require additional care and support.
- Social welfare services are delivered through the Department of Empowerment of Persons with Disabilities, for children with autism, cerebral palsy, intellectual disability and multiple disabilities.



Financial support	Education support	Shelter support	Nurturing support	To empower	Community awareness
<p>Nirmaya Health insurance cover of upto one lakh rupees.</p> 	<p>Disha Early intervention and school readiness for children (age group 0-10 years). Includes therapies, trainings and support to family members</p> <p>Vikaas Day care facilities for at least 6 hours in a day along with age-specific activities to enhance interpersonal and vocational skills.</p>	<p>Samarth Respite and residential care to those belonging to Below Poverty Line (BPL). Group home facilities including basic medical services to all age groups.</p> <p>Gharanda Lifelong shelter homes.</p>	<p>Sahyogi Creation of units to provide training in caregiving skills, including parents of children with disabilities</p> 	<p>Sambhav Access to assistive devices</p> <p>Prerna Marketing assistance for sale of products made by persons with disabilities</p> 	<p>Badhte Kadam Scheme for NGOs for creating community awareness, sensitization, social inclusion and integration of persons with disabilities.</p>

Reference

The National Trust <https://www.thenationaltrust.gov.in/content/>

6.5 Disability Registration in India

Disability Certificate and Unique Disability Identification Card (UDID)



1. **Disability Certificate** (DC, mentions type and percent of disability)

1. **UDID card** (universal card for all persons with disability (PwD) is essential to avail government subsidies and benefits

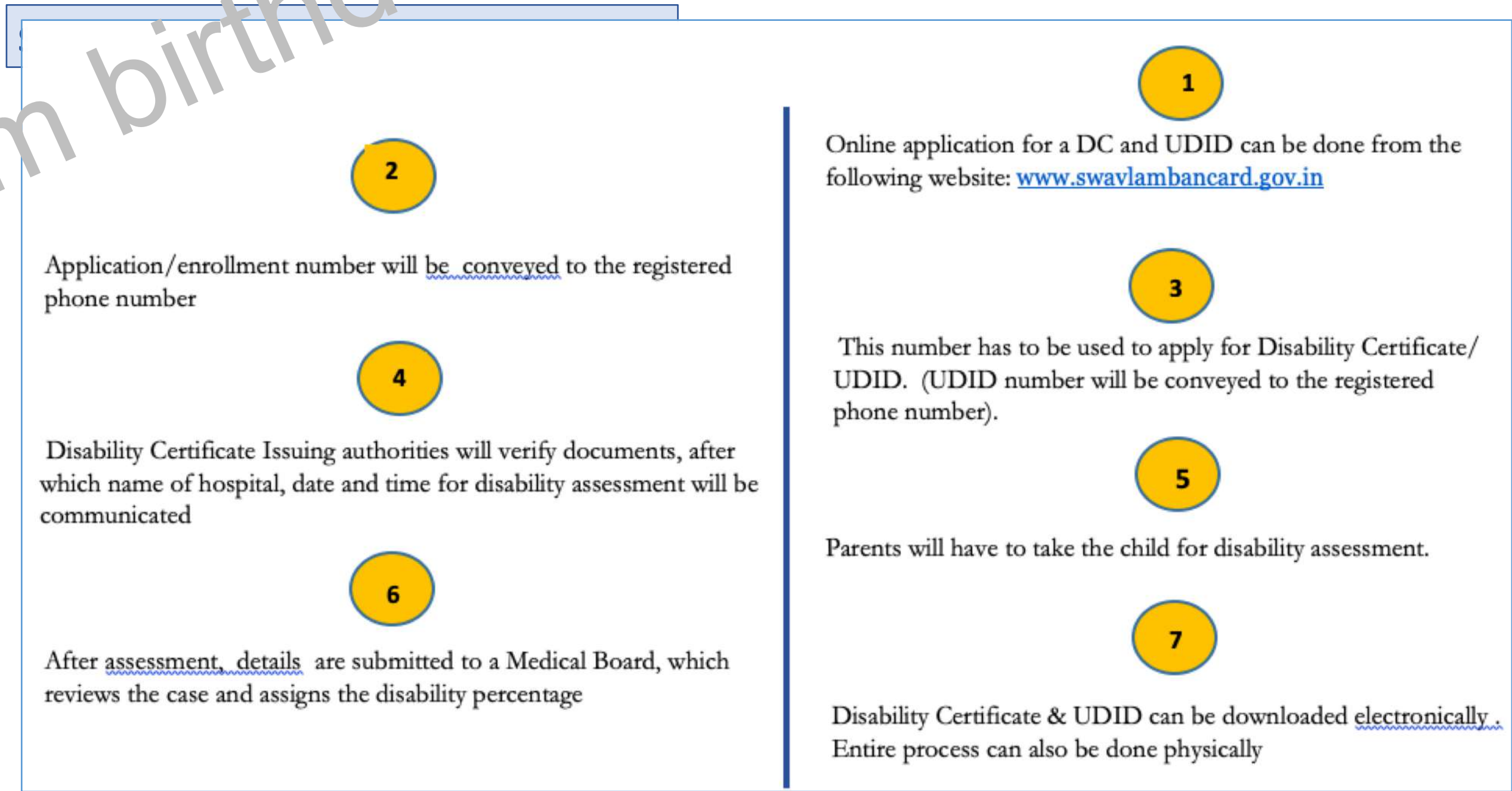
<https://www.swavlambancard.gov.in/>

Benefits of UDID and DC : Student scholarship; medical insurance; assistive devices and prosthetic aids at discounted prices; employment in the physically handicapped quota; low interest loans for business; income tax discount; free transportation on public buses, discounted railway fare; unemployment allowance

Eligibility : As per Rights of Persons with Disabilities Act

https://legislative.gov.in/sites/default/files/A2016-49_1.pdf

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| 1. Locomotor disability | 12. Specific learning disabilities |
| 2. Leprosy cured person | 13. Autism Spectrum Disorder |
| 3. Cerebral palsy | 14. Mental Illness |
| 4. Dwarfism | 15. Chronic neurological conditions |
| 5. Muscular Dystrophy | 16. Multiple Sclerosis |
| 6. Acid attack victims | 17. Parkinson's Disease |
| 7. Blindness | 18. Hemophilia |
| 8. Low vision | 19. Thalassemia |
| 9. Hearing impairment (Deaf and Hard of hearing) | 20. Sickle cell anemia |
| 10. Speech and language disability | 21. Multiple disabilities (having more than one of the mentioned conditions) |
| 11. Intellectual disability | |



While interacting with persons having vision difficulties

1. Mention your name while entering/ sharing a room
2. Initiate a conversation by introducing yourself
3. Inform when you are leaving the room or the conversation
4. Ask before offering any help. Cooperate during activities, rather than trying to do the task for the person with vision difficulties
5. Take consent before offering to hold the person's hands, for example to help in crossing the road
6. If a person with vision difficulty walks at a slower pace, it is because the person, unlike you, cannot see what is ahead. Walk at the same pace,
7. Walk next to the person with vision difficulty, not in front. Leave space for the person to direct themselves,
8. Do not walk in front for them, rather walk with them and leave space for them to direct themselves.
9. Do not speak loudly. A person with vision difficulty has problems seeing, but not hearing problems,
10. Orient a person with vision difficulties to the surroundings, such as classroom or office, including placement of furniture. Inform about any changes being made to the surroundings,
11. Do not touch the cane unless asked to
12. Demand instructions in Braille at every signboard, in elevators and at appropriate height to ensure inclusion of persons who are unable to see or have impaired sight.



<https://www.dreamstime.com/kid-blind-disabled-vector-illustration-child-cartoon-disability-glasses-aid-artwork-grade-school-handcapped-impaired-people-image157366196>

6.6 Disability Etiquette

While interacting with persons having hearing/speech difficulties

1. Do not shout while speaking, as a completely hearing impaired person will not be able to hear you. If the person uses a hearing aid, shouting might distort its function and cause difficulties in hearing.
2. If the person is accompanied by a friend or an interpreter, talk and address the person and not only the companion.
3. If a person with hearing difficulty is not responding, please remember that it is because of a difficulty in hearing you, and not because he is not intellectually competent.
4. Speech development occurs simultaneously with hearing development. In certain cases speech is impaired if hearing impairment was congenital. Gestures and sign language can be used to have a conversation.
5. Include people who have hearing/speech difficulties in your activities. Ask how they would like to communicate, whether by writing, gestures and signs or lip reading.



<https://www.dreamstime.com/clipart-artwork-illustration-girl-wearing-hearing-aid-image157366196>

While interacting with persons having movement difficulties

1. Walk at the same pace as the person with movement difficulty
2. Do not offer a place to sit but do not insist, as the person would like to do things as per his convenience
3. Take consent before assisting with the wheelchair
4. Sit while speaking, so that the person on the wheelchair will not need to look up while interacting
5. Do not speak very loudly, a person with movement difficulties has difficulties in moving and not hearing
6. Do not touch wheelchairs or assistive devices, unless specifically asked to.
7. Demand accessible spaces, ensure that buildings are equipped with ramps, mirrors in the lifts, modified washrooms in all institutions and organizations.



<https://www.dreamstime.com/illustration-kid-girl-wearing-hearing-aid-image157366196>

You can assist people with disabilities by

- Respecting diversity and individuality,
- By considering people with disabilities as capable of doing all chores, may be a little differently
- By demanding the additional facilities to improve accessibility

Public health role – Simulation exercises need to be conducted at organizations and institutions from diverse fields to better deliver the etiquettes and to spread the awareness about the importance of practicing it.

Reference

<https://www.nationaldisabilityinstitute.org/wp-content/uploads/2018/11/supplemental-guide-sensitivity.pdf>